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REMOTE SUPPORTED COMMUNICATION FOR ADULTS WITH CHRONIC APHASIA: A SERENDIPITOUS STUDY

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REMOTE SUPPORTED COMMUNICATION FOR ADULTS WITH CHRONIC APHASIA: A SERENDIPITOUS STUDY

THESIS

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in Communication Sciences and Disorders in the
College of Health Sciences
at the University of Kentucky

By

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Lexington, Kentucky

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2021

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ABSTRACT OF THESIS

REMOTE SUPPORTED COMMUNICATION FOR ADULTS WITH CHRONIC APHASIA: A SERENDIPITOUS STUDY

Supported communication is defined as anything that improves access to or participation in communication events or activities (King, Simmons-Mackie, & Beukelman, 2012). This thesis describes the results of a study that took place when a training program to provide graduate students in Communication Sciences and Disorders (CSD) with "hands on" experience in providing supported communication to persons with chronic aphasia (PWA) was interrupted by the outbreak of Coronavirus-19 and switched to a remote delivery format to fulfil service and training obligations to the PWA and the CSD graduate students respectively. The study (1) describes the actions taken to covert a program of traditional in person supported communication to a virtual program called Remote Supported Communication (RSC), (2) examines selected aspects of RSC from the perspectives of the CSD graduate student clinicians, and (3) summarizes what was learned about RSC that might guide and improve its outcomes in the future.

KEYWORDS: Aphasia, Remote Supported Communication, COVID-19,
Communication Sciences and Disorders

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REMOTE SUPPORTED COMMUNICATION FOR ADULTS WITH CHRONIC APHASIA: A SERENDIPITOUS STUDY

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Lastly, I must thank two groups of people on whom this thesis hinged. This thesis was only made possible due to the exceptional efforts of my classmates, who not only served as the Aphasia Lab clinicians who quickly and seamlessly adapted to a remote model of therapy, but who also aided my research by completing several surveys, questionnaires, and by providing detailed notes on each of the lab participants and their weekly sessions. I must not only thank my classmates, but also the participants of the Aphasia Lab and their families who inspired me and allowed me to write about their successes and difficulties during these unconventional times. These are individuals who face daily challenges in a typical year, but who faced even greater difficulties throughout the COVID-19 global pandemic. Despite these challenges, these individuals consistently persevere, overcome, and adapt; they are the true inspiration and passion behind this thesis, and the individuals to whom I owe my gratitude.

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CHAPTER 1. INTRODUCTION

Aphasia is an acquired language disorder affecting input and output modalities resulting from damage to the brain's language dominant hemisphere, usually from a stroke (Brookshire, 2007). Aphasia has profound functional, psychosocial, and emotional consequences for stroke survivors and their families. These include activity limitations such as having fewer conversations (Elman, 1994; Kagan & Gailey, 1993; Kagan, 1998), participation restrictions reflected by abandonment of formerly enjoyed activities and fewer social contacts (Cruice, Worrall, & Hickson, 2006), and strained interpersonal relationships (Croteau, LeDorze, & Morin,2008; Doyle, McNeil, Hula, & Mikolic, 2003). Research has also shown people with aphasia (PWA) to have a reduced quality of life and to suffer from depression, loss of confidence, and reduced self-esteem (Shadden, Hagsron, & Kroski, 2008; Simmons-Mackie, King, & Beukelman, 2012).

There is no medical cure for aphasia but PWA have been found to improve their ability to communicate following spontaneous recovery and treatment. The most common non-medical treatment for aphasia is speech and language therapy also referred to as aphasia therapy (Brady, Kelly, Godwin, Enderby, & Campbell, 2016). Research has shown that aphasia therapy is efficacious if provided in sufficient amounts by qualified therapists (Allen, Mehta, McClure, & Teasell, 2012; Bhogal, Teasell, & Speechley, 2003; Brady et al., 2016; Robey, 1998, 1994). In the United States most aphasia therapy is provided in the acute (0-1-month post-onset) and sub-acute (1-4 months post onset) phases of stroke recovery. During this time, the cost of treatment is usually covered, totally or in part, by health insurance and/or Medicare. Once a person's aphasia becomes chronic (4-6 months post-onset and beyond), however, funding for treatment is limited. Persons with chronic aphasia desiring to continue in treatment to maintain and/or further improve communication skills are therefore required to forego treatment, pay treatment out of pocket, or seek treatment at a lesser cost. A recent report from Aphasia Access (2018) estimated that there are approximately 2.4 million persons in the United States living with chronic aphasia.

Three approaches to aphasia treatment, impairment-based, functional, and supportive, dominate the aphasia therapy literature. Impairment-based treatments are intended to restore as much language function as the patient's damage system allows (Rosenbek, LaPointe, & Wertz, 1989) through repetitive and intensive stimulation of disrupted language processes (Coelho, Sinotte, & Duffy, 2008). Impairment-based treatments have typically been used in the acute and sub-acute phases of stroke recovery. Functional treatment is often introduced shortly before or after the patient leaves the hospital or rehabilitation center and returns to a communicating society. Functional treatments take into consideration that PWA often "communicate better than they talk " (Holland, 1977) and emphasize "communication" success over linguistic accuracy by encouraging the patient to convey his/her thoughts and needs by any means possible. Functional treatments for PWA also address the communication demands associated with "activities of daily living" (i.e., riding the bus, calling for help in an emergency, ordering takeout food) and other skills that promote independence. Supportive treatments come into play when the individual's aphasia becomes chronic. Supportive treatments for PWA have gained popularity since publication of a position paper on the Life Participation Approach to Aphasia (LPAA; Chapey, Duchan, Elman, Garcia, Kagan, Lyon, & Simmons-Mackey, 2001). Supportive treatments are holistic, socially motivated, and often target communication partner training. Supportive treatment puts the PWA and those affected by aphasia at the center of all clinical decision-making, taking into consideration that aphasia is a life-long problem, and that the goal of aphasia treatment should be to help the person live with aphasia as successfully as possible.

As its title suggests, the opportunity for the investigator to do this Master's thesis arose unexpectedly when a clinical practicum course, CSD 657, intended to provide first year graduate students in Communication Sciences and Disorders (CSD) with a "hands on" experience in providing supported communication services to PWA was interrupted by the outbreak of a global pandemic, COVID-19. The pandemic made it necessary to either discontinue the program which would prevent the affected graduate students from obtaining the necessary hours to complete the course or find an alternative. A decision was made to switch the program of supported communication from an on-campus, in-person experience to a virtual format.

The aims of this very unconventional master's thesis were twofold. One was to document and describe the events that took place when the program of supported communication for PWA was switched from an in-person to a remote (virtual) format that will be referred to as Remote Supported Conversation (RSC). The second was to examine selected aspects of RSC from the perspectives of the student clinicians, to be referred to as simply clinicians for the remainder of this paper, who provided this "unique" virtual treatment in hopes of gleaning information that might be useful in the future. It is important to recognize that this thesis was an unplanned study and was not reviewed by the University of Kentucky Institutional Review Board (IRB). The "suddenness" of the outbreak of the pandemic and the urgency with which a decision had to be made to switch to a virtual format did not allow time for this. While lack of IRB approval precludes publication of this thesis in the archival literature, it does not lessen the informative value of the study to further provision of remote therapies.

CHAPTER 2. BACKGROUND INFORMATION

Supported communication as an intervention for PWA took root approximately 20 years ago after publication of a paper entitled Life Participation Approach to Aphasia: A Statement of Values for the Future (LPAA; Chapey et al., 2001) and publication of an initial set of guidelines from the World Health Organization, the International Classification of Functional, Disability, and Health (ICF). Since this time interest in the use of supported communication as an intervention for PWA has increased markedly (Elman, 2011; Holland, 2006, 2007, Holland & Elman, 2020; Kagan, Simmons-Mackie, Rowland, Huijbregts, Shumway, McEwen, & Sharp, 2008; Kagan & Simmons-Mackie, 2007; Martin, Thompson, & Worrall, 2008; Simmons-Mackie, King, & Beukelman, 2013; Worrall, Sherratt, Rogers, Howe, Hersh, Ferguson, & Davidson, 2011). This chapter will (1) define supported communication, (2) overview three interventions representative of supported communication, and (3) highlight how outcomes are measured for PWA receiving supported communication.

2.1 Definition of Supported Communication

Supported communication is “defined broadly as anything that improves access to or participation in communication events or activities” (King, Simmons-Mackie, & Beukelman, 2013, p. 9). This could involve education and training of PWA and different communication partners (i.e., family members, relatives, friends, caregivers, and service providers) desiring to improve communication with a PWA. Support may also involve providing materials and resources to PWA and their caregivers to facilitate message exchange and interaction in authentic communication contexts. Support could also entail advocacy efforts to break down barriers, change public attitudes, and alter public policies to improve communication access for PWA. In some respects, supported communication for PWA is akin to legislative actions taken to ensure access to public buildings and spaces by people in wheelchairs (Clark & Clark, 2003; Kagan & Gailey, 1993). It provides a "communication ramp" that permits PWA to reveal the underlying communication competency "masked" by aphasia (Kagan,1998; Kagan & Gailey, 1993). This intervention philosophy is also part of the mission statement of the American Speech-Language-Hearing Associations (ASHA) which is to make effective communication a human right accessible and achievable for all (ASHA, 2020).

2.2 Representative Supported Communication Interventions

A comprehensive review of all types of supportive communication interventions for PWA is beyond the scope of this master's thesis. However, to provide appropriate context for this study, and aid the reader's understanding of the events that took place and what was learned when an in-person program of supported communication was replaced by a virtual program of remote supported conversation, three popular supported communication interventions will be overviewed here.

2.2.1 Group Therapy

In group treatment of PWA, group facilitators (i.e. SLPs or other professionals) identify the supports needed by each member of the group to stimulate conversation and engagement with fellow group members (Elman & Hoover, 2012). This offers PWA opportunities to communicate with different partners in a more natural environment than individual treatment settings (Marshall, 1999; Brookshire, 2003). A group situation also gives PWA opportunities to try out different ways of communicating in a safe, but controlled space. PWA have reported they do not feel so “alone” in a group because they share a common bond with fellow group members (Marshall, 1993). Approaches to group treatment of PWA differ in accordance with the group sponsorship, settings, funding, cultural setting, and other factors. A review of group treatment (Kearns & Elman, 2008) classified aphasia treatment groups into four categories: psychosocial, family counseling/supportive, Speech-Language, and multipurpose. Most group programs fell into the Speech-Language category, but the authors suggested these groups also served multiple and overlapping purposes such as advocacy, transitioning, and maintenance. This seems to be supported in recent textbooks on group treatment for aphasia (Avent, 1997; Elman, 2007; Marshall, 1999). In sum, group treatment is a cost-effective approach to the management of aphasia, particularly those with chronic aphasia. The aphasia treatment literature suggests the efficacy and effectiveness of group treatment is equal to that of individual treatment and that group treatment is an important part of supportive communication.

2.2.2 Supported Conversation for Adults with Aphasia (SCA)

Supported Conversation for Adults with Aphasia (SCA; Kagan, 1998) is a program in which community volunteers are trained to appreciate and recognize the communicative competence of the PWA that is “masked” by aphasia (Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001). The training not only focuses on conversation, but emphasizes the social exchange, relationship, interaction, and interdependence between the PWA and the partner (Brown & Yule, 1983). Kagan and colleagues (Kagan et al., 2001) “expand” the use of the word conversation to include all forms of expression (i.e., speech, gesture, writing, drawing, and pointing) and underscore that both the PWA and the partner are responsible for working collaboratively to ensure effective communication. SCA training involves a one-day workshop provided by Speech-Language pathologists to community volunteers and PWA attending the North York Aphasia Center in Toronto, Canada (Kagan, 1998). Workshop participants learn about aphasia and receive hands on training and supervision in providing SCA. Volunteers successfully completing SCA training then work with small groups of PWA at the Aphasia Center to provide SCA. Kagan and her colleagues have developed observational measures to assess the effects of SCA training (Kagan, Winkel, Black, Duchan, Simmons-Mackie, & Square, 2004). Pre-and post-training measures have illustrated that volunteers improve their ability to provide SCA and that PWA are observed to communicate more effectively when communicating with a trained than an untrained partner. A study by Kagan, Simmons-Mackie, and Victor (2018) also revealed volunteers trained in SCA were better social communicators when interacting with PWA than volunteers who were simply “exposed” to PWA. Other studies have also reported that volunteers and staff members that received SCA training increased their confidence in communication with PWA after SCA training (Fucetola & Connor, 2015; Jensen, Loyholt, Sorensen, et al, 2015). Kagan (1995) has indicated that SCA provides the PWA with opportunities for genuine adult conversation and interaction by allowing them to take an active role in communication through collaboration with a conversational partner. She points out that this interaction is interdependent and one in which the partner acts as a resource for the PWA and shares the communication burden (Kagan, 1998).

2.2.3 Communication Partner Training

Communication partner training has been defined as “any intervention that targets those who interact with people with aphasia; addresses the attitudes, knowledge, and skills that will facilitate social interaction, and has as its goal enhanced social participation” (Hinckley, Douglass, Goff, & Nakano, 2013, p. 240). A recent systematic review (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010) revealed that targets of communication partner training usually include family members (i.e., spouses, children, and relatives) of the PWA. The partner training literature also shows that this intervention has also targeted individuals not directly related to the PWA. For example, an early report of a partner training study (Lubinski, 1986) taught nursing home personnel to exchange social greetings with a resident with severe aphasia during her speech and language treatment sessions. Lyon and colleagues (Lyon, Cariski, Keisler, et al. 1997) trained dyads consisting of a PWA and a “friend” to communicate with one another while carrying out “everyday activities” such as planting flowers and going to the barber shop for a haircut. Hickey, Bourgeois, & Olswang (2004) trained students to communicate regularly with residents in a nursing home. Legg, Young, and Bryer (2005) taught medical students to obtain case histories from individuals with aphasia as part of their clinical training.

Speech-Language pathologists, by virtue of their training and experience, have developed the skills to communicate effectively with PWA at all levels of severity. Partner training schemes essentially involve SLPs teaching family members, volunteers, and anyone willing to serve as a conversational partner for a PWA to use some of these same skills (Hopper, Holland, & Rewega 2002). It is reasonable that a PWA with more trained communication partners in his or her midst will have more opportunities to communicate and socially engage. For many PWA, this reduces social isolation, and in some cases, may improve patient care (Page, Marshall, Howell, & Rowells, 2019; Page & Rowells, 2016). Systematic reviews and meta-analyses of the effects of partner training clearly support the use of this supported communication paradigm, particularly for individuals with severe and chronic aphasia (Douglass, Goff, & Hinckley, 2009; Simmons-Mackey et al., 2010). Health care systems research also shows communication partner training schemes provide a low-cost, long-term care alternative for PWA (McVicker, Parr, Pound, & Duchan, 2009).

2.3 Outcome Measurement

Outcomes assess the effects of interventions (Fratalli, 1998). Outcomes for aphasia therapy have traditionally been measured with pre- and post-treatment comparisons of patient's performance on standardized aphasia tests such as the Western Aphasia Battery (Kertesz, 1979) and Porch Index of Communication Ability (PICA; Porch, 1981). Proponents of supported communication and the LPAA approach to management of PWA have moved away from the use of these impairment-based tests because these measures are (1) not always sensitive to improvements in communication, social functioning, and life participation by individuals with chronic aphasia, and (2) fail to take into consideration how the PWA communicate with support. A recent paper on the development of the A-FROM model (Framework for Outcome Measurement in Aphasia) (Kagan, Simmons-Mackie, Rowland, Huijbregts, Schumway, Mcewen,Threats, & Sharp, 2008) provides a means of measuring outcomes of interventions for PWA that focuses on “counting what counts” in helping the individual with aphasia participate more fully in a communicating society.

CHAPTER 3. METHODS

The COVID-19 pandemic struck the University of Kentucky (UK) during the week of March 16-20, 2020. At this time students were away from campus on spring break. Prior to spring break, 12 first-year graduate students in Communication Sciences and Disorders (CSD) had been providing supported communication services to 26 adults with chronic aphasia and/or related neurogenic communication disorders as part of a clinical practicum course, CSD 657 in the Aphasia Lab. These services had been ongoing for the first six weeks of the spring semester. The initial decision of the UK administration after the outbreak of the COVID-19 was to close the University for the first two weeks after spring break. However, this needed to be extended to encompass the entire spring semester when the pandemic worsened. This made it impossible to continue to provide the supported communication services to the 26 adults with aphasia on an in-person basis and threatened to deprive the graduate students of the necessary hours needed to complete their clinical practicum experience because students and Aphasia Lab participants would not be allowed to come on campus. Accordingly, an inter-departmental decision was made to continue to provide the supported communication services to persons in the Aphasia Lab remotely. These services will be referred to throughout the remainder of this thesis as remote supported communication (RSC).

3.1 Remote Supported Communication (RSC)

On March 18, 2020, each of the 26 participants in the Aphasia Lab was invited to participate in an RSC program for the final six weeks of the spring semester (See Appendix A). Twenty-one participants accepted this invitation. Fifteen of these individuals lived at home with a relative or spouse; five lived alone in single-family residences; one lived in a group home.

3.1.1 Schedule Changes

Aphasia Lab participant and student schedules differed markedly for the in-person and RSC experiences. When participants were seen in person and on campus, students met with their clinical instructor and provided supported communication services between the hours of 9 a.m. to 1:00 p.m. on Mondays and Wednesdays. Two graduate students were responsible for each participant or group. Individual and/or group sessions were typically scheduled for one hour. The switch to RSC in the second half of the spring semester made it impossible to follow this type of schedule because it conflicted with participant's home schedules (i.e., meals, sleep schedules, bath times, doctor appointments, and drop in visitors) and students' class and work schedules. This pivotal move was also not conducive for students to continue to work in two-person teams. Thus, for the RSC experience each student was assigned two participants with whom they were required to schedule at least one RSC session per person each week. Because there were program participants that opted not to participate in RSC, adjustments had to be made to equalize the workload for the students. In some cases, it was necessary to "double up" on some participants. Fortunately, some students had sufficient leeway in their class and work schedules that they were able to provide extra RSC sessions to their participants. It is important to point out that students were not required to provide extra RSC sessions, but some students deemed it necessary to be altruistic and provide extra sessions to participants who lived alone and were essentially isolated by the COVID-19 outbreak.

3.1.2 Oversight

Student's RSC sessions could not be supervised directly. Students met as a group with the clinical instructor at a scheduled time each week via Zoom for 60-90 minutes to review RSC plans and participants' responses to RSC. Students were free to communicate with the clinical instructor via email or phone when problems arose. Students provided hard copy documentation for RSC sessions to the clinical instructor for all RSC sessions via email. This was reviewed weekly and students were provided written feedback by the clinical instructor for each session.

3.1.3 Student's Perception of RSC

Information on student's perceptions of the RSC program was obtained by having each student complete a lengthy questionnaire for each RSC participant (Appendix B). This questionnaire required students to provide specific information related to the RSC program to aid the clinical instructor's evaluation of performance in the clinical practicum experience.

3.2 My Thesis

I had not considered doing a master's thesis as part of my program of study in Communication Sciences and Disorders. Like my other 11 classmates in the Aphasia Lab, my initial involvement in the RSC experience was associated with a pivotal move from the in-person program to RSC; however, unlike most students in the class, I was assigned a new participant in the person of CW, to whom this thesis is dedicated (See Chapter 6).

When the RSC program ended in April of 2020, I found it necessary to continue to provide RSC to CW into the summer months because he had some special needs (See Chapter 6). I discussed these needs with Dr. Marshall, my clinical instructor on a regular basis. As a part of these discussions, Dr. Marshall and I spoke about the benefits and challenges of the RSC program for adults with chronic aphasia, and particularly for CW. He suggested that a paper based on the RSC experience might make a good master's thesis and we discussed my taking on a thesis. Dr. Marshall cautioned me that since this would not be a planned study that had not received IRB approval, he would need to check with the Graduate School to determine if it would "qualify" as a master's thesis. After a lot of discussion, I agreed to take on a thesis project pending approval of the Graduate School. In the summer of 2020, Dr. Marshall contacted Dr. Brian Jackson, Acting Dean of the Graduate School, and explained that an opportunity had come to examine the use of RSC with PWA and related disorders. Dr. Marshall informed Dr. Jackson that the study was unplanned and had not been approved by the Institutional Review Board (IRB). He asked Dr. Jackson if a study conducted under such circumstances would be acceptable as a master's thesis by UK's graduate school and explained that the results of the study would not be submitted for publication. Dr. Jackson gave his approval to move forward with the thesis.

CHAPTER 4. RESULTS

Information on the 21 individuals that volunteered to participate in the RSC program is shown in Table 4.1. Communication disorder diagnoses of these individuals were based on the results of the individualized intake evaluations of each participant by the Aphasia Lab Director when the participant enrolled in Aphasia Lab. Table 4.1 shows that 18 of the 21 participants presented with some type of aphasia; two participants had cognitive-communication disorders associated with right hemisphere damage; and one participant had moderately severe speech intelligibility problems associated with ataxic dysarthria. Clinicians estimated the severity of each participant's communication disorder as mild, moderate, or severe. The students also rated the degree of communicative burden they assumed when communicating with each participant. This was done using a 10-point scale in which a rating of 1 indicated "little-to-no" burden assumed and a rating of 10 indicated assumption of "significant" burden. Table 4.1 indicates that the 21 participants reflected a range of communication disorders diagnoses, severity levels, and communicative burden ratings.

Table 4.1 Communication disorder(s) of participants receiving RSC, clinician estimates of severity of participant's communication disorder(s), and ratings of communication burden assumed when communicating with participants

Participant Number	Communication Diagnosis	Severity Estimate	Communication Burden Rating
1	Broca's aphasia, AOS	Moderate	8
2	Wernicke's aphasia	Severe	4
3	Cognitive-Communication	Mild	4
4	Anomic Aphasia	Mild	2
5	Conduction Aphasia	Moderate	4
6	Ataxic Dysarthria	Moderate	5
7	Transcortical Sensory	Mild	1
8	Anomic Aphasia	Moderate	3.5

Table 4.1 (continued)

9	Conduction Aphasia	Moderate	2.5
10	Broca’s Aphasia	Mild	1
11	Wernicke’s aphasia	Severe	10
12	Global aphasia	Severe	10
13	Broca’s aphasia, AOS	Moderate	2
14	Broca’s aphasia	Severe	4
15	Anomic aphasia	Moderate	4
16	Cognitive-Communication	Mild	2,5
17	Global aphasia, AOS	Severe	5
18	Anomic aphasia	Moderate	5
19	Conduction aphasia	Severe	8
20	Anomic aphasia	Moderate	6

4.1 RSC Sessions and Modalities

Sessions and modalities (technology) used for RSC sessions took on a variety of forms depending on the preferences of participant-clinician pairs. These variations included one-on-one sessions; the participation of family, friends, and children; and various numbers of sessions and technologies through which RSC services were delivered. Typical sessions occurred one time per week for an hour; however, these also varied between participant-clinician pairs.

4.1.1 Sessions

Over the six-week period of RSC, the 21 participants received a total of 139 RSC sessions. Twenty of 21 participants had four or more RSC sessions. The number of sessions per participant ranged from 2-to-12 and the average number of sessions per participant was 6.2. Most sessions were 1:1 virtual meetings between the clinician and the participant. However, one clinician was able to form a virtual group consisting of herself and two participants with severe aphasia who had previously worked together in a group before pivoting to RSC. There were many occasions when participant’s significant others (i.e., spouse, child, relative, or caregiver) joined in or were invited to participate in the RSC session.

4.1.2 Modalities

Sixteen of the 21 participants had computer and internet access and five did not. Only four of the 16 participants with computer and internet access used the computer to participate in RSC via Zoom. For the most part, participants used an i-Phone or i-Pad with apps (i.e., Face Book, FaceTime, and text messaging) that were familiar to them for the RSC sessions. This was also the case for the five participants that did not have computer or internet access.

4.2 Barriers and Strategies

On the questionnaire, the clinicians listed 3 barriers that they encountered in providing RSC to each participant. They also listed 3 strategies they had found useful in providing RSC to each participant. The sections below provide summary descriptions of what the clinicians reported.

4.2.1 Barriers

A barrier was defined as “anything that interfered with delivery of RSC.” To give a clearer picture of how different barriers might have impacted delivery of RSC, the investigator reviewed the barriers listed by each student, eliminated redundancies (i.e., similar barriers listed by different students), and arbitrarily grouped the different barriers into four categories: communication, technology, scheduling, and social. Communication barriers were considered obstacles that limited information exchange between the clinician and the participants because of the participant's communication deficits (i.e., inability to use anything but speech on the i-Phone). Technology barriers occurred when the participant lacked sufficient knowledge or experience to "troubleshoot" problems that came up unexpectedly (i.e., abrupt disconnection of service). Scheduling barriers were associated with conflicts in scheduling RSC sessions around participant's home activities and making changes in the schedule on the basis of clinician or participant needs. Social barriers were encountered if a clinician had not worked with the participant in the in-person program and lacked sufficient background information to establish a relationship with the participant to share common experiences. Clinicians were also asked to determine if the barriers they identified constituted a major, moderate, or minor obstacle to the delivery of RSC. Table 4.2 shows the different communication (N=11), technology (N= 6), scheduling (N=5), and social (N=5) barriers identified by the clinicians and the number of times each barrier was considered as a major, moderate, or mild obstacle to delivery of RSC.

Table 4.2 Communication, technology, scheduling, and social barriers encountered in providing Remote Supported Communication to participants, number of times each barrier was considered to constitute a major, moderate, or minor obstacle to delivery of RSC.

Communication	Barrier	Major	Moderate	Minor
1	Prosody and rate of speech made it difficult to understand.		1	
2	Incomplete relation of thoughts.		1	
3	Lack of access to supplementary materials, i.e. paper, pen.		3	
4	Environmental distractions hindered focus on task.		1	2

Table 4.2 (continued)

5	Word-finding problems caused communication breakdown		1	1
6	Unable to elaborate on topic		1	
7	Unable to provide patient homework desired	1		1
8	Difficulties communicating with writing or gesturing	1		
9	Extra time needed for planning		3	
10	Patient stressed by communicating remotely		1	
11	Increased difficulty with comprehension			1
Technology				
1	Restricted to phone only; other technology needed		2	1
2	Cell phone batteries going dead in middle of session			1
3	Difficulty hearing using phone speaker; echoing		2	2
4	Uncomfortable using the technology		2	6
5	Loss of internet connection			1
Scheduling				
1	Not answering the phone at the scheduled time		1	4
2	Coordinating schedule with family schedule		1	1
3	Participant occupied ADL at scheduled time, i.e., bathing			2
4	Difficulty maintaining a schedule		2	
5	Difficulty making initial contact with participant		1	1
Social				
1	Family members talking to or in tandem with participant		1	1
2	No prior relationship to the patient (new patient)			1
3	Unable to talk to participant about topics, i.e. sports	2	1	
4	Lack of a social context			1
5	Inability to communication with caregivers during session		1	1

4.2.2 Strategies

A strategy was defined as anything that the clinician did that was perceived to facilitate delivery of RSC. For each strategy listed, the students designated whether they considered it to be very effective, effective, somewhat effective, or ineffective in providing RSC. To determine the usefulness of different strategies, the investigator assigned point values of 4, 3, 2 and 1 points to strategies designated by the clinicians as very effective, effective, somewhat effective, and ineffective respectively and compiled total point values for each strategy. Table 4. 3 gives the various strategies deemed useful by the clinicians in facilitating RSC, the number of times they were determined to be useful for each level of effectiveness, and the rank ordering of each strategy in terms of total points.

Table 4.3 Rank ordering of strategies by students of total points and number of rankings of effectiveness for RSC.

		Effectiveness			
Total Points	Description	Very	Effective	Somewhat	Ineffective
38	Used topic guides; keep focused on current events	5	4	3	
29	Family Involvement	5	3		
25	Sending reminders	2	5	1	
17	“Show and tell” approach in home contexts	2	3		
16	Text Messaging and email; use of writing to supplement oral communication	1	4		

Table 4.3 (continued)

12	Sharing of new information and shared experiences between clinician and participant	3			
12	Keeping to a regular schedule	3			
10	[Use of Facetime to simulate being there]	2		1	
8	Frequent repetition	2			
7	Creation of a social group	1	1		
7	Request clarification and use open-ended questions	1	1		
6	Verifying participant has comprehended continuously	1		1	
5	Use headphones; speak directly into phone		1	1	
5	Use of prior knowledge of participant (therapy strategy)	1			1
4	Provision of “Wait Time”	1			
4	Use of positivity	1			
3	Introduction of novel topic to increase engagement		1		
3	Use of one-on-one, rather than group, sessions		1		
3	Use of speakerphone combined with slowed speaking rate.		1		
3	Speaking loudly and slowly		1		
3	Directing questions to patient		1		
3	Eliminate distractions in environment		1		

Table 4.3 (continued)

2	Discussing consistencies of life amidst the inconsistencies of the pandemic			1	

4.3 Student Judgements of Participant Responsiveness to In-Person versus Remote Services

Nineteen of the 21 participants in the RSC program worked with the same clinician that they had worked with in the in-person program. This made it possible to compare participant's responsiveness and attitudes towards supported communication intervention in the two formats, face-to-face and remote. To do this, the clinicians were asked to respond to a series of seven questions relevant to the participant's communication in the in-person and remote supported communication formats. Appendix C) shows that these questions required the clinicians to examine the participant's performance with respect to (a) communication of new information, (b) responsiveness to clinician's questions, (c) expressed appreciation for services, (d) independence in communication, (e) resiliency, (f) comfort, and (g) overall effectiveness in communication as being increased, about the same, or deceased in RSC as compared to the in-person.

Table 4.4 Clinician judgements of the responsiveness of 19 participants seen by the same clinician for in-person and remote supported communication formats.

Question	Increased	About the Same	Decreased
New information	10	6	3
Responsiveness	7	11	1
Appreciativeness	17	2	0

Table 4.4 (continued)

Independence	6	11	3
Resiliency	11	6	2
Comfort	8	7	4
Effectiveness	7	8	4

4.4 Outcomes and Benefits of RSC

Clinicians were asked to list three outcomes or benefits of RSC for each participant. The student's comments were edited by the investigator to protect student and participant anonymity. All comments were then reviewed by the investigator and the thesis director to identify "themes" that might be useful to describe the benefits and outcomes of RSC. After much discussion, the investigator and thesis director agreed on four themes characterizing RSC. Specifically, RSC is helpful in (1) Establishing and maintaining a human connection, (2) improving and maintaining communication skills, (3) stimulating a PWA to share new information with a trusted partner, and (4) facilitating clinical skill acquisitions by clinicians. Appendix D provides the student's edited comments on the benefits and outcomes of RSD for each theme.

CHAPTER 5. DISCUSSION

When the pandemic closed the University of Kentucky in March of 2020 and made it necessary to stop providing in-person supported communication, each of the 26 participants in the Aphasia Lab was invited to continue the program remotely (See Appendix A). Five participants opted not to participate in RSC. Two had mild aphasia and had been attending group therapy only; two did not want to enroll in the RSC program because they felt it would be difficult to communicate with clinicians in forms other than a face-to-face situation. One person who had experienced ongoing difficulties getting to the Aphasia Lab in-person meetings due to transportation problems decided to drop out of the program entirely. Eighteen of the 21 participants that opted to participate in RSC had presented with aphasia ranging from severe-to-mild; four of these clients also had co-occurring apraxia of speech; two participants presented with symptoms associated with right hemisphere communication disorder; one had ataxic dysarthria and mild cognitive deficits. In general, these 21 individuals were representative of persons with acquired neurogenic communication disorders who continue to seek communication support when their disorders become chronic.

Over the six-week period of the remote program, the clinicians conducted a total of 139 RSC sessions. The number of sessions received by any single participant ranged from 2-to-12. On the average, participants received 6.2 sessions with RSC sessions occurring with a degree of regularity. When a participant missed a session, it was usually due to a scheduling mix-up or an unexpected event coming up (i.e. Dr. appointment) that resulted in canceling the session. For the most part, it was relatively easy for the clinicians to maintain the RSC schedule (one session per week) because the participants were seen in their own homes and did not need to travel to The University of Kentucky. Most participants, and particularly their non-aphasic drivers, expressed relief in not having to cope with the issues of parking and building access at the University. Another benefit of providing RSC remotely was that it eliminated “no shows” and allowed the clinician to obtain the hours needed for their training program.

5.1 Adapting to Use of Technology

Participants in the Aphasia Lab in 2020 ranged from 20-to-88 years of age (M=66.6 years; SD=17 years), (Waugaman, 2020). When attending the Aphasia Lab in-person, younger and middle-aged participants usually brought their cell phones and i-pads to their in-person supported communication sessions. In their in-person sessions, they often used these devices to look up and share new information with their student teams. Older participants, however, primarily used speech supplemented by low-tech augmentative and alternative communication (AAC) (i.e., writing, drawing, gesturing, and pointing) to communicate in-person in the Aphasia Lab and avoided technology. Some concerns arose when the program switched to RSC that the more senior participants would have difficulty “adapting” a new format because they lacked the experience and sometimes the manual dexterity skills to use cell phones, iPads, and computers and, in some cases relied on their significant others to “handle the technology.” For example, one older client with aphasia who was perfectly capable of communicating on the phone, always deferred to her husband rather than answering the phone at home. A second concern was that there was little time available to explore participant’s abilities to use different technology options because of the abruptness in which the pandemic struck and the fact that the semester was rapidly coming to an end.

Surprisingly, the pivotal move to RSC went much “smoother than expected.” This much-appreciated result seemed to occur for several reasons. One was that while the world was moving to the use of Zoom for meetings, parties, conferences, routine medical appointments, and other reasons to support social distancing, the 21 participants in the RSC program “kept things simple.” Although 16 of the 21 participants actually had internet access and Zoom capabilities via their home computer, only four of the 21 participants used Zoom. The others relied on an i-phone, i-pad, or cell phone to interact with their clinician for RSC.

A second reason participants may have adapted to RSC so readily may have been the threat of isolation and loss of social contact secondary to the pandemic. For many people with chronic aphasia, opportunities to receive supported communication services in the form of a weekly group and/or individual session in university clinic, not-for-profit clinic, or community-based program, or attendance at a support group is the “highlight” of their week. For some persons with aphasia, these social encounters are one of the few they can count on. It is possible that the fear of “social disconnection” and other restrictions of the pandemic provided the “motivation” for participants to embrace technology as “best they could” because it was the technology that provided the vehicle to allow them to connect and socialize.

Finally, many of the clinician’s comments reflected positively on the use of simpler technology (i.e., the i-phone, i-pad) particularly when coupled with apps such as Facebook, FaceTime, and texting. Documentation of each RSC session by clinicians appeared to support this observation. One of the positive features of the simpler technologies is portability. Armed with an iPhone and using FaceTime, RSC participants were able to do things such as (1) take their clinician on a tour of their home, (2) introduce their clinician to their pets, (3) show the clinician their vegetable garden, and (4) “shoot some hoops.” However, while the technology is important it only serves as a means of connecting to the person with aphasia. The true value of RSC may be the mere fact that it takes place in the home of the patient where he or she can be himself. This is the environment where people with chronic communication disablements spend most of their time and where generalization of any treatment is likely to occur. For persons with chronic aphasia, it may be necessary to make this the therapy arena whenever possible.

5.2 Barriers

The 12 clinicians identified 61 barriers in providing RSC to the 21 participants. Review of these barriers revealed that many were duplicates. In the final analysis 26 different barriers remained. The 26 barriers were grouped into four categories by the investigator: communication (11 barriers), technology (5 barriers), scheduling (5 barriers), and social (5 barriers). These are shown in Table 4.2. Each of the students also rated the degree to which each barrier they identified constituted a major, moderate, or minor obstacle to providing RSC. Table 4.2 clearly shows that the students rated most barriers as minor (46%) or moderate (48%) rather than major (6%) obstacles. That so few of the barriers identified were considered to be major obstacles came as a surprise. For example, one might expect that the loss of one’s internet connection or having cell phone batteries going dead in the middle of an RSC session, would be perceived as a “major” barrier to the conducting the session. However, it may be possible that the clinicians did not perceive many of the barriers identified as major obstacles because college students are sophisticated users of cell phone and computer technology, accustomed to troubleshooting problems. Moreover, college students are often required to alter and adjust schedules and develop time management skills. Moreover, they do not typically have aphasia. In other words, the barriers they identified were “no big deal.” In retrospect, a better understanding of how different barriers affected RSC might have been obtained by having the participants with aphasia do the ratings of how the different barriers affected their ability to participate in RSC.

To try to obtain a better understanding of how different barriers might have impacted the participation in RSC, a post-hoc analysis of the data in Table 4.2 was carried out. This focused on the barriers listed by clinicians two or more times within each category. The number of times each barrier was listed by a student were summed for each category. This figure was divided by the sum total of all barriers identified (N=61) to derive an impact score for each category. For example, in the technology category, the barriers “uncomfortable using/understanding technology, “difficulty hearing using phone speaker;” and “restricted to phone only; other technology needed” were identified 10, 4, and 3 times respectively. The estimated impact of technology barriers on RSC was therefore calculated as follows: (10 + 4 + 3 =17; 17/61 = 27.9 %)

5.2.1.1 Technology Barriers

A lack of comfort with technology appeared to be the single biggest barrier to providing RSC across participants. For many of the individuals in the Aphasia Lab, the use of technology is not part of their routine. When the Lab made the switch to RSC, participants were asked to quickly jump in and use technology to connect with their clinicians. For most, this meant speaking to clinicians on the phone to help walk them through the steps of using technology such as Zoom or FaceTime. For others, it meant learning to troubleshoot technological difficulties. No matter the level of comfort with the use of technology, participants and clinicians alike were forced into a world where everything from business, to doctor’s appointments, to social connection of all forms were moved to a technology-based form of communication where it was “sink or swim”. While all of the participants did not learn to swim, some of them were able to “tread water.”

5.2.2 Scheduling Barriers

Brain injured individuals prefer routine and can be resistant to change. The estimated impact of scheduling barriers on RSC was 21.3%. It goes without saying that nothing was the same with the Aphasia Lab after March of 2020. What typically would have been a series of designated appointments between the hours of 9 a.m. to 1 p.m. on a Monday and/or Wednesday, suddenly became a “free for all" scheduling frenzy. Clinicians were asked to schedule participants around their own class schedules, as well as around the now “upside down” schedules of the participants. While this proved to be chaotic, more so challenging was the barrier of participants failing to answer their phone at their scheduled time. This occurred across participants for the entirety of the six weeks of RSC; however, this barrier was easily combated through the use of strategies, such as “reminders”, which will be discussed shortly.

5.2.2.1 Communication Barriers

The estimated impact of the salient communication barriers on RSC was 14.75%. Three barriers were noted to impact RSC from this category. Interestingly, the barriers that appeared to have the greatest impact on RSC in this category had more to do with the clinician concerns that the communication abilities of the participants. For example, three clinicians indicated that “lack of access to supplementary materials (i.e., paper and pen) in the RSC program because participants did not have these materials available and/or because it was difficult to communicate using writing and drawing while using an iPhone. Clinicians also pointed out on three occasions that increased time for planning was needed to conduct an RSC session and that distractions in the participant’s environment (i.e. television noise, children playing, and appliance noise from appliances) interfered with RSC.

5.2.3 Social Barriers

Two social barriers impacted the conduct of RSC. Overall, the impact of social barriers was estimated at 9.8%. One social barrier identified by three clinicians was that of “no prior relationship to the patient” which highlights the importance of the clinician, student or otherwise, having some knowledge about the client’s interests (i.e. sports) to be able to engage the client in personally relevant supported communication activities of RSC. The other social barrier identified, “family members talking to or in tandem with the participant,” has both positive and negative ramifications. Some clinicians considered family involvement in the RSC session a positive thing; others pointed out that on occasions spoke for or in tandem with the participant and negatively impacted the session.

5.3 Strategies

Strategies were considered tactics the clinician employed to facilitate delivery of RSC. Most strategies listed by the students were individualized to meet the needs of a particular participant. Table 4.3 lists the different strategies identified by the clinicians and the number of times each strategy was deemed to be very effective, effective, somewhat effective, or ineffective by the students. To quantify the perceived usefulness of the different strategies, the investigator assigned 4, 3, 2, and 1 points each time a strategy was perceived to be “very effective”, “effective”, “somewhat effective”, and “ineffective” respectively, and calculated a point total for each strategy. Table 4.3 rank orders the different strategies in terms of total points. Here it can be seen that four strategies stand out from the others in terms of their perceived usefulness in providing RSC by clinicians.

The number one strategy (38 points) involved using topic guides developed by the students to prepare the client for the RSC session. Prior to sessions, clinicians would prepare a list of topics to discuss with the participants. The topic guides aided in keeping communication flowing between the clinician and participant. When one topic had been thoroughly discussed, the next subject could be promptly broached.

The second strategy deemed useful to the clinicians for RSC (29 points) was to involve other individuals in the session. In the in-person program, family members typically stayed in the waiting room or watched the session through an observation window. Sometimes, the family member dropped the participant off for his/her in-person session in order to run errands. RSC allowed the clinician not only to include family members in the sessions, but it also made it feasible to include other potential communication partners that could not be part of the in-person sessions (i.e. parents, relatives, and children), friends, and sometimes pets. This allowed the clinicians to provide some “unplanned communication partner training” to people important to the participant that might facilitate generalization. Sometimes family members became important interpreters for their communicatively impaired loved one and helped resolve or avert communication breakdowns. The addition of family members and other potential partners also provided clinicians with insight into the everyday conversations and interactions of participants and their families. It allowed clinicians to witness ways in which families overcome the barriers that they faced daily when communicating with the participants, and it allowed them to observe and learn ways in which they could become better supporters of communication for their loved one. The point total for the “Family involvement” strategy would probably have been much higher had all RSC participants had family members to co-participate in the sessions, but there were five RSC participants that had no family members at home and lived alone.

A third strategy used by eight of the 12 clinicians was the use of “reminders” in the form of text messages, emails, or phone calls. Reminders were helpful in several ways such as alerting participants to their session times, helping them to remember to bring certain items with them, or preparing the participant to be ready to talk about certain topics during an upcoming session. Reminders also provided a simple, yet effective means to help participants overcome the inclination not to answer their phones, and to be ready for a call from the clinician at a certain time.

A fourth strategy referred to as “Show and tell in home contexts” by some clinicians is similar to what is done in PACE therapy (Promoting Aphasic Communicative Effectiveness; Davis & Wilcox, 1985). When using the “show and tell” the participant and clinician selected personally relevant items to share information about. Typically, these were bits of new information the person wanted to share such as a newspaper clipping of a current event, a picture of a place or a person. The clinician and the participant took turns sharing information about their selected item. The clinician used prompts when appropriate and modeled how to communicate information in modalities other than speaking (i.e., gesture, writing, drawing, and pointing) until the message transaction was complete. This was something which both participants and clinicians alike enjoy, and one in which they can share new, rather than old, information.

5.4 In-Person Versus Remote Communication Support

Nineteen of 21 participants in the RSC program worked with the same clinician that they had worked with in the in-person program. Clinicians responded to seven questions (see Appendix C) that asked them to determine if the participant's (a) communication of new information, (b) responsiveness to clinician's questions, (c) expressed appreciation for services, (d) independence in communication, (e) resiliency, (f) comfort level, and (g) overall effectiveness of communication had increased, decreased, or stayed about the same from the in-person to the RSC program. Table 4.4 (See Chapter 4) shows that participants were perceived by their clinicians to increase their appreciation of supported communication services when delivered remotely from the in-person condition in 17 of 19 cases. It is possible participants were grateful for not being abandoned during the pandemic, but the reasons for this are not clear because student judgments were completely subjective. Table 4.4 also shows that students perceived participants showed increased resiliency and ability to communicate new information in the remote versus the in-person sessions. Again, while perceptions are subjective, it may be the case that the participants "tried a bit harder" to communicate when the switch to RSC occurred.

5.5 Outcomes and Benefits

While the switch from in-person to remote supported communication was abrupt, unplanned, and sometimes unnerving, clinicians provided numerous anecdotal comments that suggested the RSC experience was a positive one for them and for the participants. The investigators edited and reviewed these comments and extracted four themes. These were that the RSC experience had (a) reduced participant's social isolation by providing them with a human connection and respite during the pandemic, (b) helped participants maintain communication skills in the in-person program, (c) allowed participants to share new information with a trusted listener, and (d) permitted the clinicians to acquire clinical skills they might not have learned in the absence of the pandemic.

5.5.1 Connection

Much of the qualitative research indicates that people with aphasia lose their friends and become socially isolated. Human connection is something for which all humans long and when our social networks are disrupted, quality of life suffers. One needs only to reflect upon the last months of living with the pandemic to realize the importance of human connection. Numerous times, clinicians reported that RSC provided participants and clinicians with an escape from the reality of their current life situations; they had an individual in whom they could confide; they had a friend. Friendship was perhaps the dominating benefit of RSC. Because of the restrictions and precautions to limit social connections amidst a lockdown, RSC sessions proved to be a way in which new friendships could be built by getting to know each participant on a more personal level where both the clinician and participant relied on each other for human connection in a time of very little connection.

5.5.2 Communication Skills

Contrary to what one might assume for a cohort of individuals with chronic aphasia, RSC allowed some participants to improve and/or maintain communication skills. Despite the fact that these improvements varied from participant to participant, it was consistently reported among clinicians that participants were indeed benefiting from the RSC. Many clinicians reported these benefits were due to the fact that participants were forced to use creative means of resolving their communication breakdowns. For example, typical supplementary aids, such as pen and paper, were not as easily implemented into RSC. Because of this, participants were forced to think "outside the box." Some participants referred to photographs on their walls, objects from their home, or simply their iPad or iPhone cameras to take you on a tour of their homes or to areas that would help them overcome whatever communication breakdown they were facing. Aside from creative means of communication, it was also reported by several clinicians that they felt that participants were able to both maintain and improve communication skills simply because they were better able to focus on practical communication skills. Skills such as having a phone conversation, writing and sending an email, and writing a quick note down on paper were all able to be targeted within the participants' contexts of home. It seems that when all of the additional materials and therapeutic tasks were set aside and each participant-clinician pair was left with the undistracted basics, functional, everyday tasks and communications situations could be effectively addressed.

5.5.3 New Information

The sharing of new information can be difficult for individuals with aphasia, especially when communicated without obvious context. While it could be assumed that the use of technology to deliver RSC would strip participants and clinicians of all shared context, the opposite proved true. In fact, since participants were in their own homes, it was actually easier to establish a communication context. Participants were able to show clinicians the items, or pictures of people that they had been discussing in their in-person sessions, but that had previously been difficult to communicate about because they were not accessible. Clinicians also reported that they gained a better appreciation of the daily lives of participants due to the increase in information sharing surrounding their typical routines and environments. Lastly, without the typical topics of conversation associated with coming to UK for services such as basketball and football, participants and clinicians were forced to branch out on a more diverse group of meaningful subjects such as family and daily life.

5.5.4 Clinical Skills

Most clinicians expressed that the RSC experience helped them acquire new clinical skills. One of these skills was the "age old" problem of avoiding communication breakdowns when interacting with a person with aphasia. For example, some clinicians reported that they became adept at phrasing questions differently and making supportive statements to keep a conversation moving forward. Many clinicians reported that RSC had helped them develop greater empathy for the participants. This allowed them to better understand the participants' experiences and feelings of living with aphasia. They helped them gain insight into the difference that supported communication, the understanding of aphasia, and the simple act of listening can make in the life of individuals with aphasia.

CHAPTER 6. CLINICAL IMPLICATION

Most masters theses conclude with a chapter on clinical implications or address clinical implications at the conclusion of the discussion chapter. This study, however, came up abruptly because of the pandemic. It was not a planned study and any clinical implications that could be drawn about RSC, positive or negative, would be premature without a lot of further research. I have elected to entitle this final chapter “Clinical Implication” because of what I learned about myself and my patient, CW, from the RSC experience

6.1 Background Information

CW was a 27-year-old male who experienced a left-hemisphere embolic stroke in April of 2016 resulting in moderately severe Broca’s aphasia and co-occurring apraxia of speech, along with right sided upper and lower extremity weakness. After his stroke, CW received extensive inpatient and outpatient rehabilitation services (PT, OT, and Speech) in Southern California and made good progress. In the spring of 2017, he and his mother moved to Kentucky to be closer to her family. CW then received approximately six months of outpatient rehabilitation (PT, OT, and Speech) at a Lexington Rehabilitation Hospital before his insurance benefits ran out and he was discharged and referred to Dr. Robert Marshall of the University of Kentucky Communication Disorders Clinic Aphasia Lab. CW was evaluated by Dr. Marshall, whose findings were consistent with that of the previous hospitals and rehabilitation centers CW had attended. From the fall of 2017 until March of 2020, CW attended the UK Aphasia Lab where he was seen for individual and group treatment sessions by graduate students in Communication Sciences and Disorders in the Aphasia Lab. Over this time frame, CW attended the Aphasia Lab once or twice a week; his mother was usually present for all sessions observing through the observation window. Early in 2018, CW’s mother was diagnosed with cancer. She was CW’s only source of transportation to the Aphasia Lab and she continued to bring him to the Aphasia Lab until her medical condition no longer allowed this. CW’s attendance at the Aphasia Lab was sporadic in the months before the pandemic, but the switch to RSC caused by the pandemic made it possible to include CW in the program again.

6.2 The Very Beginning

When the global pandemic initially began, I had the unique opportunity of being chosen to work with CW. Unlike many of my peer graduate clinicians who had worked with their participants on a weekly basis in the face-to-face lab, I had no prior relationship, aside from two brief interactions within the lab, with CW. Because of this new and unique situation, I was able to meet and to begin forming a relationship with CW through the provision of remote supported communication. Our RSC experience began with weekly 30-minute sessions delivered over FaceTime where we simply worked on basic communication that would allow us to get to know one another. While CW had previously inconsistently participated in the in-person Aphasia Lab, the remote model provided him with the ability to participate more consistently and to use the richer and more personal communicative context of “home”.

6.3 A New Friendship

While our sessions began with the simple focus of communication, they soon developed into a more psychosocial dynamic with the focus being on friendship, connection, and the expression of emotions/feelings. CW began by showing me his home; his constant companion and friend, “Uma” the dog; sharing with me his love of favorite activities prior to his stroke, such as skateboarding and snowboarding; his favorite pass times of video games and scary tv shows and movies; and the items he liked to cook, specifically steak on the grill. However, as time progressed and our friendship developed, CW “dug a little deeper” and expressed his emotions surrounding the health of his mother who was nearing the end of her long battle with cancer. This was a unique situation which called for CW to be able to clearly express his feelings surrounding the agonizing experience of losing his mother during a global pandemic, which was proving only to further separate CW from the world at large. In return, I was able to lend a listening and supportive ear, and even invite CW into my personal life by sharing some of my favorite things, stories and pictures of my own dog, and stories about my family and friends. Because of the newfound ability to share personal information and to “invite” one another into what each called “home”, CW and I were able to build a personal relationship, a true friendship which lent itself to new and better ways of communicating the things that truly mattered, the joys, struggles, and emotions that surround the circumstances of everyday life. This newfound friendship proved to be one much greater than that found in the clinic alone. It was not simply a clinician and patient sharing of information, but it was a true and reciprocated peer-to-peer friendship

6.4 Digging Deep

In the weeks following the closing of the Aphasia Lab for the summer break of 2020, CW and I were able to continue our weekly sessions via FaceTime. At this point, CW's mother had been moved to a hospital due to her illness and CW found himself at home and on his own with family members checking in and bringing food, with sporadic visits to his mother through the hospital window. During these weeks, CW and I were able to continue to share with each other the simple happenings of our everyday lives, as well as his emotional journey in dealing with what was happening to his mother. I tried to provide funny stories to alleviate some of the heaviness of CW's situation, if even for a moment. In return, CW continued to share with me his feelings surrounding his mother's health, the most recent movie that he had seen, what he would be cooking for dinner, and what he and Uma, his dog, were up to that day.

6.5 A Fresh Start, A New Beginning

In the weeks of the summer of 2020, CW's mother's health continued to rapidly decline. With the help of his father, CW was able to share with me about the declining health of his mother and how he was doing with his current situation. Sadly, CW's mother passed away during the summer of 2020. While I tried to remain connected, CW's process of grieving, as well as moving to another state to be with his father and other relatives, led to a loss of connection. It would not be until February of 2021 that Dr. Marshall and I would once again be put into contact with CW and his father. At this time, we were informed of the wonderful transition that CW had been able to make over the course of several months. Not only was CW communicating with several word phrases, as opposed to his former 1-2 word phrases, but he was also starting to re-embrace life. With the help of his father, CW was once again returning to activities that he had previously enjoyed prior to his stroke. Not only was he weightlifting/exercising with a trainer, but more notably, he was returning to snowboarding, something that he had previously shared in detail with me.

This return to the things he once loved, as well as the notable increase in communication, while certainly not due to my work or RSC, are life gains for CW that have brought much joy to me to see and hear. My hope is that the provision of RSC in the midst of a global pandemic provided the social connection, emotional support, and supported communication needed for CW and all of the patients of the Aphasia Lab. The hope is that the delivery of RSC, with the context of the home environments allowed CW to communicate the emotions, difficulties, and happy parts of life in the midst of the global pandemic and social isolation. While I cannot derive clinical outcomes or implications across patients, I believe that I can confidently state that the delivery of RSC was not taken for granted by CW or myself, but that it was a priceless means of connection that allowed for connection and friendship in a time where face-to-face contact was an impossible task.

APPENDIX A. INVITATION OF PARTICIPATION

Invitation to participate in Remote Supported Communication program sent to participants in the Aphasia Lab.

March 18, 2020

Dear Aphasia Lab Participants. I emailed you a few days ago saying I would get back to you on the operating policies for the Aphasia Lab for the rest of the semester. Yesterday, a decision was made by the UK administration to not have students return to campus for “in class” instruction for the remainder of the semester. This means that we will not have our normal Aphasia Lab group and individual sessions until the fall.

It is important for all of us to support “social distancing,” but this does not mean we need to “socially disconnect.” We can remain connected through “communication” and that is what the Aphasia Lab is all about.

In the spirit of staying connected, each of you can expect a call from one of your student clinicians next week (March 23-27). The call should come near the time when you are usually seen for your session in the Aphasia Lab. The student that calls or perhaps emails you will be available to work with you at least ONCE per week for the remainder of the semester. This will be done using whatever technology is available and/or convenient for you.

I feel it is important to do this as part of our student’s education and to let you know we care about you. However, you are not obligated to having students connect with you on a regular basis. I want you to understand that if you don’t want to do this, it has no impact on your participation in the Aphasia Lab in the future.

Speaking of the future, we plan to have our usual Meet and Greet Session for old and new Aphasia Lab Participants in the Summer (TBA in July) and to resume Aphasia Lab Operations in the fall semester. These are difficult times, but we will prevail. Thank you all for your understanding.

If you have any questions or comments for me, please email be (rcmarsh@uky.edu) or call me on my cell (859-230-7593).

Robert C. Marshall, Ph.D., Professor,
Department of Communication Sciences and Disorders
CCC/SLP, BC-ANCDS, F-ASHA, H-ASHA

APPENDIX B. QUESTIONNAIRE: REMOTE SUPPORTED COMMUNICATION EXPERIENCE

Informational questionnaire completed by student clinicians at the end of the RSC program. Student clinician responses to questions about 18 participants seen by the same clinician for in-person and remote supported communication formats.

1. Aphasia Lab Clinician (Name):
2. Aphasia Lab Participant (Initials):
3. What is the participant's communication disorder diagnosis (X all that apply)? Designate the severity of each problem, (1 = mild; 2 = moderate; 3 = severe) in parenthesis.

    Aphasia:

    Apraxia of Speech:

    Dysarthria:

    Cognitive-Communication Disorder:

4. Rate the degree of communicative burden you assumed when conversing with this participant on a 1-10-point scale (1 = little-to-none; 10 = significant):

5. Does the participant have a computer? (yes or no):

6. What's the participant's living situation? (X)

    Lives alone:

    Lives with a significant other spouse or relative):

    Describe any unusual circumstances:

7. How many remote supportive communication sessions did you provide for this participant? (any contact is considered a session as long as you documented it for me):

8. Aphasia Lab Clinician (Name):

9. Aphasia Lab Participant (Initials):

10. What is the participant’s communication disorder diagnosis (X all that apply)? Designate the severity of each problem, (1 = mild; 2 = moderate; 3 = severe) in parenthesis.

Aphasia:
Apraxia of Speech:
Dysarthria:
Cognitive-Communication Disorder:

11. Rate the degree of communicative burden you assumed when conversing with this participant on a 1-10-point scale (1 = little-to-none; 10 = significant):

12. Does the participant have a computer? (yes or no):

13. What’s the participant’s living situation? (X)

Lives alone:
Lives with a significant other spouse or relative):
Describe any unusual circumstances:

14. How many remote supportive communication sessions did you provide for this participant? (any contact is considered a session as long as you documented it for me):

15. What technology did you use to provide remote supported communication for this participant? For example, some of you might have conversed exclusively by cell phone; others may use a combination of email, cell phone, and face time. Give be flavor for what

- POTS (Plain Old Telephone Service)
- Cell phone/I-phone:

- Texting:
- Face time:
- Face book:
- Email:
- Zoom:
- Skype:
- Other (specify):
- Other (specify):

16. Barriers: List 3 barriers you encountered in providing remote supported communication for each participant. Designate if this barrier was a major (3), moderate (2), or minor (1) obstacle to providing remote supported communication. Note: Barriers are not limited to technological problems. It could be something else like scheduling or the patient’s attitude toward this type of therapy.

    1.
    2.
    3.

17. Strategies: List 3 strategies that were helpful in facilitating remote supported communication with this participant. Rate the effectiveness of each strategy as very effective (4), effective (3), somewhat effective (2), and not too effective (1),

    1.
    2.
    3.

18. Outcomes: Briefly describe 3 outcomes of your remote supported communication experiences with this participant or for yourself.

  1.

  2.

  3.

19. Remote supported communication was carried out with:

  The participant only:

  The participant and other people. Please list the other people:

20. Comments: Use this space to make any comments you wish about this experience:

APPENDIX C. QUESTIONNAIRE OF OPINION: IN PERSON VS. REMOTE

Questions for student clinicians related to participant's communication during in-person and remote supported communication

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Clinician's Name: ____________

Patient's initials: _____________

____ Seen both face-to-face (meaning that you saw them in person in the lab) and remotely
____ Seen remotely but not face-to-face.

1. New information: Patient provides information to clinician (makes a statement, points or shows something to the clinician, brings something on his own to share) or requests information from the clinician (asks a question).

How would you rate this patient's use of "new information" during delivery of remote supported communication versus f2f supported communication?

____ Increased
____ About the same
____ Decreased

2. Responsiveness: Patient attends to clinician's questions, statements, and requests for information and does not need added information from the clinician in the form of a repeat, prompt or cue.

How would you rate this patient's "responsiveness" during delivery of remote supported communication versus f2f supported communication?

____ Increased
____ About the same
____ Decreased

3. Appreciativeness: Appreciation for therapy is expressed by people with aphasia in many forms, verbally, attitudinally, willingness to try new things, compliments, and giving positive feedback.

How would you rate this patient's "appreciativeness" during delivery of remote supported communication versus f2f supported communication?

___Increased
___ About the same
___ Decreased

4. Independence: This refers to the degree to which the patient is able to communicate his/her thoughts, feelings, and needs without assistance from others.

How would you rate this patient's "independence" during delivery of remote supported communication versus f2f supported communication?

___Increased
___About the same
___Decreased

5. Resiliency: This refers to the persistence with which the patient tries to communicate in the face of the adversity imposed upon him by the aphasia.

How would you rate this patient's "resiliency" during delivery of remote supported communication versus f2f supported communication?

___Increased
___About the same
___Decreased

6. Comfort: This refers to the ease or comfort exhibited by the patient when communicating with you or other persons in the environment.

How would you rate this patient's "comfort" during delivery of remote supported communication versus f2f supported communication?

___Increased
___ About the same
___Decreased

7. Effectiveness: When aphasia treatment is effective, it implies that what is being done is making a difference in the patient's life.

How would you, as a clinician, rate the effectiveness of remote supported communication versus f2f supported communication?

___More effective
___ No difference
___Less effective

APPENDIX D. THEMES OF OUTCOMES AND BENEFITS

Themes reflecting outcomes and benefits of remote supported communication (RSC) for participants and students. Student comments are verbatim but were edited to preserve participant and student anonymity.

Maintaining a human connection

- This weekly conversation gave both the participant and me a positive escape from reality and a new conversation partner. The participant reported he enjoyed and looked forward to the weekly conversations and updates.
- This experience provided both me and the participant with a positive escape from reality.
- The participant reported that it gave him something to look forward to each week.
- She was able to have someone to listen to her issues and what was going on in her life, with her family, her husband, etc. especially in the midst of this pandemic, which I think was very good for her mental health as well as conversation skills.
- He was able to vent and process issues in his personal life, particularly as he is caring for his older parents in the midst of the COVID-19 pandemic, and stay connected with other individuals outside of his household
- I met someone new and formed a nice relationship.
- Provided the participant with someone new to talk to, as she spends much time alone.
- I said this previously and I will say it again here – I feel like I made a friend in the participant. He and I share differing opinions on a lot of topics, but he has become one of my most favorite people with whom to debate. We're open-minded to each other's opinions, we acknowledge areas of common ground, and we mix in a healthy amount of humor into every conversation.
- I feel like I gained a friend. Perhaps it's a little silly on my part, but I think of the participant almost like my grandmother in a lot of ways. My grandparents have all passed away, and I have just found it especially enjoyable being able to connect with someone who reminds me so much of them. The participant is a gem.
- This experience allowed me to connect with this participant on a deeper level. He was more willing to share with me about the hardships that he has faced over the years. This allowed me to understand him as a whole person versus the person with aphasia that I saw once a week in the clinic.
- Another outcome from this experience would be how comforting it can be to hear from someone in this time of uncertainty. The participant has expressed his appreciation for the continuance of the aphasia lab throughout this pandemic because it provided him with some degree of normalcy to look forward to.
- Being upbeat, positive, and a listening ear is important, especially when a global pandemic is occurring, and stress levels are high.
- We were each able to build a more personal relationship with him.
- Our weekly calls were somewhat therapeutic for the both of us in this hard time.
- We learned more about each other.

- I got to know the patient more personally, rather than just focusing on his communication barriers.
- A final outcome of this remote supported communication experience with the participant is providing her with companionship and being an active listener in conversation.
- One outcome of my remote supported communication with the participant was furthering my relationship with him, outside of face-to-face interaction in the aphasia lab.
- This hour served as a distraction from the state of the world. Her husband mentioned it calmed the participant down multiple times and I always felt better after our phone calls as well.
- An outlet for the participant to discuss his past freely.
- Something to look forward to, and help build a routine among the chaos (for both of us).
- Remote supported communication allowed me to get to know the individual, their personality, and communication styles on a deeper level.
- Successfully involved the participant's daughter in this part of his life and let her feel as though she was very helpful.
- This experience also allowed for the participation of the participant's wife. Especially when they were utilizing the car speakerphone for our session. These remote sessions did not limit them to their home, which I thought was interesting because they could be on the run and not waiting for a call.
- I got to know the participant better by getting to know his family and speaking with him in a setting that is comfortable to him.
- We were able to have a better look into his personal life and family interactions.

Improving and maintaining communication skills

- She was able to keep up with the skills she has been practicing by maintaining a conversation and not lose skills during this time of isolation. He was able to practice his conversation skills and word finding abilities
- First and foremost, I really feel like the participant continued to improve. We were only seeing each other once per week when the Aphasia Lab was still occurring on campus; since moving to remote communication, we upped our sessions to twice per week. The participant is also now receiving weekly phone calls from another participant in the lab, which is an added bonus to say the least.
- When communication breakdowns occur, he was able to get creative to come up with new strategies to communicate effectively.
- The patient was able to work on her writing
- The patient learned it is easier for him to read messages rather than come up with them on his own.
- A second outcome of this remote supported communication experience with the participant was helping to facilitate her ability to get back to writing.
- One outcome of my remote supported communication experience with the participant is exercising the ability to communicate both on the phone and over email.

- A third outcome of remote supported communication with the participant was getting to practice real life skills with him, such as having a conversation over the phone.
- A second outcome of remote supported communication with the participant was discovering multiple ways that he is able to successfully communicate including talking over the phone and sending emails.
- We did not have the question cards that we had in the clinic available to us during the remote conversations. In these sessions, we focused more on having detailed conversations between the two of them. With a little help, they were able to convey some complex thoughts and were able to extend conversations to several exchanges.
- The participant reported that these one-on- one interactions forced him out of his comfort zone in a positive way.
- In the clinic, the participant. and a fellow participant. were working on motor speech practice. A clinician would sit across the table from them and try to guess the word they said. During remote communication, participant 1. and participant 2 also had to think about how to get their message across and use strategies such as giving the topic or related words to help the other understand their message. While not intentional, their sessions in the clinic served as preparation for speaking using distance technology.

Sharing new information

- The participant made sure to keep me informed on all of the current events, and I looked forward to hearing about the latest current news since I rarely watch the news myself. The participant, it seemed, really came out of his shell in these remote-supported conversations. He shared with me that when he attended the men’s group in the Aphasia Lab, he would say very little and mostly listen. However, the version of the participant that I got to know was very opinionated, sarcastic, and funny. I’m thankful that he let me see that side of him.
- I gained a greater appreciation for what the participant’s life looks like outside of the Aphasia Lab. Through our remote conversations, I’ve learned that the participant really enjoys sitting at her window and watching the landscapers take care of the grounds in her community, she sees her daughter on Wednesdays, and she loves walking out to her mailbox on sunny, Spring days. Rather than always being focused on therapy when we’re together, this experience has helped me to better get to know the participant, the person.
- This experience facilitated more laid back conversations which lead to the participant and I learning a lot about each other. This experience also seemed to take away our roles as clinician and participant and leveled the playing field which made conversations more free flowing and comfortable.
- During our first session, he seemed pretty disinterested and his wife carried most of the conversation. However, once he understood that he could show me things that he previously could not show me, he began to initiate much more frequently. He often brought pictures and objects to talk with me about.

- I found that during our remote supported communication the participant began to ask lots of questions about me, and it seemed like he was interested in what was going on in my life rather than the focus of the sessions being solely on him.
- One outcome that I observed was that the client seemed to be more social and interactive during our remote supported communication versus the clinic. I think this platform of communication allowed the patient to be more open because he was in an environment (home) that he is more comfortable in.
- We talked about a much greater variety of subjects during the remote sessions than we did in the in-person sessions. In the clinic, we mostly talked about UK basketball. This gave us shared context since we were both able to watch the games. We were not able to establish a shared context about subjects such as his dogs, his family, or dog shows as I was not familiar with those subjects and he was not able to adequately describe them to me. However, with the remote sessions he was able to show me how he works with his dogs, his trophies, and many aspects of his home and daily life
- He began to ask me questions, creating more of a natural discourse rather than a routine of question-answer.
- He was able to initiate conversations about topics other than his topic of interest more.
- He became more comfortable talking about himself and sharing information about his life before his stroke.
- Using FaceTime allowed me to see a glimpse of his life at home. He was able to show me his garden, his dog, and other things that he often talks about.
- The participant was able to better convey thoughts and stories because of the added context from being in the natural environment.
- The participant asked more self-initiated questions than I was previously seeing in the clinical setting.
- The participant was more involved, bringing pictures, books, articles, and activities to the remote session
- The context from the patient's natural environment aided in communication comprehension and provided several more communication contexts for discussion.
- This provided a window into his daily life and allowed me to see a different side of the participant than we had seen in the clinic.

<u>Acquisition of clinical skills</u>

- I learned how to better anticipate and circumvent word-finding difficulties. The participant would periodically lose his train of thought or not be able to come up with certain words – and he would get noticeably frustrated by this. As I got to know him better, I figured out how to fill in gaps and keep the conversation moving without having to call attention to his troubles. I think he appreciated this. I learned a lot about the importance of empathy and relating to patients in a difficult time through this pandemic and the participant has dealt with her husband's illness during this tough period of time

- I gained more insight on what it is like to be living with aphasia based on the participant’s personal experiences and feelings.
- I gained a sense of family attitude towards a family member with weak communicative abilities.
- I learned about how to keep the conversation going if it stalled and to prepare topics ahead of time or make mental notes of topics of interest to relate to him/other patients in general
- Schedules and consistency matter with persons who have experienced a stroke
- When conversation breakdowns occur multiple strategies have to be used to figure out what the client is trying to express. Not being able to see the client face to face and not having other mediums such as paper to help aid in breakdowns can be challenging at times.
- I learned how to dance around a subject to avoid asking a direct question.
- A new found appreciation for the difference we make In their lives.
- I began the semester unsure of how to support the participant. Our remote communications showed me to just lend a listening ear and adjust my expectations. These individuals are so appreciative of us, and we make a lasting impact on their lives. The participants husband mentioned appreciating that he didn’t have to explain aphasia. This hour was a time for them to just be themselves
- I believe that I personally learned how to phrase questions in a way that aids in better comprehension for patients with Aphasia.

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