

The University of Maine

DigitalCommons@UMaine

Honors College

Spring 5-2017

The Effects of Social Media on the Quality of Life of People With Aphasia

Megan Morey
University of Maine

Follow this and additional works at: <https://digitalcommons.library.umaine.edu/honors>



Part of the [Communication Sciences and Disorders Commons](#)

Recommended Citation

Morey, Megan, "The Effects of Social Media on the Quality of Life of People With Aphasia" (2017). *Honors College*. 459.

<https://digitalcommons.library.umaine.edu/honors/459>

This Honors Thesis is brought to you for free and open access by DigitalCommons@UMaine. It has been accepted for inclusion in Honors College by an authorized administrator of DigitalCommons@UMaine. For more information, please contact um.library.technical.services@maine.edu.

THE EFFECTS OF SOCIAL MEDIA ON THE QUALITY OF LIFE OF PEOPLE
WITH APHASIA.

by

Megan Morey

A Thesis Submitted in Partial Fulfillment
of the Requirements for a Degree with Honors
(Communication Sciences and Disorders)

The Honors College

University of Maine

May 2017

Advisory Committee:

Dr. Judy P. Walker, Associate Professor of Communication Sciences and
Disorders, Advisor

Dr. Edith Elwood, Honors Preceptor

Judith Stickles, Clinical Director of Communication Sciences and Disorders

Dr. Nancy J. Fishwick, Associate Professor of Nursing

Dr. Fayeza Ahmed, Assistant Professor of Clinical Psychology

Dr. François G. Amar, Professor of Chemistry, Dean of the Honors College

ABSTRACT

This thesis reviews the literature regarding the effects of social media on the quality of life of people with aphasia. The review focuses on communication deficits, social isolation, quality of life, types of social media, aphasia technology and aphasia. The literature suggests that communication deficits in aphasia lead to feelings of social isolation, which then lead to a lower quality of life. However, less is known about the impact of social media on people with aphasia. Findings from this literature review suggest that technology may improve social connectedness, thereby decreasing social isolation and improving the overall quality of life of people with aphasia.

ACKNOWLEDGMENTS

First, I would like to thank my committee members for being a part of this project and allowing for some last minute changes. Second, I would like to thank my thesis advisor, Judy Walker, for all of her knowledge and guidance throughout the thesis process and for everything that she taught me along the way. I would also like to thank everyone that helped me complete my senior year despite becoming ill. Lastly, I would like to thank my friends and family, it has been a long road with many twist and turns, but we made it.

TABLE OF CONTENTS

THE EFFECTS OF SOCIAL MEDIA ON THE QUALITY OF LIFE OF PEOPLE WITH APHASIA.....	i
ABSTRACT.....	ii
ACKNOWLEDGMENTS	iii
TABLE OF CONTENTS.....	iv
Introduction.....	1
Literature Review.....	4
Background	4
Communication Deficits in Aphasia	4
Synthesis.	7
Social Isolation in Aphasia.....	7
Synthesis.	9
The Quality of Life in People with Aphasia	10
Synthesis.	12
Types of Social Media.....	13
Synthesis.	15
Technology and Aphasia	15
Social Media and Aphasia.....	17
Conclusions.....	21
Future Directions	22
Outline for a Proposed Study	24
Title.....	24
Rationale	24
Methods.....	25
Participants.....	25
Informed consent.	26
Confidentiality.	26
Risks.....	26
Benefits	26
References.....	27
Appendix A: Sample Questions.....	31
Biography.....	35

Introduction

Throughout an undergraduate career in Communication Sciences and Disorders, students learn about the different types of diseases, ailments and conditions that cause communication difficulties, as well as how to treat them. Specific topics of interest to me were those involving the brain including neurodegenerative diseases, traumatic brain injuries, and aphasia. Based on my interests in this area, I strive towards a career working in a hospital helping people with traumatic brain injuries, strokes, and aphasia. Having acquired a traumatic brain injury when I was 12, I have personal experience knowing how difficult recovery and life after impact can be. This further inspires me to work with people suffering from traumatic brain injuries.

My focus for this thesis was to examine post stroke recovery using adaptive strategies such as social media. If there is a positive connection between social media and quality of life then therapy after a stroke people could use social media as a reconstructive tool. In order to come across this topic I met with Dr. Walker to incorporate one of my minors, psychology, with the brain and communication. Specific to this thesis, psychosocial factors were included which take into account psychology and the social environment.

The proper functioning of the brain is essential for the things we do every day, including communication. If the brain is affected by stroke, the most common cause of aphasia, or a traumatic brain injury, then communication is often impacted. Aphasia leads to many different types of communication deficits, which will be outlined further in this paper. Social media allows for communication, and may help those with aphasia

communicate more efficiently. There are many psychosocial factors that influence quality of life (Mitchell, Benito-León, González & Rivera-Navarro, 2005). Therefore, psychosocial factors can be tested to determine if quality of life is impacted by social media use. By combining all of these areas, I can use literature to determine if social media has a negative or positive effect on quality of life for people with aphasia. If there is a positive effect, then social media could be implemented into different therapy techniques.

However, as social media gets more popular, people have also begun to notice how it affects people's well being. Social media has been shown to have both a positive and negative side. A study done by Iannotti, Kogan, Janssen and Boyce (2009) note that screen based media use by adolescents was negatively related to most positive health indicators while being positively related to several negative health indicators. Contrary though, screen based media was positively related to the quality of peer relationships. Because this thesis is examining quality of life as it relates to social media, it is possible to create a hypothesis. This hypothesis states that the results of screen based media being positively related to quality of life of peer relationships would mean that quality of life could be positively affected by social media use of the aphasia population.

Findings from the Iannotti, Kogan, Janssen and Boyce (2009) may also be relevant to the quality of life of people with aphasia. This is because, looking further at the adolescent population, it is clear that social media can cause anxiety and loneliness (Davey, 2016). Social media plays a larger part in the friendship networks of adolescents and, depending on how they perceive their social media use, it is possible to have a negative impact on loneliness, anxiety, paranoia, and mental health (Davey, 2016).

The studies and articles referenced so far only examine the relationship between social media and adolescents. Most people with aphasia are not adolescents though, so it is not possible to know how social media will affect them without further study. This constitutes the main question to be explored by this thesis: how does social media affect quality of life of those with aphasia? While conducting the literature review, several additional questions were raised. One such question was if age played a factor in how social media affects quality of life. Another question was if different types of aphasia make a difference in how social media affects quality of life. While conducting the literature review, it was important to keep all these questions in mind. The thesis addresses how communication deficits can affect someone with aphasia as well as how those communication deficits can lead to social isolation. There may also be barriers that interfere with someone who has aphasia using social media, therefore, there is a section addressing different aphasia assistive technologies. Social media is also a broad term so a conceptual definition is provided which guided the literature review. Overall, these more specific questions help to answer the larger questions of how social media affects quality of life of those with aphasia.

Literature Review

Background

Social media plays a big part in many peoples' lives because of the ways it is used to communicate, influence relationships and impact the overall well-being of individuals. People with aphasia frequently experience social isolation due to difficulties in their ability to communicate (Parr, 2007). There is a possibility that the use of social media may improve the quality of life for people with aphasia. The guiding question for this paper is: *how does social media affect quality of life of people with aphasia?*

Communication Deficits in Aphasia

Aphasia is defined as "an impairment of language, affecting the production or comprehension of speech and the ability to read or write" (National Aphasia Association, n.d.). According to Damasio (1992), the most common cause of aphasia is a stroke in the left language dominant hemisphere. The National Stroke Association (2017) reports that nearly 800,000 people, annually, will have a new or recurrent stroke and about 20 to 40 percent, approximately 180,000 of stroke survivors, will acquire aphasia. Although aphasia is more common in older people, it can occur in people of all races, ages, nationalities and genders. Aphasia can also be caused by head injury, cerebral tumors and degenerative diseases, such as Alzheimer's disease.

According to the Boston Classification System (Goodglass & Kaplan, 1972), different types of aphasia can be delineated according to fluency and modality of impairment (i.e., auditory comprehension, verbal expression, repetition). Nonfluent

aphasia is characterized by labored and flat verbal expression, where the melody that goes along with normal speech is lacking (Damasio, 1992).

According to Hillis and Caramazza (2003), one type of nonfluent aphasia is Broca's aphasia. Verbal expression in a Broca's aphasia is halting and agrammatic. Sentences tend to contain meaningful content words, such as nouns and verbs, but there is an omission of grammatical morphemes, such as prepositions, conjunctions and verb inflections. Sentence repetition mirrors verbal expression, as it is effortful while omitting essential words. However, the gist of the sentence is usually retained. With respect to auditory comprehension, single words are often understood, while the comprehension of complex syntactic sentences is usually impaired (Hillis & Caramazza, 2003).

Also according to Hillis and Caramazza (2003), transcortical motor aphasia is similar to a Broca's aphasia in which auditory comprehension is relatively good for simple sentence structures and verbal expression is nonfluent, containing content words that carry meaning. However, repetition is actually quite good in comparison to verbal expression (Hillis & Caramazza, 2003).

Damasio (1992) describes another type of nonfluent aphasia, which is global aphasia, where all modalities are severely impaired. Auditory comprehension is limited to the comprehension of a small number of nouns, verbs and automatic expressions, but more complex aspects of grammar are not understood. Whether appropriate or not, the same word will often be repeated in an effort to get a message across. Hillis and Caramazza (2003) state that verbal expression and repetition are characterized by nonword utterances and perseverative words, which do not convey meaning.

Fluent aphasia is "effortless, melodic, well woven together and produced at normal or even faster than normal rates" (Damasio, 1992). According to Hillis and Caramazza (2003) one type of fluent aphasia is Wernicke's aphasia. People with a Wernicke's aphasia have a severe impairment in the understanding of spoken words and sentences. Although verbal expression is effortless and retains basic grammatical structure and melody, word selection is poor resulting in meaningless sentences (i.e., jargon). Repetition is similar to verbal expression characterized by fluent jargon (Hillis & Caramazza, 2003).

Hillis and Caramazza (2003) detail that anomia is a fluent type of aphasia characterized by an impairment with naming or word retrieval. People with this type of aphasia, have relatively good auditory comprehension and repetition abilities, but difficulty retrieving words (Hillis & Caramazza, 2003).

Another type of fluent aphasia described by Hillis and Caramazza (2003) is conduction aphasia, which is characterized by relatively good auditory comprehension and fluent, well-formed sentences in verbal expression. However, repetition is impaired at word and sentence level (Hillis & Caramazza, 2003).

The last type of fluent aphasia outlined by Hillis and Caramazza (2003) is transcortical sensory aphasia in which the comprehension of language and the content of verbal expression are impaired. However, sentence repetition is mostly correct. This is very similar to Wernicke's aphasia, except there is a stronger ability to repeat words and phrases (Hillis & Caramazza, 2003).

According to Hillis and Caramazza (2003) most people with aphasia will have a co-occurring deficit in reading which parallels their auditory comprehension deficits. Written output is usually impaired as well and errors tend to be similar to the errors seen in verbal expression. There have been cases of full auditory word deafness where spoken word comprehension is severely impaired, while written language comprehension is intact. In other cases, it is seen that patients are better able to write their name than to speak it (Hillis and Caramazza, 2003).

Synthesis. With every type of aphasia there are communication deficits. Communication is how people ask for things, get their points across or even tell their name. The loss of communication can cause people to feel alone or isolated (Johansson, Carlsson & Sonnander, 2012). Communication is essential for a social life and to function, without it a person can be left feeling helpless. With specific types of aphasia people will have difficulty understanding and producing meaningful language. This will often times cause frustration as the person with aphasia cannot create the words that he/she wants to say. This also causes frustration for the caretaker as they cannot figure out what the person is trying to say. These feelings of frustration can easily strain friendships reducing a person with aphasia's ability to practice communication. Overall, communication deficits that are common in aphasia are likely to cause feelings of frustration and loneliness (Johansson, Carlsson & Sonnander, 2012).

Social Isolation in Aphasia

Communication deficits associated with aphasia may reduce the frequency of communication interactions with others, thereby leading to feelings of social isolation (e.g., Parr, 2007; Davidson, Howe, Worrall, Hickson & Togher, 2008; Johansson,

Carlsson & Sonnander, 2012; Brown, Davidson, Worrall & Howe, 2013). For example, Johansson, Carlsson and Sonnander (2012) examined changes in the frequency of communication interactions following aphasia. A total of 11 subjects, four women and seven men, ages 48 – 79 participated in this study. Each subject was at least one-year post onset stroke at the time of this study. To determine the frequency of communication interactions, the subjects were asked to respond to semi-structured interviews that addressed how communication difficulties for people with aphasia impacted their conversations and, as a result, impacted the frequency in which they entered into conversations. The questions were adapted to match the ability of each participant, utilizing yes and no questions, pointing to pictures, and ideas that the participant could reject or approve. The interviews were video recorded, transcribed word for word and analyzed by qualitative content analysis. Results indicated that overall the participants had fewer conversations after the onset of aphasia. Further, the researchers found that the participants still spoke with families and friends after onset of aphasia but spoke less frequently to other people. The fewer interactions were attributed to communication difficulties. The authors concluded that people with aphasia desired to integrate back into society in the same way as before the stroke but were unsuccessful. The participants conveyed that they were not able to express their feelings, thoughts, opinions or personality as easily as before their aphasia often leaving them frustrated, unwilling to enter into conversations and feeling lonely.

Another study by Brown, Davidson, Worrall and Howe (2013) explored the role of friendship and successful living following aphasia. Twenty-five subjects, 12 females and 13 males, participated in this study. They were two or more years post onset left

hemisphere stroke and between 38-86 years of age. Successful living was measured through an “aphasia friendly” interview and also through photos taken by the people with aphasia. Questions in the interview focused on general ideas about what it means to live successfully with aphasia (e.g., examples of why they or others were successful and contributing factors). Family members or friends were also present to help with the interview. Following the interview, subjects were then asked to take pictures that represented successful living and were asked to explain the significance of the images and provide reasons for why that picture had been chosen. A qualitative comparison of the verbal and pictorial responses revealed three main themes. One theme that arose is that the subjects experienced negative changes and losses in friendships they had before their strokes, which was primarily attributed to communication difficulties. Another theme was that the subjects desired to have positive experiences with friends and to feel emotional support from those friends. Lastly, the study found that it is important to have friends who also have had strokes and aphasia as they have a mutual understanding, ease of communication and can support each other. In conclusion, this study found that friendship played an important role in living successfully with aphasia and there were both positive and negative changes in friendship following a stroke. People with aphasia tend to lose long-standing friendships often leaving them feeling socially isolated. However, they can develop new friendships with those who share similar experiences following a stroke.

Synthesis. The feelings of social isolation discussed arising from communication deficits often affect the social life of a person with aphasia. There are studies that show how social isolation may lead to depression and other mental illnesses (Rohde,

D'Ambrosio, Tang & Rao, 2016). It is reasonable to hypothesize that social isolation may lower quality of life for those with aphasia. This is based off the referenced study above as well as the idea that social isolation causes a person to feel alone or separated from the normal group, specific to communication deficits they may feel isolated in groups as they are not able to be active communication partners. This can cause people with aphasia to avoid going into community as they are not easily able to have a conversation.

The different degrees of social isolation could also be correlated with the type of aphasia. For instance, someone with global aphasia will have the most severe communication deficits as all modalities are impaired (Damasio, 1992; Hillis & Caramazza, 2003). Compare this to conduction aphasia in which repetition is impaired, and the person with global aphasia will most likely cause greater feelings of isolation (Hillis & Caramazza, 2003). This is because global aphasia will allow a person to communicate less compared to the person with conduction aphasia (Damasio, 1992; Hillis & Caramazza, 2003). The more communication is affected, the less the person is going to want to participate in conversations as it is more difficult. It is common knowledge that the harder something is to do, the less we want to do it. It is possible that depending on the type of aphasia, a person will have greater communication difficulties leading to more feelings of social isolation, thereby lowering quality of life more.

The Quality of Life in People with Aphasia

The communication impairments and social isolation experienced by many people with aphasia have been found to negatively impact quality of life (e.g., LaPointe, 1999; Cruice, Worrall, Hickson & Murison, 2003; Ross & Wertz, 2003; Spaccavento, Craca, Del Prete, Falcone, Colucci, Di Palma & Loverre, 2014). According to Spaccavento et

al., (2014) “quality of life may be defined as an individual's perception of his/her well-being. Health related quality of life reflects the impact of a health state of a person's ability to lead a fulfilling life, and covers the individual's satisfaction in physical, functional, psychological and social domains”. These researchers investigated the impact aphasia may have on quality of life, specifically addressing difficulties in interpersonal relationships and the loss of independence. They examined 146 subjects who had sustained a left hemisphere stroke and right hemiparesis and varying degrees of aphasia. They also included 37 control subjects as a comparison group. In order to determine the role of aphasia in quality of life the researchers created a quality of life questionnaire for people with aphasia. Questions within the questionnaire addressed the ability to perform basic functions, the ability to convey health problems, the psychological changes due to the disability, the ability to socialize and the ability to comprehend and express language in routine daily activities. The questionnaire was given by a speech therapist using gestures and drawing if participants showed trouble with communicating their thoughts. The results indicated that people with aphasia reported significantly worse quality of life than the control subjects because their aphasia influenced independence, social relationships and access to their environment. The statistically significant findings between people with aphasia and the control subjects led researchers to conclude that aphasia affects a person's quality of life by affecting his/her communication, autonomy and psychological well-being.

These findings corroborated the results from an earlier study that also found that communication difficulties negatively impacted different aspects of quality of life in people with aphasia (Cruice, Worrall, Hickson and Murison, 2003). Cruice et al., (2003)

investigated the quality of life in 30 people 57-88 years of age (mean=70.7) with mild to moderate chronic aphasia. Thirteen standardized instruments were used that evaluated health related quality of life, emotional health and well-being. Multiple regression analyses indicated that the communication abilities of people with aphasia were predicative of their psychological well-being and emotional health. More specifically, they found that better communication abilities enhanced the psychological well-being and emotional health of people with aphasia thereby improving their quality of life. They also found that older age correlated with lower functional communication ability, involvement in fewer communicative activities and participation in fewer social activities. The researchers concluded that the quality of life of people with aphasia is best understood from their social participation, emotional health and psychological well-being.

Synthesis. There are many psychosocial factors that can influence quality of life (Mitchell, Benito-León, González & Rivera-Navarro, 2005). Earlier it was discussed how social media in adolescents can cause anxiety and loneliness (Davey, 2016). If these same feelings were felt by people with aphasia, than it would indicate a lower quality of life. This would make it clear that social media has a negative effect on quality of life meaning it should not be used in therapy techniques. However, these same studies have not been carried out on the aphasic population, so it is only possible to speculate the connection. A study on the general adolescent population states that screen based media leads to a higher quality of peer relationships (Iannotti, Kogan, Janssen and Boyce, 2009). Since this a higher quality of relationships, it could also mean that quality of life would be higher. Therefore, if the study's conclusion also applied to people with aphasia

then social media, as a form of screen based media, could positively impact their quality of life.

Types of Social Media

Advances in technology over the last decade have created a significant increase in overall social media use as a way in which people maintain relationships and remain socially active anywhere in the world. According to Perrin (2015) of Pew Research Center, nearly two thirds of American adults use social networking sites. Ninety percent of young adults or ages 18 to 29 are most likely to use social media and social media use in people 65 and older has increased from 2% to 35% over the last decade. The data were also analyzed according to gender where 68% of women were more active in using social media as compared to 62% of men. The center also reported a larger percentage of suburban (68%) and urban residents (64%) used social media compared to rural residents (58%).

Takaoka (2016), an employee of Social Media Marketing and Consulting, lists several types of social media platforms. According to this site, Facebook is one of the more mainstream sites, having 1.04 billion active daily users as of December 31, 2015. LinkedIn is another similar type of platform designed specifically for the business community. The platform allows users to create profiles, which are then used to create "friends" that they trust professionally. Both platforms primarily use reading and writing to convey messages that can be accompanied by images or videos. Microblogging also uses reading and writing to share information, but in shorter spaces, usually limited to a certain number of characters. For instance, Twitter has a limit of 140 characters, and users tend to post more frequently than other platforms. Tumblr has a reblog feature, like

twitter that allows the user to share content from other people, as well as other people to share yours.

Takaoka (2016) describes other platforms that rely primarily on pictures for communication. Instagram allows users to post and view images which friends view and comment on. Instagram will work on a computer, but is best used on a smartphone or tablet. Snapchat allows users to send pictures back and forth, while also having a conversation. Therefore, it is a cross between a messaging platform and an image platform. The videos or pictures only last up to 10 seconds, then they are gone. Flickr is popular with photographers as a great resource for images.

Likewise, Takaoka (2016) talks about video sharing including platforms that allow users to upload videos that can be shared. For example, Youtube is one such site, having 1.3 billion users who watch almost 5 billion videos per day. Vimeo was the first videosharing platform that was able to support HD video, often this is used in place of Youtube for video professionals. Google+ offers Hangouts allow up to nine people to video chat at the same time on any device.

Several studies have investigated the influence of social media on improving social connectedness and emotional well-being of people across different demographics (e.g., Erickson & Johnson, 2011; Ahn & Shin, 2013; Quinn & Oldmeadow, 2013). For example, Ahn and Shin (2013) examined how social media and seeking connectedness to others through social media impacts a user's emotional well-being. In this study, 150 males and 150 females whose ages ranged from 19 to 39 were given a questionnaire containing three sections. The first section asked about emotional well-being, social isolation and social connectedness. The second section asked about the amount of time

the subjects spent on social media and face-to-face communication. Lastly, the survey asked about demographic backgrounds such as age, gender, education and annual income. The results indicated that users of social media tend to use it to stay connected but that does not necessarily reduce social isolation. Whereas, face-to-face communication not only connects people but also reduces isolation. Therefore, the authors concluded that individuals may use social media and face-to-face interactions when seeking connections to others, but face-to-face interactions are much better than social media in reducing social isolation and improving emotional well-being.

Synthesis. Aphasia primarily affects those in the older population because strokes are much more common as people age. However, it is important to note the effects of social media on the younger generation. As stated before, the younger population is more prone to anxiety and loneliness from social media (Davey, 2016). This idea could possibly be applied to people with aphasia who use social media, but ultimately they are different ages so social media may not have the same effect. This suggests the importance of doing a study on social media and people with aphasia.

Technology and Aphasia

People with aphasia have difficulty communicating in face-to-face social situations. Those same communication deficits can also interfere with the ability to use social media. However, many different types of technology that assists in regaining and/or compensating for language deficits in face-to-face social situations can be adapted for social media use. The National Aphasia Association (n.d.) details different assistive technologies that can be helpful for persons with aphasia, caregivers, and speech-language pathologists working with aphasia clients to compensate for communication

deficits. For example, Prologuo2Go is an assistive technology application for an iPad, iPhone, and iPod touch that provides a voice for people who are unable to speak or have difficulties speaking. Lingraphica offers three communication devices for adults with aphasia. The first, AllTalk, is available on laptops, and can be used with EyeGaze technology to help individuals that have physical limitations and use hands-free devices to communicate. TouchTalk and MiniTalk are available on tablets to provide an easy way to communicate by touching icons on a screen that correspond to language used in activities of daily living. All of the devices come with 17 voices, email and instant messaging abilities, and therapy activities. Tapgram allows a user to create messages by tapping on images, the messages can then be posted on social media or sent to friends through email. The app requires a connection and works with phones, tablets, and computers.

Many of the programs mentioned above can be used on iPhones, iPads and laptops to assist people with reading and writing deficits in accessing Facebook and other social media sites. For instance, Lingraphica can use eye gaze on a computer to type out words, which could then be posted on social media such as Facebook, Twitter or a blog. Many phones contain assistive technology like word prediction software, which will suggest a variety of word choices, making it easier to create messages. Phones and laptops also have built-in features, such as text-to-speech and increasing font size, which can help with reading deficits.

People with aphasia can also communicate over social media through pictures. By using pictures, people with aphasia are able to communicate how they are feeling when they are unable to form words. For instance, through Snapchat, people could use different

filters and settings to show when they were upset versus happy, simply by clicking buttons on their phone. The same goes for the social media site Instagram, which is all done through pictures with minimal captions.

Overall, different types of assistive technology can help people with aphasia to access social media. Brandenburg, Worrall, Rodriguez and Copland (2013) emphasized the importance of technology for non-rehabilitative uses and suggested that improving access to mobile technology can enhance social participation in addition to compensating for communication deficits associated with aphasia.

Social Media and Aphasia

Many people with aphasia have limited physical access to support networks, which compels them to turn to the Internet in order to seek resources that they may not find in their own communities. Hinckley, Hasselkus and Ganzfried (2013) investigated what people living with aphasia thought about the availability of aphasia resources. The study included 302 participants with aphasia that were broken up into four focus groups that also included their caregivers. They were given an online survey about the availability of aphasia resources and an analysis of the responses from the survey formed the focus group questions. The results showed that people rated aphasia resources as somewhat difficult to find, health care providers do not have many recommendations on aphasia resources and there is an overall lack of awareness of aphasia. The most important resources that people felt were the most needed included local aphasia support groups that provided the opportunities for social interaction and networking.

The Internet provides access to a wide variety of social media options that will access online aphasia support groups, such as AphasiaNow (n.d.), whose mission is

"people with aphasia helping each other to become independent, communicate with other aphasic people and overcome aphasia together". This website offers links to AphasiaNow on Facebook, Twitter and a variety of blogs. Another website, the Aphasia Recovery Connection (n.d.), states that over 95% of people with aphasia are not located near an aphasia center, and most have never met another person with aphasia. The aim of the group is to allow people to get advice, share experiences and get to know others with aphasia and their caregivers through online networking, such as Facebook and other social media. The ASHA Leader Blog (2017) also offers a blog that has a separate section just on aphasia topics.

The research on the use of social media by people with aphasia is limited. However, research does exist regarding social media use by people with disabilities. For instance, Shipigelman and Gill (2014) investigated Facebook use by persons with disabilities, including physical, mobility, sensory, communication, intellectual and/or mental disabilities. The researchers administered an online survey which contained 19 questions across three main sections including: frequency of Facebook use, number of disabled and non-disabled Facebook friends, online activities, how users perceive and experience Facebook, demographic information (gender, age, education, occupation, ethnicity and disability type), as well as open ended questions to add additional comments. One hundred seventy two people with disabilities responded to the survey. Six of those people had communication deficits. The majority of respondents reported that they have other disabled friends on Facebook. Some respondents also reported that they view Facebook as an accessible environment to have interactions and an easy way to communicate with others. One person reported that using Facebook has helped to reduce

her feelings of isolation and loneliness as she rarely leaves the house and this is her main social life. The same person also reported that spending time on Facebook can cheer her up. Respondents also noted that Facebook was a good way to relax during leisure time for enjoyment. Overall, people with disabilities that participated in this study viewed Facebook as an online environment that offers social, emotional and professional support. Although this study did not mention people with aphasia directly, they fall within the disabled population and therefore may also benefit from using Facebook to reduce social isolation.

Whittemore (2016) investigated the relationships between accessing and using Facebook and quality of life of people with aphasia. Four participants with aphasia that were at least one-year post onset stroke participated in the study. Whittemore used a single subject design and aphasia friendly materials to train the participants to use assistive technology to access the social media site Facebook. Specifically, she gave each participant a color coded binder with step by step aphasia friendly instructions such as, pictures, large text and highlighting, for using an iPad and Facebook. Using this binder she had one-on-one sessions with each participant to introduce new information and for them to each ask questions individually. The researcher measured quality of life by using the *Assessment for Living with Aphasia (ALA)* (Kagan, Simmons-Mackie, Rowland, Huijbregts, Shumway, McEwen & Sharp, 2008) before training and four weeks after training. Facebook activity was also recorded and participants were given a self-report survey to measure changes in comfort and knowledge with regards to Facebook and the accessibility features. The results of the study demonstrated that training people with aphasia to access Facebook increased the number of original posts, likes, comments and

shares for three out of the four participants. The study also found that participants scored higher on the post-training self-report questions on the ALA that were indicators for quality of life. With assistive communication devices, people with aphasia are able to communicate with more people through social media, which positively impacted their quality of life.

Blogs are gaining popularity as a way for people with aphasia to post personal information in the public domain. By analyzing the entries in aphasia blogs, researchers are able to gain better insight into what people with aphasia are thinking and feeling. Fotiadou, Northcott, Chatzidaki and Hilari (2014) researched the impact of stroke and aphasia on a person's relationships with family, friends and a larger network by analyzing blogs written by people with aphasia. Six women and four men with chronic aphasia aged 26 to 69 participated in this study. All of the participants lived in the community and were at least one-year post onset stroke. The researchers used blog search engines to find blogs that were written by individual authors who had aphasia following a stroke, and that discussed their social networks. The results showed that participants had less contact with friends partially due to communication and physical difficulties. Participants stated that it was more difficult to take part in family activities and reported changed family dynamics following their strokes. Some participants reported that they had become motivated to join stroke support groups. However, using blogs did enable them to connect with a larger network to share their thoughts and feelings. In conclusion, the study found that social relationships do play an important role in people's lives following a stroke and family relationships, friendships and social exchanges were all impacted by

aphasia. The authors suggested that the use of social media by people with aphasia should be further explored in therapy and as a means for social networking.

Conclusions

Based on this literature review, research suggests that social media can be a factor in determining quality of life of people with aphasia. There is evidence to suggest that communication difficulties as part of aphasia can lead to feelings of social isolation (e.g., Johansson et al., 2012; Brown et al., 2013). These feelings of social isolation then negatively impact quality of life (Cruice et al., 2003; Spaccavento et al., 2014). Over the last decade, there have been many advances in technology leading to an increase in social media use by people throughout the world to stay connected (Perrin, 2015). Studies have found that using social media in addition to face-to-face interactions improves social connectedness and quality of life in people without disabilities (Erickson & Johnson, 2011; Ahn & Shin, 2013; Quinn & Oldmeadow, 2013), although subjects in one study reported that face-to-face interactions were better than social media to improve emotional well-being (Ahn & Shin, 2013). Many people with aphasia reportedly do not live near an aphasia center and have limited access to face-to-face social interactions with others who have aphasia (Hinkley, Hasselkus and Gazfried, 2013). Therefore, the Internet and the use of social media may provide a variety of ways for people with aphasia to communicate with each other. To help compensate for language deficits when using social media, there are a multitude of programs that assist with speaking, writing and reading. With these programs, a person with aphasia has access to almost every social media site depending on his/her functional level of communication. Social media allows

people with aphasia to connect with others that have aphasia through chats and groups on sites like Facebook and Twitter, as well as through blogs. This connectedness may enable them to form bonds and get support, which may in turn improve their quality of life. Emerging evidence suggests that by using social media, people with aphasia are able to connect with others, which has been shown to improve quality of life (Whittemore, 2016).

Important takeaways from this thesis include the idea that age may play a factor into social media affect. Those in the younger generation are less likely to have aphasia, however, they are more likely to succumb to feelings of anxiety and loneliness (Davey, 2016). Studies also show that psychosocial factors have an influence on quality of life in people with multiple sclerosis (Mitchell, Benito-León, González & Rivera-Navarro, 2005). It is also important to understand that one study found that screen based media positively impacted quality of peer relationships in adolescents (Iannotti, Kogan, Janssen & Boyce, 2009). This could mean that social media has a positive effect on quality of life. There may be similar correlations between adolescents and adults with aphasia regarding the use of social media and quality of life that should be explored in future studies.

Future Directions

As mentioned in the conclusion, the research on social media's influence on social isolation in people in aphasia is just emerging. Therefore, future studies need to continue to focus on how social media impacts the social isolation and quality of life of people with aphasia. Future research should also examine more deeply the different factors that determine quality of life, as they differ from study to study. It is also interesting to think

about the relationship between geographical location and social isolation. People who live in rural areas, may have less physical access to talk to people face-to-face, as they are further away from people compared to someone who lives in an urban area. Therefore, research should address how a rural versus urban area affects social isolation and social media use. Further research may also continue to address the relationship between reading and writing and social media use. While there are apps to help with communication, a person with reading and spelling deficits may have more difficulty using the platforms that require words. I would also propose that more research address all different types of social media. Most of the research addresses asynchronous social media sites and has not yet included platforms that provide synchronous visual and verbal social interactions, such as video conferencing. For example, (Walker, Jacques & Price, in progress) just completed a study that addressed reducing isolation by connecting people with aphasia in a synchronous online aphasia communication group. Findings from this study revealed that language abilities, functional communication, establishing friendships and emotional well-being improved from participating in this group.

Future studies should also look into how different types of aphasia used social media in different ways. One person might choose to use a word prediction software in order to communicate through social media. Another person who has reading deficits may choose to use text-to-speech in order to help with social media use. This software could enable them to listen to the different postings on something like Facebook instead of having to read them, making it much easier. Depending on the type and severity of aphasia it is possible to determine which ways people adapt social media to help them communicate, which further studies should research.

Outline for a Proposed Study

Title. Exploring the effects of social media on the quality of life of people with aphasia.

Rationale. As discussed in the literature review, it is clear that there is a lack of understanding as to how social media affects people with aphasia. This study aims to explore this area in hopes of influencing therapy and treatment options. The communication deficits associated with aphasia may reduce the frequency of communication interactions with others, thereby leading to feelings of social isolation (e.g., Parr, 2007; Davidson, Howe, Worrall, Hickson & Togher, 2008; Johansson, Carlsson & Sonnander, 2012; Brown, Davidson, Worrall & Howe, 2013). These communication deficits and feelings of social isolation have been found to negatively impact quality of life (e.g., LaPointe, 1999; Cruice, Worrall, Hickson & Murison, 2003; Ross & Wertz, 2003; Spaccavento, Craca, Del Prete, Falcone, Colucci, Di Palma & Loverre, 2014). The advances seen in technology over the last decade have created a significant increase in overall social media use as a way for people to maintain relationships and remain socially active. Studies show that social media has been used by people when seeking connectedness (e.g., Erickson & Johnson, 2011; Ahn & Shin, 2013; Quinn & Oldmeadow, 2013). People with aphasia have difficulty communicating in face-to-face social situations. The same deficits may also interfere with the ability to use social media. The National Aphasia Association (n.d.) outlines many different assistive devices that can be helpful for people with aphasia to use to access social media. Many people with aphasia have limited physical access to support networks, which compels them to seek resources they may not have in their own community. By using assistive devices

outlined, people with aphasia are able to access social media mostly unhindered allowing them to stay connected to others with aphasia. This study explores the assertion that *by using assistive technologies to access social media and find resources, as well as to connect with other people who have aphasia, there is a reduction in social isolation thereby increasing quality of life.*

Methods. This study will involve an online survey administered through the social media website, Facebook. The survey will not take longer than a half hour to complete and will include both Likert scale response questions and open-ended response questions. Likert scale questions will be analyzed to determine mean, mode and range of responses. Open-ended questions will be analyzed to determine common themes among a few of the answers. A sample list of questions is provided in Appendix A.

By administering the survey through Facebook, people with aphasia will be able to use aphasia friendly technologies that are discussed earlier in the thesis. The survey will have a larger font to make it easier to read, but people could also use text-to-speech for the questions to be read to them. Sentences will be as short as possible and contain everyday words to make them clearer for the person with aphasia. They can use their mouse to click on the answer for Likert scale questions. The survey will mostly be Likert scale questions because those are the easiest to answer. The questions will be in a pattern to make them easier to follow. It is also possible for the caretaker to assist the person with aphasia in completing the survey.

Participants. Participants will be found through the Aphasia Center of Maine. Participants may be any age, gender or race. They may also have any occupation or type

of aphasia. The proposed number of participants is 25. This number will be sufficient to find a variety of responses and still identify common themes.

Informed consent. At the beginning of the survey there will be a page containing informed consent, which participants will need to agree to before answering questions in the survey.

Confidentiality. Precautions will be taken so that confidentiality is ensured. Only Dr. Walker and I will have access to the direct answers given. Summaries of answers received will be included within the thesis. A surveying site will be used that will only determine the participant based on age, gender, race, occupation and type of aphasia. No names will be used to ensure complete confidentiality.

Risks. Risks to participants include use of their time and possible inconvenience. If aphasia is severe, completing the survey may also cause frustration.

Benefits. Participating in this study may benefit future therapeutic techniques. Determining how social media affects quality of life for people with aphasia will allow the researchers to make recommendations on how social media can be used in therapy. If social media is found to have a positive impact, then more aphasia groups could be formed online for people to stay in contact with others who have aphasia. Results could also influence if social media should be used in therapy sessions, such as teaching people with aphasia how to access and use social media so that they may use it to access others with aphasia.

References

- Ahn, D., & Shin, D. (2013). Is the social use of media for seeking connectedness or for avoiding social isolation? Mechanisms underlying media use and subjective well-being. *Computers in Human Behavior*, 29(6), 2453-2462.
doi:10.1016/j.chb.2012.12.022
- Aphasia Now. (n.d.). Social Networking. Retrieved April 10, 2017, from http://www.aphasianow.org/What_is_Aphasia/Aphasia_Social_Networks/
- Aphasia Recovery Connection. (n.d.). Retrieved April 10, 2017, from <https://www.aphasiarc.org>
- Brandenburg, C., Worrall, L., Rodriguez, A. D., & Copland, D. (2013). Mobile computing technology and aphasia: An integrated review of accessibility and potential uses. *Aphasiology*, 27(4), 444-461. doi:10.1080/02687038.2013.772293
- Brown, K., Davidson, B., Worrall, L. E., & Howe, T. (2013). "Making a good time": The role of friendship in living successfully with aphasia. *International Journal of Speech-Language Pathology*, 15(2), 165-175.
doi:10.3109/17549507.2012.692814
- Cruice, M., Worrall, L., Hickson, L., & Murison, R. (2003). Finding a focus for quality of life with aphasia: Social and emotional health, and psychological well-being. *Aphasiology*, 17(4), 333-353. doi:10.1080/02687030244000707
- Damasio, A. R. (1992). Aphasia. *The New England Journal of Medicine*, 326(8), 531-539. doi:10.1056/NEJM199202203260806
- Davey, G. C. (2016, December 15). Social Media, Loneliness, and Anxiety in Young People. Retrieved June 09, 2017, from

<https://www.psychologytoday.com/blog/why-we-worry/201612/social-media-loneliness-and-anxiety-in-young-people>

- Davidson, B., Howe, T., Worrall, L., Hickson, L., & Togher, L. (2008). Social participation for older people with aphasia: The impact of communication disability on friendships. *Topics in Stroke Rehabilitation, 15*(4), 325-340. doi:10.1310/tsr1504-325
- Erickson, J., & Johnson, G. M. (2011). Internet use and psychological wellness during late adulthood. *Canadian Journal on Aging/Revue Canadienne Du Vieillissement, 30*(2), 197-209. doi:10.1017/S0714980811000109
- Fotiadou, D., Northcott, S., Chatzidaki, A., & Hilari, K. (2014). Aphasia blog talk: How does stroke and aphasia affect a person's social relationships? *Aphasiology, 28*(11), 1281-1300. doi:10.1080/02687038.2014.928664
- Goodglass, H., & Kaplan, E. (1972). *The assessment of aphasia and related disorders*. Philadelphia: Lea & Febiger.
- Hillis, A. E., & Caramazza, A. (2003). Aphasia. In L. Nadel, *Encyclopedia of Cognitive Science*, (Vol. 1, pp. 175 – 184). London, UK: Nature Publishing Group.
- Hinckley, J. J., Hasselkus, A., & Ganzfried, E. (2013). What people living with aphasia think about the availability of aphasia resources. *American Journal of Speech-Language Pathology / American Speech-Language-Hearing Association, 22*(2), S310. doi:10.1044/1058-0360(2013/12-0090)
- Iannotti, R. J., Kogan, M. D., Janssen, I., & Boyce, W. F. (2009). Patterns of adolescent physical activity, screen-based media use, and positive and negative health indicators in the U.S. and Canada. *Journal of Adolescent Health, 44*(5), 493-499. doi:10.1016/j.jadohealth.2008.10.142

- Johansson, M. B., Carlsson, M., & Sonnander, K. (2012). Communication difficulties and the use of communication strategies: From the perspective of individuals with aphasia. *International Journal of Language & Communication Disorders*, *47*(2), 144-155. doi:10.1111/j.1460-6984.2011.00089.x
- Kagan, A., Simmons-Mackie, N., Rowland, A., Huijbregts, M., Shumway, E., McEwen, S., & Sharp, S. (2008). Counting what counts: A framework for capturing real life outcomes of aphasia intervention. *Aphasiology*, *22*(3), 258-280. doi:10.1080/02687030701282595
- LaPointe, L. L. (1999). Quality of life with aphasia. *Seminars in Speech and Language*, *20*(1), 5.
- Mitchell, A. J., Benito-León, J., González, J. M., & Rivera-Navarro, J. (2005). Quality of life and its assessment in multiple sclerosis: Integrating physical and psychological components of wellbeing. *The Lancet. Neurology*, *4*(9), 556.
- National Aphasia Association. (n.d.). Retrieved April, 2017, from <https://www.aphasia.org/>
- National Stroke Association. (2017). Retrieved April, 2017, from <http://www.stroke.org/>
- Parr, S. (2007). Living with severe aphasia: Tracking social exclusion. *Aphasiology*, *21*(1), 98-123.
- Perrin, A. (2015, October 08). Social Media Usage: 2005-2015. Retrieved from <http://www.pewinternet.org/2015/10/08/social-networking-usage-2005-2015/>

- Quinn, S., & Oldmeadow, J. (2013). The martini effect and social networking sites: Early adolescents, mobile social networking and connectedness to friends. *Mobile Media & Communication*, 1(2), 237-247. doi:10.1177/2050157912474812
- Rohde, N., D'Ambrosio, C., Tang, K. K., & Rao, P. (2016). Estimating the mental health effects of social isolation. *Applied Research in Quality of Life*, 11(3), 853-869. doi:10.1007/s11482-015-9401-3
- Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology*, 17(4), 355-364. doi:10.1080/02687030244000716
- Shipigelman, C., & Gill, C. J. (2014). Facebook use by persons with disabilities. *Journal of Computer-Mediated Communication*, 19(3), 610-624. doi:10.1111/jcc4.12059
- Spaccavento, S., Craca, A., Del Prete, M., Falcone, R., Colucci, A., Di Palma, A., & Loverre, A., (2014). Quality of life measurement and outcome in aphasia. *Neuropsychiatric Disease and Treatment*, 10, 27-37.
- Takaoka, K. (2016, April 14). 10 Types of Social Media Platform. Retrieved from <http://sbtvirtual.ca/10-types-social-media-platform/>
- The ASHA Leader Blog [Web blog]. (2017). Retrieved from <http://blog.asha.org/>
- Walker, J.P., Jacques, K. & Price, K. (in progress). Building Community in a Telepractice Aphasia Communication Group: Feasibility Study.
- Whittemore, J. K. (2016). *Using accessibility features to access social media and improve quality of life for people with aphasia* (Master's thesis). Retrieved from <http://www.library.umaine.edu/auth/EZProxy/test/authej.asp?url=http://search.proquest.com/docview/1808210793?accountid=145>

Appendix A: Sample Questions

1. What is your gender? Female, Male, Prefer not to answer
2. What is your ethnicity? White, Hispanic or Latino, Black or African American, Native American or American Indian, Asian/Pacific Islander, Other
3. What is your age? Fill in the blank
4. How old were you when you had your stroke? Fill in the blank
5. What do you have trouble with? Listening, Speaking, Reading, Writing
6. What is your level of education? Did Not Complete High School, High School Diploma, GED, Some College, Associates Degree, Bachelors Degree, Masters Degree, PhD
7. What is your occupation? Fill in the blank
8. I use social media often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree
9. I use Facebook often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A
10. I use Twitter often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A
11. I use Instagram often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A

12. I use Snapchat often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree.

N/A

13. I use Flickr often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A

14. I use Youtube often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree,

N/A

15. I use Vimeo often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A

16. I use Google+ often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree,

N/A

17. I use LinkedIn often. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree,

N/A

18. I have a positive experience with Facebook. Strongly Agree, Agree, Neutral,

Disagree, Strongly Disagree, N/A

19. I have a positive experience with Twitter. Strongly Agree, Agree, Neutral, disagree,

Strongly Disagree, N/A

20. I have a positive experience with Instagram. Strongly Agree, Agree, Neutral,

Disagree, Strongly Disagree, N/A

21. I have a positive experience with Snapchat. Strongly Agree, Agree, Neutral, Disagree,

Strongly Disagree, N/A

22. I have a positive experience with Flickr. Strongly Agree, Agree, Neutral, Disagree,

Strongly Disagree, N/A

23. I have a positive experience with Youtube. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A

24. I have a positive experience with Vimeo. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A

25. I have a positive experience with Google+. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A

26. I have a positive experience with LinkedIn. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree, N/A

27. Social media has improved my social connections. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

28. Social media has helped me communicate in a way that I could not do face-to-face. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

29. Social media has helped me feel socially connected. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

30. Social media has helped me to create new friendships. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

31. Social media has helped me find more aphasia resources than I could find in my community. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

32. My social media use has helped me keep friendships I had before aphasia. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

33. My social media use has made my quality of life better. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

34. Social media has made my communication better. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

35. Social media has made my overall mood better. Strongly Agree, Agree, Neutral, Disagree, Strongly Disagree

36. What is your favorite form of social media? Facebook, Twitter, Instagram, Snapchat, Flickr, Youtube, Vimeo, Google+, LinkedIn, other

37. What types of aphasia technology do you use to access social media? Prologuo2Go, Lingraphica, Tapgram, word prediction software, text-to-speech, increased font size, speech-to-text, other

Biography

Megan D. Morey was born in Concord, New Hampshire on March 5th, 1995. She was raised in Chichester, New Hampshire and graduated from Bishop Brady High School in 2013. Majoring in Communication Sciences and Disorders, Megan has minors in Psychology and Interdisciplinary Disabilities Studies. She is a member of Phi Beta Kappa, Gamma Sigma Sigma, Best Buddies, and National Student Speech Language Hearing Association. She has received a University of Maine Black Bear Scholarship and spent a semester abroad studying in Stirling, Scotland. Upon graduation, Megan plans to work as a Paraprofessional, Speech Language Pathologist Assistant or Behavioral Therapist before going to Graduate School for a Masters in Speech Language Pathology.