

Self-Efficacy in People with Speech or Language Disorders: A Qualitative Study

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A thesis submitted in partial fulfillment of the
requirements for the degree of

Master of Science

University of Washington, Seattle

2012

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Abstract

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The construct of self-efficacy has emerged in recent research as potentially influencing outcomes for people with chronic health impairments. Individuals with speech and language disorders have been understudied with regards to whether or not self-efficacy is a significant factor impacting communicative participation. The purpose of this study was to examine the relationship between self-efficacy and a person's choice to participate in life roles involving communication by inviting the experts (i.e., people with speech or language disorders) to share their experiences. Five adults with aphasia or dysarthria caused by stroke participated in qualitative interviews as part of this study. Interview transcripts were analyzed by applying codes (i.e., key words that represent topics or ideas that participants discussed) and preliminary themes were developed. In general, there was minimal indication that self-efficacy consciously affected participants' decisions to participate in communicative interactions. While most of the participants did not acknowledge purposeful consideration of confidence, or self-efficacy for communicative situations in those specific terms, the experiences they discussed did contain elements of Bandura's (1977) theoretical sources of self-efficacy. Further research is needed to determine self-efficacy's role in communicative participation for adults with speech or language disorders.

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Introduction

People with chronic speech and language disorders face challenges in their everyday communication. Some of these challenges are due to the nature of the impairment, but others may be due to societal or environmental factors. The World Health Organization's International Classification of Functioning, Disability and Health (ICF) advocates for consideration of social and contextual factors when assessing and treating a person's health problems (World Health Organization, 2001). While the main focus of speech-language pathologists in the past has been the disorder and treatment at the impairment or activity level of functioning, recently there has been a shift to extend the focus to be consistent with the WHO model with the inclusion of participation in the communication aspects of life roles (i.e., communicative participation). Prior research has suggested that communicative participation may be influenced by many variables including the characteristics of the speech or language disorder, aspects of the communication environment, and personal factors such as coping. A variable related to personal factors that is starting to receive attention in the broader rehabilitation literature, but has received limited attention in the speech pathology literature, is that of self-efficacy. Emerging evidence suggests self-efficacy may have potential to influence health outcomes. Investigation of self-efficacy for communicative participation is warranted to determine if it might be a variable influencing outcomes for people with speech and language disorders, and amenable to change as a potential target in intervention programs.

Literature Reviewed

Definition of Self-efficacy

The term self-efficacy stems from research and theory proposed by Bandura (1977)

and refers to an individual's self-appraisal of his/her ability to successfully perform a behavior leading to a desired outcome. Another way of thinking about self-efficacy is a person's confidence in his/her ability to perform a task¹. Because the ultimate result of a person's behavior may be dependent upon factors outside the individual's control, self-efficacy beliefs are not the same as having control over the outcome (i.e., locus of control). Self-efficacy is the person's belief that he or she can perform a task or influence an outcome, while acknowledging that the outcome of a situation may be controlled by a range of variables including, but not constrained to, that person's performance.

Efficacy beliefs can be characterized in several important ways. One is the magnitude of the efficacy belief. When the magnitude of a person's self-efficacy is low, their confidence may be confined to behaviors or tasks that are not considered difficult. In that case, once a more difficult situation is encountered, the person may not have enough confidence to take action. Self-efficacy can also vary in terms of generality. If a person's self-efficacy beliefs have been increased in a therapeutic context, this confidence may be limited to only that exact treatment situation, and it is important to determine if it has generalized to real-world situations. The last facet of self-efficacy is its strength. A person who has strong self-efficacy beliefs will continue performing a behavior even in the absence of a positive outcome. This can be crucial when a task requires perseverance in order to be successful. In general, when people encounter a situation that falls within their perceived capability, they will attempt to deal with it.

Bandura (1977) proposed that a person's behavior can be altered by changing his or her self-efficacy beliefs. At the time, this was in stark contrast to behaviorism which

¹ While self-efficacy and confidence are slightly different constructs, it can be helpful to conceptualize self-efficacy using the more familiar term confidence. Most of the literature reviewed for this thesis used the terms interchangeably.

proposed that the way to change behavior was via conditioning the response to a stimulus. Pure behaviorism ignored the role of cognition, but the construct of self-efficacy directly addresses the role of cognitive influences on behavior. Bandura (1977) suggested four different mechanisms that influence a person's level of self-efficacy for a specific task which are potentially amenable to intervention: performance accomplishments, vicarious experience, verbal persuasion, and physiological states. Performance accomplishments refer to individuals completing a behavior that previously they were not confident they could do. The next time they encounter similar circumstances, their self-efficacy will be greater for that behavior. Another way self-efficacy can be changed is through vicarious experience. Bandura (1977) proposed that watching someone else perform a task successfully or listening to someone else talk about a successful experience will change the confidence-level of the observer or listener. However, the observer or listener must believe that the characteristics and capabilities of the person performing the task are similar to himself or herself otherwise the other person's success may be written off as due to some inherently different quality. Yet another way to increase self-efficacy is through verbal persuasion, which is when another person simply tells individuals with lower self-efficacy that they can perform the behavior and attempts to convince them of this truth. The last way Bandura (1977) reported that self-efficacy may be altered is through people's feedback from their own physiological states. When a person feels symptoms of anxiety such as increased heart rate immediately prior to or during a task, that person's confidence may be affected the next time they are in a similar situation.

Of the above four influences on self-efficacy, performance accomplishments are the most powerful as evidenced by research conducted by Bandura, Adams, and Beyer (1977)

with adults who had a chronic phobia of snakes. The treatment condition which required the participants to perform the behavior, not simply view it modeled by the therapist, produced the highest, strongest, most generalized self-efficacy.

Self-Efficacy in Healthcare²

Self-efficacy is a construct that has gained recent attention in a wide range of healthcare fields. Researchers have examined self-efficacy as a factor influencing a patient's behavior and treatment outcomes in many healthcare disciplines including rehabilitation populations that are similar to those that are treated by speech-language pathologists. Since the purpose of this literature review is not to provide an exhaustive overview of research that has been completed in the area of healthcare and self-efficacy beliefs, only a small representative sample will be discussed before focusing on self-efficacy directly related to communication disorders.

In general, self-efficacy has been associated with beneficial influences on quality of life, memory, psychological state (e.g., depression) and independence with physical functioning (e.g., balance, activities of daily living) in the stroke population (Aben et al., 2011; Hellstrom, Lindmark, Wahlberg, & Fugl-Meyer, 2003; Jones & Riazi, 2011; Pang, Eng, & Miller, 2007; Robinson-Smith, Johnston, & Allen, 2000). Several studies have attempted to create a better measurement tool for self-efficacy for functional performance for people who have suffered strokes (Jones, Partridge, & Mandy, 2005; Jones, Partridge, & Reid, 2008), while others have proposed treatments that enhance self-efficacy as a way to improve behavior outcomes (e.g., mobility or activities of daily living) in that same population (Jones, 2006; Jones, Mandy, & Partridge, 2009; Neubert, Sabariego, Stier-Jarmer, & Cieza, 2011). The latter studies provided preliminary evidence that treatment based on

² For further information about the studies cited in this section, please see Appendix A.

self-efficacy principles increases a stroke survivor's self-efficacy for functional tasks (e.g., walking, getting comfortable in bed), but the other measures of mobility, activities of daily living, and mood did not show statistically significant change during the relatively short treatment period.

While the bulk of the literature located for this review focused on the stroke population, a recent systematic review examined self-efficacy and other psychosocial factors in neurological populations other than stroke (Eccles & Simpson, 2011). That systematic review found no literature about self-efficacy in people with Parkinson's disease or motor neuron disease. For people with Multiple Sclerosis, the literature review revealed inconsistent relationships between psychological state, quality of life, and general self-efficacy (Eccles & Simpson, 2011). The authors suggested several reasons for the inconsistent results: the concepts of control and self-efficacy may be unclear, the time post-diagnosis might affect a person's self-efficacy beliefs, and changes in self-efficacy may be better captured by longitudinal instead of cross-sectional study designs. There was limited evidence of an association between ratings of self-efficacy for healthcare and well-being in that higher self-efficacy was associated with greater well-being (Eccles & Simpson, 2011).

There have been several studies examining self-efficacy in adults with traumatic brain injury. Cicerone and Azulay (2007) measured the correlation between perceived self-efficacy for management of symptoms and global life satisfaction in 97 adults who had sustained a traumatic brain injury at least six months prior. The researchers used multiple questionnaires and rating scales to measure aspects of perceived self-efficacy and life satisfaction. Self-efficacy, as measured by the TBI Self-Efficacy Questionnaire, was separated into 3 subcategories: self-efficacy for acquiring assistance from the community to perform activities

and receive emotional support, self-efficacy for managing cognitive symptoms, and self-efficacy for managing emotional symptoms (e.g., feeling overwhelmed). Results of the statistical analysis indicated there was a strong association between self-efficacy for managing cognitive symptoms and global life satisfaction. However, one limitation of the study was the rating scale used to measure self-efficacy, adapted from a scale for a different chronic health condition, was not independently validated with a group of individuals with traumatic brain injury. Another research team led by Cicerone completed a randomized, controlled trial investigating the effectiveness of two different types of treatments (Cicerone et al., 2008). One of the secondary outcome measures was the TBI Self-Efficacy Questionnaire. For the treatment condition that received intense cognitive rehabilitation in the form of group treatment, there was a statistically significant improvement on measures of self-efficacy. Participants in the other treatment condition did not demonstrate a significant increase in self-efficacy. Another study with the traumatic brain injury population investigated the construct of general self-efficacy as a factor for resilience (Dumont, Gervais, Fougeryollas, & Bertrand, 2004). In this study, 53 participants completed rating scales and questionnaires regarding self-efficacy, personality, and social participation. They also participated in qualitative interviews to determine other factors affecting recovery. Self-efficacy was one of the top three variables that was associated with improved social participation based on statistical regression.

Another study explored self-efficacy in neurologically impaired populations (e.g. stroke, traumatic brain injury) experiencing difficulty with self-care or mobility by using qualitative interviews after inpatient rehabilitation treatment (Dixon, Thornton, & Young, 2007). The themes that emerged mirrored Bandura's proposed sources of self-efficacy in

terms of performance accomplishments, vicarious experience and verbal persuasion.

However, this study excluded people with ‘severe linguistic problems’ (p. 238) and did not discuss the degree of, if any, communication impairment of the participants, which lends support to the need for research in this area for people with communication disorders.

Self-Efficacy in Communication Disorders

Because self-efficacy beliefs depend on the specific task or situation, Zorn, Roper, Broadfoot, and Weaver (2006) borrowed the term communicative self-efficacy from Koensten, Miller and Hummert (2002) when referring to a person’s beliefs about their competence in communication situations. Zorn et al. (2006) conducted focus groups of participants with no identified communication disorder where communication about a controversial scientific subject was discussed and participants completed a rating scale developed by the authors which contained a measure of communicative self-efficacy. These researchers stated that people without any communication disorder may have high communicative self-efficacy for discussing one subject matter (e.g., math problems) and low communicative self-efficacy for another topic (e.g., sports).

Self-efficacy in people with hearing impairments.³ The area of communication self-efficacy has begun to be studied with people who have hearing impairments, which is another population closely associated with speech-language pathology. At least two self-efficacy scales have been developed for use in the hearing impaired population. Sweetow and Sabes (2010) developed the “Communication Confidence Profile”, which consists of 12 questions regarding self-efficacy for auditory communication skills (e.g., “Are you confident you can understand conversations when you are talking with one or two people in your own home?” p. 24). The authors developed this self-report measure as a tool for clinicians to

³ For further information about the studies cited in this section, please see Appendix A.

assess outcomes of audiologic rehabilitation that were not being captured with existing measures. Sweetow and Sabes (2010) state:

The elements of listening and communicating can be negatively altered by a lack of confidence in one's communication skills. Confidence is a critical element for eventual success from therapeutic intervention, be it hearing aids, auditory training, or other forms of aural rehabilitation. A lack of confidence may lead to avoidance behavior and anxiety. If listeners lack confidence in their ability to communicate in various circumstances, they may develop maladaptive strategies, including disuse of hearing aids or withdrawal from social situations. (p. 17).

Another scale for hearing impairment, the Listening Self-Efficacy Questionnaire (LSEQ) was recently developed by Smith, Pichora-Fuller, Watts, and La More (2011) to provide a measure of self-efficacy for people with hearing loss in different listening situations. Their rating scale consists of 18 statements (e.g., "I can understand an announcement over a loudspeaker in a noisy place, such as a sporting event." p. 422) which are grouped into three main categories: dialogue in quiet, directed listening, and complex listening. These statements are rated on a scale from 0 to 100 with 10-unit intervals where 0 corresponds to "cannot do this at all" and 100 is "I am certain I can do this". Results of the study indicate self-efficacy in certain listening situations may be more related to perceived difficulty versus actual performance based on analysis of the correlations between the LSEQ, hearing handicap, pure tone audiometry, and word recognition measures. (Smith et al., 2011). Another study from the hearing impaired population looked at the factors which predicted an individual's choice for audiologic rehabilitation intervention (Laplante-Lévesque, Hickson, & Worrall, 2011). People with hearing impairment who had higher levels of communication

self-efficacy, as measured using an unpublished scale developed by Jennings (2005), were less likely to choose hearing aids as an intervention strategy. The authors recommended that practitioners be aware of how this variable may affect a person's choice for intervention.

Self-efficacy in people with speech or language disorders.⁴ The concept of self-efficacy has begun to appear in speech-language pathology research although so far to a limited extent and scattered across different areas of study. Three self-efficacy scales related to communication disorders have been developed, in the areas of stuttering, aphasia, and voice problems.

Ornstein and Manning (1985) developed a scale called the "Self-Efficacy Scale for Adult Stutterers" (SESAS), for people who stutter to rate their confidence about their approach to a communicative interaction, and their ability to maintain fluent speech during that interaction. The SESAS consists of 50 speaking situations (e.g., "ordering through a speaker at a fast food restaurant" p. 314) with two questions about each situation. One question asks about the confidence of the person when entering into the situation, and the other asks about the person's confidence in maintaining fluent speech throughout the spoken interaction. Respondents rate their self-efficacy on a decile scale ranging from 10 to 100, where higher numbers correspond to greater confidence. Research conducted as part of developing the SESAS showed significantly lower self-efficacy for adults who stuttered compared to those who did not stutter (Ornstein & Manning, 1985). The participants who stuttered had relatively higher self-efficacy for "approaching" (i.e., entering into) situations than for "performance" in the situations (i.e., maintaining fluent speech) while the participants who did not stutter demonstrated the opposite pattern. The SESAS has been used in many subsequent stuttering research studies. For example, Langevin et al. (2006) selected

⁴ For further information about the studies cited in this section, please see Appendix A.

it as an outcome measure to show the effectiveness of a specific treatment program (Langevin et al., 2006). In that study, there was a statistically significant difference (i.e., increased confidence) on the approach scale of the SESAS two years post-treatment for the participants receiving stuttering treatment.

Babbitt and Cherney (2010) used the SESAS and the ASHA's Quality of Communication Life scale (Paul et al., 2005) as foundations for developing the Communication Confidence Rating Scale for Aphasia (CCRSA) as an outcome measure for aphasia treatment. The CCRSA consists of 8 questions regarding communication situations (e.g., "How confident are you about your ability to speak on the telephone?" p.217). Ratings are indicated by pointing or circling a vertical mark on a horizontal scale from 0 (not confident) to 100 (very confident), with marks to designate each set of 10 points, but it was unclear how the authors defined "points". Currently, only a single case-study exemplar exists documenting use of the CCRSA before and after therapy focusing on rehearsing personalized scripts for aphasia. Results showed increased self-confidence as measured by the CCRSA that were associated with improved performance on the Communicative Effectiveness Index (CETI) and Communication Activities of Daily Living, 2nd edition (CADL-2). The CCRSA later underwent psychometric testing using a sample of 47 participants, some of whom completed the scale up to 5 times while they continued to receive various treatments unrelated to the study (Babbitt, Heinemann, Semik, & Cherney, 2011). The scale now consists of 10 items and has improved psychometric properties⁵.

Influenced by the SESAS and the Voice Handicap Index, Gillespie and Abbott (2011) created the "Voice Self-Efficacy Questionnaire" (VSEQ) to measure any impact clinical

⁵ While the development of the self-efficacy scales for aphasia is promising, this study appeared to have some methodological issues that readers may want to consider before using the scale.

terminology had on self-efficacy for voice with potential consequences for adherence to voice treatment. The VSEQ contains 4 questions (e.g., “How confident are you in your ability to use your voice without harming it?”) rated on a 100 millimeter visual analog scale. On the left side of the scale are the words “Not at all confident” and on the right side, “Extremely confident”. Gillespie and Abbott (2011) exposed teachers with self-identified voice problems to the terms “vocal abuse/misuse” or “phonotrauma/muscle tension” during a video presentation depending on which experimental condition to which they were assigned (p. 93). The VSEQ was administered as a pre- and post-test. Exposure to the “phonotrauma/muscle tension” terminology was associated with improved self-efficacy for voice.

Self-efficacy has been raised as a potential variable influencing adherence to therapy for individuals with voice disorders by van Leer, Hapner, and Conner (2008). Successful voice therapy depends on clients’ readiness and willingness to change behaviors, and van Leer and colleagues posit that a person must have a certain level of self-efficacy to consider and make changes in their behavior. One cause of poor adherence to voice therapy might be related to low self-efficacy for behavior change. Van Leer and colleagues suggest that voice clinicians modify their strategies to incorporate assessment and bolstering of self-efficacy in order to improve treatment adherence.

In summary, there is a very limited literature on self-efficacy as related to communication disorders. However limited, these studies do suggest that self-efficacy is a growing area of interest in the field of communication disorders and may have a role in understanding treatment outcomes for speech and language disorders. There are many questions that need to be addressed to build on this early research. For example, how does

self-efficacy influence communication behaviors and a person's implementation of various communication strategies? What variables increase or decrease an individual's confidence in their communication in daily activities? Do people with communication disorders take into consideration their level of confidence when deciding whether to participate in activities involving communication? What is most meaningful to measure concerning communication to understand self-efficacy for communication? Is self-efficacy a potential area of intervention that would increase communicative participation in people with chronic communication disorders?

Research Questions

Because self-efficacy is understudied in people with communication disorders, it is appropriate to use qualitative methods to investigate this phenomenon in order to gain a broad understanding of this construct from the viewpoint of people who live with communication disorders. The purpose of this study is to examine how self-efficacy may relate to communicative participation for people with speech and language disorders. Communicative participation is defined by this study as the communication that occurs in the context of daily activities "where knowledge, information, ideas, or feelings are exchanged" (Eadie et al., 2006, p.309). The specific research questions are:

1. What role does self-efficacy play in communicative participation for adults across a variety of speech or language disorders?
2. What factors influence self-efficacy for communication from the perspective of people with speech or language disorders?
3. What advice would people with communication disorders give to others in a similar situation regarding communicative participation and does their advice

relate to the construct of self-efficacy?

The long-term goal of this line of research is to understand which variables, including self-efficacy, might be useful to include in a self-management intervention for people with chronic communication disorders to improve communicative participation.

Methods

This research study employed qualitative research methods consistent with the phenomenological tradition (Ritchie & Lewis, 2003). This tradition seeks to understand a phenomenon that is experienced by informants who are the recognized experts. It is rooted in interpretivism which values the human ability to think about and interpret our experiences (Ritchie & Lewis, 2003 p.7). The cognitive processing that occurs is not observable to outsiders and thus qualitative researchers have developed ways to discover the informants' views embedded in the context of their lives. One way to achieve this is through face-to-face interviews, which were used in this study. The interviews and analysis of them were patterned after the methods in previous research by this research team (e.g., Baylor, Yorkston, & Eadie, 2005; Baylor, Yorkston, Eadie, & Maronian, 2007; Yorkston, Klasner, & Swanson, 2001).

Participants

Unlike randomization used in quantitative studies, qualitative research subscribes to “purposive selection” which means intentionally finding individuals with specific characteristics who can describe their experiences on the topic(s) of interest. Many factors (e.g., diversity of the population) influence the number of participants required to reach saturation (described in detail later) and develop themes from qualitative interviews. Often in phenomenological qualitative research, at least twenty participants are included (Mason,

2010). Due to the time constraints of this thesis, only 5 interviews were completed and analyzed. The study will continue on to include more interviews in the future.

Inclusion criteria. Participants were required to be adults age 18 years or older who were at least 3 months post-onset of a diagnosed communication disorder. A wide range of chronic communication disorders was desired, including acquired language disorders (e.g., aphasia), voice disorders (e.g., spasmodic dysphonia or vocal fold paralysis), speech or voice disorders due to head and neck cancer, motor speech disorders due to either acute (e.g. stroke) or degenerative diseases (e.g., Parkinson's disease) and stuttering. The severity of the communication disorder was to be mild to moderate to allow participants to convey their messages with relative independence to ensure the participants' viewpoints were represented. Judgments about ability to participate in the interviews were made by the lead researcher on the project (Carolyn Baylor) based on her interactions with the participant during the informing and consenting process. Participants who were able to engage in conversation and express their views were candidates for the study. They needed to have sufficient cognitive and language skills to productively contribute to an interview. Participants were required to use speech as their primary means of communication, although some use of Augmentative and Alternative Communication (AAC) was acceptable. Speech-language pathologists conducted the interviews and provided communication support as needed. In order to represent a broad range of treatment status, participants may have been receiving any type of intervention for their communication disorder, but they were not required to be receiving any treatment. They must live in a community setting in the Puget Sound region because the interviews during this phase were in-person. All participants were native English-speakers and had adequate hearing (aided or unaided) to understand verbally presented information.

Exclusion criteria. Adults living in any type of care facility (e.g., skilled nursing facility) were not eligible to participate in the qualitative interviews because the purpose of the study was to explore the role of self-efficacy in communication interactions that are typical of community-dwelling adults. Individuals who reside in skilled nursing facilities do not participate in the same types of community-based interactions and warrant consideration in separate research. Individuals who used AAC exclusively were excluded from this study because the focus of the questions, consistent with the line of research preceding this study, was to explore the communicative participation of individuals who use speech for communication. Issues surrounding AAC and participation are critical to explore but were not included in this study because there may be unique concerns related to the use of augmentative communication systems that warrant more in-depth exploration in research dedicated to that topic. Additionally, if it had been less than 3 months since the onset of the communication disorder, a person would not qualify for this study because he or she may not have had time to experience the wide range of communication situations and to have attempted and scrutinized different strategies for participation which were the focus for this study.

Recruitment. Participants were recruited from outpatient medical facilities serving people with communication disorders as approved by the institutional review board at the University of Washington. Flyers were distributed to the following clinics: University of Washington Speech and Hearing Clinic, University of Washington Outpatient Rehabilitation Clinic, and University of Washington Voice Disorders Clinic. The clinical speech-language pathologists working in those settings were provided with recruitment fliers and background information about the study. They were asked to post a flier in the waiting area in addition to

distributing the fliers to any of their clients who met the inclusion criteria. The fliers instructed interested individuals to contact the lead researcher (Baylor) directly for further information and enrollment. Participation in this study was unrelated to any clinical care that participants may have been receiving at any of the recruitment sites.

Data Collection

Interview format. Qualitative interviews took place face-to-face in private rooms on the University of Washington campus. Participants were offered the opportunity to be interviewed in their natural environment (e.g., home), but all declined. Two of the three “core” researchers were present (myself, Carolyn Baylor, and Kathy Yorkston) at each interview. This research team often uses two interviewers because interacting with people with communication disorders may require one interviewer to provide communication support while the second interviewer focuses on taking field notes in particular to capture non-verbal communication aspects of the interaction. Interviews lasted between one to two hours. The exact duration of the interview was shortened based on participant comfort. Interviews were audio recorded and the interviewers present also took written field notes.

Interview content. Participants were informed at the beginning of the interview that the purpose was to understand people’s experiences with confidence in communicative interactions. They were told that we were seeking this information as a first step towards developing an intervention aimed at improving communicative participation in people with chronic communication disorders.

The semi-structured interviews began with a “mini-tour” question, which is an open-ended question that serves as a vehicle for starting the conversation but focuses on a specific experience (Seidman, 1998). Follow-up questions were specifically focused on self-efficacy

in communication situations while allowing for the participant to lead the conversation in the direction he/she chose. For a list of questions that served as a guide for the interviews, please see Appendix B.

Data Analysis

Data processing. Interview recordings were transcribed verbatim by a researcher who was present during the interviews. After transcription, all identifying information was removed and the participant was assigned fictitious initials. Additionally, participants were offered the opportunity to review their own transcript and have any information removed that they wished, however none of the participants expressed the desire to review the complete transcript.

To determine the reliability of transcription, two methods were used. First, a second researcher that was not present during one interview reviewed that entire transcript. Only minor discrepancies were noted which did not affect the overall meaning conveyed by the participant (e.g., the word *somebody* instead of *someone*). Second, participants were asked to verify the transcription. Instead of having participants review the entire, lengthy transcript, the researchers created a short synopsis (e.g., approximately two pages long) of each interview with salient points from that particular participant. The written summary was mailed to the participant along with a request to review the summary, to offer any changes or additional information that they desired, and to return the information in a self-addressed, stamped envelope that was included. They were also offered the possibility for follow-up in-person discussions should the researchers wish to clarify any questions they had with participants, or if participants thought of additional information they would like to add. The following statement appeared at the end of the summary: "I think this is an accurate summary

of some of my key experiences with communication after my stroke.” Four of the five participants responded that they agreed with this statement. One participant included additional information that was incorporated into data analysis. The fifth participant did not respond.

Interpretation. Transcripts were read multiple times by the “core” team members listed above and codes were determined for coding the transcript. Preliminary codes (i.e., key words that represent topics or ideas that participants discussed) were not chosen a priori but were developed in response to the content of the transcripts. These codes were operationally defined by the research team and agreed upon by at least three members of the research team. After an initial reading of one transcript, the first draft of a code dictionary was developed. The codes were then applied to the transcript by three members of the research team. Codes were assigned to a segment of the transcript where the participant discussed that topic. This included one sentence or a much longer section of the transcript. A segment of the transcript could also be assigned multiple codes.

During a meeting of the research team to discuss this initial round of coding, a second draft of the codes was formulated. The revised codes were applied to a second transcript by the research team. The group met again and determined that a list of 18 codes was appropriate for initial coding of all the transcripts. These codes and their definitions are listed in the Code Dictionary in Appendix C. Due to feasibility issues, the results reported here focus on 7 of the 18 codes. This subset of codes, as defined in Appendix C and found in Table 1, were: *advice*, *goals*, *good quote*, *participation*, *practice*, *SLP treatment*, and *salient messages*. Given that this thesis represents a preliminary portion of the broader study and included only the first 5 interviews in a series of future interviews, the codes developed as

part of this thesis are preliminary in nature.

Table 1

Code Dictionary Subset

<i>Code</i>	<i>Meaning</i>
Advice	Insight, suggestions, etc., meant for other people with communication disorders.
Goals	Any reference to long or short-term goals.
Good Quote	Any quotes that represent a participant's viewpoint particularly well, in order to make these quotes easier to locate in the transcript.
Participation	Any reference to participating in societal or familial roles, including hobbies, job, etc., following the WHO model.
Practice	Situations which allowed for communication practice (not with therapist or in clinic room)
Salient Messages	Participant's important, key messages. Includes activities participant felt were beneficial to recovery.
SLP Treatment	Description of what occurred during SLP treatment past or present, positive or negative, including hypothetical changes desired.

In order to assist with organization of the transcript data, the web application Dedoose[®] was used (Sociocultural Research Consultants, 2011). The program allowed researchers to assign codes to segments of transcripts and to sort transcript segments according to the codes, which facilitated within and across participant comparison of the coded excerpts. Along with coding, part of the interpretive analysis was to record the thoughts of the researcher while reviewing the transcripts which is called “memo-writing” (Lincoln & Guba, 1985). Dedoose[®] allowed memos to be attached to segments of the transcript. The preliminary code dictionary was entered into Dedoose[®] and each interview was coded by one primary researcher. Coding of one transcript was reviewed in its entirety by a second researcher. One disagreement in coding was resolved via discussion.

Thematic analysis. Once the coding of the data was complete, transcripts were sorted according to the codes. Coded excerpts were compared within and across participants. A summary of the most salient experiences discussed by the participants was completed.

There was the potential for a wide range of experiences and an effort was made to represent participants' unique experiences as well. These summaries were brought together into key themes, which were similar ideas expressed across participants. Quotations from the interviews served as exemplars of the themes.

Trustworthiness. Interpretation of the data from the interviews must be trustworthy. Lincoln and Guba (1985) state that in order for qualitative research to be trustworthy, it should be credible, dependable and confirmable. The trustworthiness of the data was protected in the following ways:

Credibility. According to Lincoln and Guba (1985) there are two overarching ways to increase the likelihood of finding credible results: conduct the study in a manner that lends itself to credibility and have the findings confirmed by the experts (i.e., participants). In order to set aside existing beliefs and be open to novel interpretations of the participants' viewpoints, prior to the first interview the researchers discussed their thoughts about the anticipated findings. Once the thematic analysis was complete, the researchers compared their thoughts with the results in an effort to ensure the results were not unduly influenced by the researchers' biases. Another way to establish credibility is through triangulation, where multiple data sources converge on the same interpretation (Lincoln & Guba, 1985). One mode of triangulation described by Lincoln and Guba (1985) is the use of multiple investigators who hold each other accountable for the interpretation and theoretically eliminate the bias that can occur in a single researcher. Partly for that reason, there were three researchers involved in this study. The inclusion of multiple participants also increased the likelihood of authentic interpretation.

Sharing the interpretations of the interviews with the participants to determine if the

description actually represents their experience is called “member-checking” and is a crucial step in determining the credibility of the results. Member checking in terms of sharing the final themes of the study with participants did not occur due the preliminary nature of the analysis, but providing the opportunity for participants to review a summary of their transcripts did contribute to the credibility of the data.

Confirmability. Creating an audit trail is one technique Lincoln and Guba (1985) suggest to demonstrate confirmability that was used in this study. An audit trail consists of raw data plus data processing notes and products, including field notes, such that a researcher not involved in the original collection or analysis of the data would be able to review it and come to the same interpretation. Using Dedoose[©] assisted with organization of the audit trail.

Transferability. In order for the interpretation of the data to be a useful contribution to research literature, the researchers must provide enough detailed description of the participants for clinicians to be able to apply (or transfer) the themes developed to their particular clients. While protecting participants’ privacy, detailed information such as demographic information, characteristics of the communication disorder, length of time post-onset of the speech or language disorder and participant’s profession are specified in the results section.

Saturation. Usually interviews continue until a saturation point is reached, where no new viewpoints are expressed and there is confirmation of the data already received. The saturation point was not reached in this thesis for feasibility reasons, but the longer-term plan is to complete future interviews to reach saturation.

Results

Participants

Five adults with speech or language disorders participated in individual interviews. Please see Table 2 for demographic information. All participants experienced at least one stroke, which caused their communication difficulties. The participants' primary language was English and they were residents of Washington. They all either lived alone or with family members (e.g., spouse, parent). All were able to use speech as their primary means of communication and did not have problems with communication prior to neurological lesion. Four of the five participants reported no hearing difficulties. The fifth participant reported hearing loss since age 17 without the use of assistive devices. All of the participants were in the chronic stage of the disease process and were over age 50.

Table 2

Participant Demographics Information

<i>Fictitious Initials</i>	<i>Gender</i>	<i>Age</i>	<i>Ethnic Group</i>	<i>Highest Level of Education</i>	<i>Current work status</i>	<i>Occupation</i>	<i>Time Post-stroke</i>
J.D.	M	53	Asian (Japanese)	2 years technical school	Volunteer & attending school	Car Sales	7 years
P.G.	M	51	Asian	College graduate	Retired early because of medical condition	Information Technology	3 years
D.F.	F	58	Caucasian	Post-graduate	Working part-time outside the home	Career Coach	7 years
N.C.	F	68	Caucasian	Some college	Not working or retired early because of medical condition	Secretary	14 years
S.U.	F	68	Caucasian	Post-graduate	Semi-retired	Former Healthcare Provider; now part-time in at-home business	9 years

Participants' communication was either affected by aphasia or dysarthria. When asked to choose a description of their speech/language from a list of five choices on the demographics page, two participants reported their speech and language as being "normal" while two others reported theirs "sounds different but people understand me." The fifth participant selected "sometimes have to repeat words to be understood". Participants with dysarthria had speech which was understandable in the conversational context. For those with aphasia, anomia ranged from mild to moderate. Four of the five participants independently conveyed their ideas. The fifth participant required a moderate level of co-construction of the message. Please see Table 3 for further details. All of the participants had

received professional treatment by a speech-language pathologist for their communication disorder; at least four were currently receiving outpatient treatment either individually or in a group setting.

Table 3

Participant Communication Profiles

<i>Fictitious Initials</i>	<i>Communication Disorder</i>	<i>Self-Description of Speech/Language^a</i>	<i>Communication Description by Interviewer(s)</i>
J.D.	Spastic Dysarthria	Sometimes have to repeat words to be understood	Dysarthria c/b ^b occasional articulatory distortion, mild-moderate hypernasality, slightly unnatural prosody. Able to independently convey a high level of information. Comprehension: answered questions in relevant, appropriate manner.
P.G.	Non-Fluent Aphasia	Sounds different but people understand me	Aphasia c/b mild anomia, but able to self-correct or circumlocute in most instances. Self-described short-term memory problems & 3-5 times needed questions to be repeated, but was aware he'd lost track. Independently able to convey ideas. Comprehension: impacted by memory, but answered questions appropriately.
D.F.	Ataxic Dysarthria	Sounds different but people understand me	Ataxic dysarthria c/b fast rate of speech, imprecise articulation. Required moderate amount of listener effort to understand. Expressive/receptive language intact.
N.C.	Non-fluent Aphasia	Normal	Aphasia c/b mild-moderate anomia. Compensated with gestures, facial expressions, tone of voice. Required some co-construction. Receptive language better than expressive.
S.U.	Non-fluent Aphasia	Normal	Aphasia c/b mild anomia, some linguistic disfluencies (e.g., word repetitions, filler words "um" "you know", pauses). Some incorrect verb tenses were self-corrected. Able to independently convey a high level of information. Comprehension: answered questions in relevant, appropriate manner.

a: Each participant selected a description from a choice of 5

b: c/b= characterized by

Interview Results

The purpose of the interviews was to learn how participants manage their communicative participation in daily situations, the possible role of self-efficacy, and advice they would share with others in similar situations. Because future interviews with additional participants are planned, analysis of the interviews was preliminary in nature. The stories and experiences shared by these participants seemed to contain information that would be helpful to other stroke survivors, to families and caregivers, and to healthcare providers. The current thematic structure of the results follows this pattern and consists of three themes: Messages to other stroke survivors with communication disorders, Messages to family and community members, and Messages to healthcare professionals. Please see Table 4 for an overview of the messages to each group. In the following sections where quotes from the participants are used, symbols from transcription were included. Table 5 contains the meaning of the symbols to aid in understanding.

Table 4

Preliminary Messages and Their Intended Recipients

<i>Recipients</i>	<i>Message</i>	<i>Sub-Message</i>
Other stroke survivors	Progress requires hard work and effort	Set up practice situations for yourself Set attainable goals
	Progress takes a long time	
	Work with what you have	Draw on your personality and past experiences “You have to grasp how you have changed” Don’t fight against the changes
Family and Community Members	My viewpoint is different than yours	
	How to help	Encourage me Allow others to take on important roles Don’t put words in my mouth, unless you receive permission
Healthcare Professionals	Progress continues long after one year post-stroke	
	Desirable traits in a professional	
	Treat me as a unique individual	Take time to get to know who I am Make therapy relevant to my life Find the proper level of support

Table 5

Transcription Key

<i>Symbol</i>	<i>Meaning</i>
[]	Transcriber comments, including words that were removed to protect the privacy of the participant
()	Mazes
<>	Overlapping speech
{ }	Notes about non-verbal aspects of the interaction
^	Abandoned utterance
*	Incomplete word

Messages to other stroke survivors. Participants were specifically asked what advice they would share with someone who recently experienced a stroke and was having communication problems similar to their own. Three sub-themes emerged from their interviews including *progress requires hard work and effort*, *progress takes a long time*, and *work with what you have*. Each of these sub-themes is described in detail in the following sections.

Progress requires hard work and effort. The interviews revealed that hard work and effort were involved in making progress towards regaining lost communication skills for all five participants. P.G. said, “Be positive and try to work hard to try to get back to where you were.” According to S.U.:

Well there’s a lot of work. There’s a lot of work. Just to learn how to speak. Just to learn how to write. Just to learn how to read. It’s a hell of a lot of effort, but the rewards are a hell of a lot of gift.

One participant, D.F., had multiple analogies for the work required. She reported, “Up front (my therapist,) my rec therapist said, ‘[participant’s name] you have a new job. Your new job is getting better.’” She also had the following exchange with an interviewer:

D.F.: I tell people that losing 20 pounds is not unlike trying to learn to speak again.

Or like trying to get a job. You have to kinda figure it out. You have to learn (learn) not to eat chocolate, learn what not to do and learn what to do. You have to do some changes, but you can get there. You have to believe you can get there. And if you don't lose 20 pounds, you lose 10, okay what the heck? It's still 10 pounds.

Interviewer: You've made progress.

D.F.: That's right.

Two of the participants warned about the consequences of not putting in the necessary effort.

As said by D.F.:

Some speech is (is) temporary, it is. Some goes away. But some doesn't and you don't know the first couple months. But (if you don't really) if you don't do your work, I can tell you what's going to happen: nothing!

This was confirmed explicitly by S.U.:

I would say first of all, "You benefit or you lose." That's the simple fact of the matter. The effort you put in, you will get the rewards. Nobody else will give them. And you make the effort. If you don't make the effort, nothing's gonna happen, you know.

Set up practice situations for yourself. Participants displayed hard work by setting up practice situations. Four of the five participants discussed specific ways they practiced either with others or alone. These practice situations took a variety of formats. Instead of waiting for a professional to provide him with practice, P.G. stated, "When I got home, right away I started looking on the computer and tried to look on the internet for things that would help me." He found interviews and classes involving repeating words and sentences. One of P.G.'s aunts called him every day to practice. As he said, "So she would talk about one of the things that I did in (class um) therapy and we did practice (every hour) every day for an hour

at night.” He also reported going to the mall to initiate conversations with store employees. At the suggestion of a family member, he went to the library, interacting with staff and adults in an English Language Learner class. J.D. discussed practicing communication skills at a nursing home where he volunteers approximately 20 hours per week. He worked up to this through the intermediary step of practicing communication with mental health interns, which was arranged by his mental health therapist. D.F. became more comfortable with telephone calls by speaking with strangers. She reported, “I mean I kinda started talking on the phone by calling people on [credit card company] accounts. I would talk to the customer service reps. . . .And they have to listen to you, no matter how bad you are.” S.U. talked about more solitary activities. She stated:

A nurse told me on the rehab floor one day, “[Participant’s name] you can sing. Sing! Sing!” She said, “It’s amazing how much better your speech will become if you allow yourself to sing. So sing every single day. Whether it’s ‘100 bottles of beer on the wall’ or whatever it is, you know, just sing.” And I thought, you know? I was a good singer at one time. Why not? It’s fun you know. And that really helped. So, it was something that I could [do] by myself.

In addition to practicing her speech and expressive language, S.U. discussed improving her receptive language in the written modality:

And I don’t remember who introduced that book to me but somebody said, “You know [participant’s name] I think you could read that book.” And I sat out on my deck, it was a nice time of year and I think it took me about three or four months to get through that book. But I eventually read it. What happened to my brain, I don’t have a clue. I really don’t understand any about that because I had gone through being

not able to talk. Not able to spell. Not able to read, and I read a book within the first year, you know. And that kind of convinced me of I will never let anybody tell me what I cannot do regarding this situation because I have proven, and I didn't mean to prove it to myself. I really didn't. But I proved to myself. It's a blank slate. Whatever you want, that's what you can do.

Set attainable goals. Three of the participants mentioned creating goals to guide the effort towards recovery. P.G. reported, "I would say also to (you know) have a plan for what you're trying to do (you know). (What) Where you're gonna go, what your goals are." J.D. went into more detail about goals:

And to set up short term goals and have them written down and mark each goal off once they're completed, and then immediately write another one down. But short term goals. . . . (I don't mean) I don't mean like in a day or two, I mean like maybe 3 months out, 6 months out at the longest.

He also spoke to the importance of making attainable goals in the following excerpt:

Take baby steps at first. And (and) do it until you feel comfortable. Just don't say "6 weeks of this and then 6 weeks of the next step". (like) If it takes 8 weeks, okay. If it takes 3 weeks, okay.

In S.U.'s experience, goals emerged and changed over time. She was unsure of what she wanted to achieve at first.

Progress takes a long time. All of the participants mentioned the lengthy timeline for progress to occur. As N.C. stated:

But it was[has] been 14 years, so you know, in the beginning I remember the group[aphasia treatment group]. This man said, "In 5 years you'll be able to talk." I

said, {whispering} “5 years!” And then 5 years came, and I thought, “Oh, I’m much better, but I’m not there.” But I thought, “You just don’t understand how long it takes.”

At 8 years post-stroke N.C. started to read books. Although it has been 7 years since D.F.’s stroke, she affirmed, “But I tell you what, I get better every single month. (I’m never) I’m never getting worse. I’m still improving.” She asserted the importance of taking a long-term perspective. In her own words, “But people tend to take the short-term and do what people want in the short-term, against the long-term. Having my stroke and speech problems is a long-term thing.” One way that D.F. focuses on the long-term nature of progress is by prioritizing her healing over everything else. As she said:

So my self-confidence comes by putting myself first and (my) my healing first, and then everything else falls in place. Now that’s not counterintuitive. Most people think (they) they do the immediate things and then maybe do the health things second, it might work. No! You need to be health things first, and then everything else falls in place after that.

Work with what you have. Several participants discussed their personality characteristics before the stroke and the distinct past experiences they continue to draw upon as they improve. S.U. and others mentioned recognizing their own limitations in order to move forward. They also indicated it was better to not fight against the changes by learning to be calmer and listen more.

Draw on your personality and past experiences. Participants talked about their past experiences and how they related to their current outlook on progress. For example, D.F. spent time in a foreign country where English is not spoken. This experience provided insight

into her difficulties with communication post-stroke. She also discussed another experience:

When you have a speech problem you learn to be more succinct. I was always pretty succinct because of my sales training. But I've learned to not go into long explanations. Also I've learned to ask more questions. People think I'm smarter if I don't talk so much.

Several participants revealed that their personality traits (e.g., stubbornness, optimism) assisted with their progress. P.G. had an optimistic outlook. He reported, "The main thing is that (I was very um uh very um) I wanted to do the best that every day. And (um) I was always positive at what I was trying to do every day." S.U. talked about how her strong will influenced her progress. In her words:

I'm stubborn. I'm really really, really, really, really stubborn. I'm not exaggerating.

I'm really stubborn. If I set out and I focus on something. Come high or hell or [come hell or high water] I'm going to do it. I am going to do it!

D.F. discussed how her achievement-oriented mindset affected her perspective on progress.

The following is the exchange concerning this:

Interviewer: Did you have to do kind of anything conscious or purposeful to kind of keep yourself positive? Or do you think that was kind of "my natural disposition"?

DF: I think I kept myself unknowing.

Interviewer: You kept yourself^

DF: Unknowing.

Interviewer: Unknowing.

DF: Just in the moment. They said "Do this this week", well I did that this week. I didn't try to think too far ahead. I can't control it anyway. So that's what my

meditation, my zen, taught me. Just stay back in the moment. Just the moment you're in, if it hurts, try to figure it out, how to not make it hurt. Just don't go too far away, cause you go too far out, you're afraid. The idea of I would have to learn the whole language again was overwhelming. Especially when I was first sick. She [speech pathologist] was only having me do one word. Two words. Speak five words and then try to do a paragraph. And then if I didn't do the paragraph good, she bumps me back to one word. I get mad at her! You know cause I felt like I'd been demoted. (But I had to^) And she'd get mad at me she said, "[Participant's name] don't be such an achiever. Don't do that. It's today." I said, "Well I didn't do the three words good enough so now you're giving me one word. I flunked!" She said, "Don't feel that way. (Just^) It's a progression. You know, you'll get there. Don't try to be such an achiever."

Interviewer: So don't look too far ahead too fast.

DF: (We) In our success society we try to achieve things. And god knows I'm more than [company name] person. I'm more than that. I had to relearn to just take it for what it is right now.

"You have to grasp how you have changed". In order for stroke survivors to work with what they have, they need to understand their limitations. S.U. said it best:

The stroke experience is a lot of things to all kinds of different people, but I think what is central is that you have to grasp how you have changed. And that's not an easy thing to do because it's really about limitations. And I don't think any of us want to be forced to admit our limitations. You know? And you have to. You have to, you know? And it's very upsetting. It's really in it and how you deal with it, you know,

makes a difference. It just makes a difference.

J.D. also reported that at first he did not realize what had changed. For example, he thought he could drive when he was not able to do so. P.G. expressed the change in his communication this way:

You know the big thing with my stroke is that (hmm) before my stroke of course whenever I wanted to talk with anybody or anything it just comes out, right? You don't have to think about it. But now after my stroke, every time I have to think about what I'm gonna say.

Three participants discussed the strategy of telling their communication partner they have had a stroke and have limited communication skills. When they do this, sometimes the communicative interaction goes better. P.G. stated, "And sometimes (um) if I don't understand I'll say, 'Can you slow down because I had a stroke'. (You know and) right away, 'oh'. Then they slow down (and) and it's good." Although N.C. uses this strategy, she does not like to admit she has had a stroke:

I feel (I d*) I do pretty well. So (and) I hate to say I'm a stroke survivor or I'm having a stroke I don't want to anything but sometimes I strumble[stumble] a little bit and then I say 'I had a stroke so it doesn't come out quite' and when I say that 'excuse me I had a stroke I have difficulty' and then when I do (it) it just perfect.

When participants discussed understanding how they had changed, one issue they considered was how they see themselves was impacted by others. This included perceptions from other people which changed their self-image and portraying confidence. Three participants indicated that their self-image was impacted by the way other people responded to them. D.F. discovered that some people perceived her speech as being a foreign accent.

She related the story this way:

One day a guy came up to me he said “You, what language, what country you from?” on the bus. I said, “Oh my god, what country?” I said, “I could hug you!” I said, “People have been telling me I sound like a derelict, like a drunk, and now I sound like a foreigner. That’s a promotion!”

D.F. also discussed the concept of entitlement and disability. Her dentist and a sibling do not view her as disabled and therefore do not want to accommodate her preference for using email instead of the telephone. D.F. wanted to be the one to determine whether she is disabled or not. N.C. talked about portraying confidence during a communicative interaction as follows:

N.C.: And I think my presence, I think [I] look confident. Sometimes I don’t, but (I my) who I am, I think other people think I am. [I portray myself as confident sometimes and people think I’m confident even if I’m not] {laughing}.

Interviewer: You portray.

N.C.: Yes.

Interviewer: You portray.

N.C.: Yes. Yes.

Interviewer: It’s all in the look.

N.C.: (which which) And I think that helps with the whole thing.

J.D. explained how he became intensely aware of his speech symptoms when he was around former co-workers. He said:

And everyday stores and restaurants I don’t have a problem but (I) when I get with people (in) in the business that I was in, (I) that’s when I feel it. (I) I can tell that I’m

too slow for what they're used to and what they like (and). The car people's kinda fast paced. And so rather than deal with it they'd just rather pass it up or put it aside. So it seems like (it's there's not much {pause} there's there's) right now I can't keep up the pace. No matter what it is. It's like Mr. Ed running in the Kentucky Derby.

Don't fight against the changes. Instead of fighting against the changes, a few participants mentioned other ways to deal with the changes. D.F. said, "I do meditation. I've learned to be very calm. (I've learned to make my) I've learned to make my (my) mind run slow so my mouth can catch up." S.U. also mentioned the value of meditation and breathing, along with slowing her speech and "practicing patience". Both N.C. and D.F. discussed learning to listen, which maximizes their comparatively strong receptive language skills. As D.F. said:

. . . So I guess take a long-term perspective. This is your second life. . . . And it's gonna be a good one. It is. Because you're going to learn to listen. And not talk so much. And when you listen a whole world of things come into play. You learn about the people around you, learn about the world.

N.C. reported, "I learned people talk a lot. And they don't need to talk all, all the time and they have nothing to say anyway. Just, they need be quiet too."

Messages to family and community members. While participants were not specifically asked about advice they would give family and other communication partners, their discussions of their experiences revealed many things that were helpful, or sometimes not helpful, in terms of how their family members and other community members interacted with them. The following messages appeared in their stories. Two sub-themes emerged: *My viewpoint is different than yours* and *How to help*.

My viewpoint is different than yours. All of the participants discussed how their internal reality was different from the way they felt they were perceived by the outside world. This was most acute in their closest relationships. P.G. talked about how his family saw him as the same person as he was pre-stroke. He said, “(you know) even now (you know) they think I’m the same (now) but I’m not. . . .Even though I look like I’m okay, I’m not (you know). Inside (you know) my brain is different.” S.U. discussed how she chose not to share her internal viewpoint with some people because she did not think they would understand. She related it this way:

Again, I’m aware of my limitations. What I don’t have. What I’m missing you know, and that’s not something that anybody else can participate in. That’s not anything that anybody really can understand because it’s you that is experiencing that limitation, and to express that doesn’t make a whole hell of a lot of sense.

Although many of D.F.’s family members and friends informed her that her speech is intelligible via phone, her internal belief is that it is more difficult to communicate using that method. Her view was that people stopped accommodating her. She discussed it in the following excerpt:

So I guess, you become very aware how people communicate. I had friends who insist on calling me on my cell phone. I hate it! But that’s all they are able to do. They don’t do email. So I have problems with people who don’t do email. And people who want to use phone. I find that it’s really preferences on communications. So that is one thing when you have communications and you lose one. (The thing that people don’t quite^) They get sick of accommodating you. They do. And they expect you to come over to their side.

Because of this difference between how the stroke survivors view themselves and the interpretation of those on the outside, it is easy to misinterpret the situation. In particular in the area of communication, where the participants were most limited, misunderstandings occurred. P.G. provides an example of how his family would mistake his struggles to communicate with him being upset:

P.G.: ... I think your communication (uh) with your family too is sometimes hard. (uh you know like your) Maybe your wife or anybody they'll think you're talking to them and then they think you're saying something else. But really (it's not) you're not trying to say something wrong, you're just not saying it right. {laughs} You understand what I'm saying?

Interviewer: Oh.

P.G.: (so if I say um {pause} I don't know like uh I don't know) Sometimes if I say something maybe I say it the way I say it, and then they'll say I'm mad or something, but I'm not mad. I'm just trying to talk so then it comes out like I'm mad or something.

Interviewer: Right.

P.G.: Yes, especially in the first six months to a year (you know) it's like that. I think.

Interviewer: Oh, okay.

P.G.: Yeah. Because they think I'm the same person like I was before my stroke.

How to help. Since it is difficult for many stroke survivors to communicate their desires in the acute stage of recovery, the participants offered suggestions of how others can assist them in a respectful manner.

Encourage me. Two of the participants spoke directly about valuing encouragement

from others. However, this encouragement needed to be at the right level and without glossing over the survivor's problems. S.U. discussed talking with her sisters and friends in other cities. She reported, "And I really paid attention to what they were saying to me as far as my progress." One friend in particular would offer encouragement:

S.U.: We're very good friends and she would oftentimes say to me, "[Participant's name] you're doing great. You're just doing great! I can't believe from one conversation to the next (that) the improvement." In my mind I didn't see it that way. I really didn't see it that way. Again, I'm aware of my limitations. What I don't have...

Interviewer: Yeah, but how did you feel when your [occupation] friend said that to you? Did that make you feel, 'she doesn't know what she's talking about' or 'that's really good'?

S.U.: Sometimes it made me feel that she doesn't know what she's talking about. Most of the time, I smiled and said, "Way to go [own name]."

N.C. related how some people were discouraging and what she would have preferred they said:

N.C.: And people say dumb things to you.

Interviewer: Okay. Like^

N.C.: Well my neighbor says, "Well my friend had a stroke and (sh* she) the next week she was just fine." And I mean it's like "Ah!" {exasperated sigh}

N.C.: Well, with my stroke. We with grocery store and people say, "Oh, you're just fine". Well how dumb to say that because I can hardly speech[speak]. (I I) I just don't understand. They wanna say something {pause} that's pretty dumb and they're smart

people. <And I mean>

Interviewer: <They don't know> what to say.

N.C.: But I mean I just {laughs}

Interviewer: That wasn't the right thing though!

N.C.: No! I don't know what I want, but I mean^

Interviewer: Well, I was gonna ask, what would be really genuinely encouraging to people?

N.C.: "It's gonna get better", I mean something like that. (you're) "I see you're struggling but you're getting better." I mean something like that. But to say "Oh, I didn't realize you" Well, come on!

Interviewer: So just ignoring what's evident wasn't helpful.

N.C.: Yes! I mean {laughing}

Interviewer: It's okay to be honest and <acknowledge there's a struggle>.

Allow others to take on important roles. Two participants reported that their closest family members were unable to fulfill some important roles in their communication recovery, but the participants indicated that these family members had many other critical roles that they did fulfill and that it was acceptable for other people in their lives to help with their communication recovery. S.U. said her partner had difficulty encouraging her in the same way as her friends. She had friends attend her medical appointments instead of her partner, who was not particularly comfortable in medical situations. P.G. needed practice partners, however, he quickly realized that his immediate family members were not the best people to fill that role:

. . . So with my wife I think it was hard for her and (I) I thought it would be good that

my wife (is uh) should not really (um) do the therapy (like you know) practice. At first (I started) I thought it would be good but it's hard for her (you know). She's my wife. It's a little different because (um) she would ask me how to do something trying to do it and then I can't do it she doesn't understand why I can't say these things. So I thought well, that's not good (you know). Cause it's hard for her and she's thinking about other things and (you know) it's hard for her and so that's why I decided to come (here) somewhere else and ask other people...Even with the kids. At first I told the kids that for half hour a day you should help me every day. But that didn't [last] long. That didn't go very good.

Fortunately, P.G. had extended family (e.g., aunts, mother) who were available to practice with him.

Don't put words in my mouth, unless you receive permission. Participants reported how some people tried to be helpful by attempting to guess the missing words during moments of anomia. P.G. said he was not upset that his friends tried to speak for him, but he wanted to attempt to say the word himself first. N.C. felt differently; her sister used this strategy unsuccessfully:

... She'd drive me crazy cause I'd be trying to say something and she'd put it her own words and it was wrong. I'd go, "No, no" {gesturing wildly to stop} and she kept going. "No no!" She's still going. I think, "Aah." (she doesn't) In telling me what to say (she's) it was wrong and she wouldn't let it go. (so that's) All her life it's always been like this so yeah. But in the beginning, oh! Drive me crazy.

Messages to healthcare professionals.

During the interviews, participants were asked to comment about their experiences with

healthcare providers, specifically speech-language pathologists. They also shared experiences with doctors, physical therapists, occupational therapists, and mental health professionals.

This third theme contains the messages from the interviews that are relevant to healthcare providers. The following sub-themes emerged: *Progress continues long after one year post-stroke*, *Desirable traits in a professional*, and *Treat me as a unique individual*.

Progress continues long after one year post-stroke. All participants strongly expressed that they continued to make progress in their speech and language skills despite being 3 to 14 years post-stroke. They were discouraged by medical professionals who told them the only progress they would see would be in the first year. N.C. indicated it caused her to panic when she was not experiencing the changes in her communication skills she desired during that year. She said, “Because the doctors, this doctor told me in a year (that’ll) that’ll be it. Well that’s why I was like ‘What? I gotta (I gotta) get going here’ and nothing was coming, you know.” P.G. said it this way:

You know the doctors always say (you know you know) maybe a year and maybe that’s it (you know). But I think it took me about 2 years till I thought I was doing pretty good (you know) like maybe I’m 80% of 100.

S.U. relied on her determination and strong will to reduce the impact of statements of that nature made by healthcare workers, as follows:

I told you one thing over the phone and that was that if I were a patient – a new – I would never – and I have said that I think in passing – I would never let anybody tell me that “This is the cut-off point. If you don’t have X, Y, and Z now you’ll never have it.” And I don’t - maybe it is because I didn’t want to remember it, but I don’t remember who said it at what time. And I remember two different occasions that

people made those comments to me. And I thought, “I’ll be damned.” It’s not nice to tell people. Even if you’re not the kind of person that I am. It’s not nice. You don’t do that with people who are struggling, who (are) really need to be encouraged to get beyond their limitations.

Being unsure if there was truth to the belief that the most progress occurs within the first year post-stroke, J.D. lamented that he did not receive intense rehabilitation treatment. He wondered how much further along his speech, cognitive, and physical skills would be if that had happened:

Cause (like) everything that I’ve gained back, I’ve gained back through hard work. So if I can gain this much back as late as it is in the stroke, you know I could gain a whole bunch more the first year if they would have (g*) showed me what to do.

Not only did progress happen gradually over a long time, patients’ needs for information from healthcare professionals also changed. From their memories of the acute stage of this process, three participants wanted information about what was happening to them, but it was challenging for them to understand any information provided. Although J.D. was provided information about potential communication limitations caused by the stroke, he stated, “For me it wasn’t too helpful because after the stroke my attention and my retention was really limited.” N.C. also reported a similar experience immediately post-stroke by saying, “Well you know they give you all this literature. But aphasia? I mean I couldn’t even say it. I mean (and) I’d read it, and (I) it didn’t make sense.” She recommended providing the information and then reviewing it multiple times in weekly or monthly intervals. J.D. agreed that by repeating the message over and over, a seed might be planted in the person’s head.

Desirable traits in a professional. Two participants commented specifically on

characteristics of healthcare workers they encountered that were beneficial. D.F. mentioned the positive outlook her speech-language pathologist took in the face of uncertainty. She said:

(I mean what was really um) At first I would ask my therapist will I ever talk again? And she would say, “Yes!” And she didn’t know it was “no”, but (she didn’t) she says “yes”. Okay. The fact that maybe I could do something to talk again, okay.

S.U. worked with a therapist whose self-confidence engendered trust. She stated, “. . . She’s confident. When you meet someone who is trying to help you and they’re confident, it goes a long way with me.”

Treat me as a unique individual. All the participants expressed the desire for healthcare professionals, in particular those providing therapy, to approach them as individuals. This took three main forms: first, to get to know them, and second, to make therapy relevant to their individual situations, and third, to find the proper level of support.

Take time to get to know who I am. Some of the participants urged healthcare professionals to understand their world in order to gain credibility with the treatment being provided. S.U. expressed it this way:

You do know what to do. But you don’t know me, and you don’t know my motivation and you don’t know my attitudes. Unless you really listen. Unless you really listen, then you may glean what’s it’s all about. But if you don’t listen and you’re on a roll of ‘this is what I want you to do’ ‘this is what you’re going to do’ ‘this is for your own good’. That’s maybe, absolutely true. But it doesn’t take care of me.

D.F. echoed her sentiments in the following excerpt:

When I first was meeting with therapists, they called me ‘motor-mouth’ because I talk

all the time cause I was scared. I wanted to make sure they understood me, before they told me what to do. I didn't know that. So I wanted to make sure they understood (what I) what my situation was. Maybe they knew more about my condition than I did. I didn't care about that. (I was it was more im* I was more um) I wanted them to understand my world, what I was being asked to do.

Some of the participants also suggested what professionals should pay attention to and specific questions to ask. D.F. indicated, "So I guess when you do therapy you have to be cognizant of what the people have for resources and what they have for disposition." In terms of questions to ask the stroke survivor, J.D. recommended finding out ". . .what is important to them, and what do they think they lost (with the) caused by the stroke, (and would they like or) what would be (the most) the most important thing that they would like to regain. . . ." He provided the example that he worked with cars his entire life, but not being able to drive has not been significant as might be assumed by his previous profession. S.U. proposed setting aside time during sessions in order to listen to the stroke survivor. She said:

And I think it's always good to give the person a chance to express what is on their mind as far as the therapy itself. Ask them, "What do you expect? What do you want? What are you afraid that you can't have?"

Make therapy relevant to my life. Four participants discussed either positive or negative experiences with treatment they received being relevant to their life. N.C. disliked one particular therapist because she wanted N.C. to use a communication notebook. N.C. lives alone, and was unsure if a notebook would be appropriate. J.D. also talked about a negative experience in the following excerpt:

(I don't think I don't) The two [therapists] I had didn't (take) take (my) into account

my previous job or my previous lifestyle. (and they didn't take it and then) into the their therapy, they didn't take into [consideration] what direction I wanted to go in, or what I thought I had the most problem with. It was mostly their agenda and what they wanted to accomplish rather than have me involved.

S.U. offered insight into the need for therapists to modify their plans based on in the individual. She said:

I'm thinking of things like, take into consideration the personality in front of you, you know. Some people are really, really gung-ho and some people are really scared, enough not to engaged. And a plan is nice. And it's essential. But I think if you're not willing to look at the person and revamp what your schedule is, I think you lose a patient. I think you lose what the patient is maybe able to do but not right now.

Additionally, D.F. desired an overview of a relevant treatment program to know what she is working towards. She expressed it this way:

DF: The one big thing that I really had a hard time with in speech therapy is you are just one of four or five other therapies. And also I have quite a load of things I should be doing to recover. So I need a good set program of what I'm going to be doing, I need to have an overview. I need to have some goals. I need to see we're working towards something instead of every time I come it's like 'the flavor of the month'. This was my biggest gripe against all therapy. Which is you just go in there they assume you're going to be there 4 or 5 times, you're not gonna get any results. And (you know) we just throw something at them to make them feel better.

Interviewer: Just an activity to do today.

DF: Right. And sometimes I don't see how it's gonna make me better.

2nd Interviewer: Yeah.

Interviewer: So you really wanted to see the plan laid out.

DF: That's why I love this place here. (This is a place where I can talk about^ be the first se*) The first (um) session here we always set up a goal and we relate it to what we're going to for the quarter. I love that. (and then.) We see progress every quarter towards that. And every quarter I get a report. So I can see "Okay I made this progress, this progress, this progress". Now some people aren't that anal. I happen to be.

Find the proper level of support. Overall, stroke survivors need varying levels of support. Some participants spoke about the necessity of finding the proper amount of support, which may change over time, and the consequences of inadequate assistance. J.D. discussed the vulnerability of needing a high level of support in the following excerpt:

. . .I was 47 when I had this stroke (you know) that's pretty old to be talking about baby steps, but (you know) when you have a stroke the way I was. (I was a lot of things) I was embarrassed because I couldn't keep my balance, like to the outside [world] I would be ashamed or embarrassed, but then to a professional I will[would] say (you know I need) I need help like I'm a baby. And get me past the baby steps, so I can walk. And then once I can walk, I'll get up on my own, I'll run on my own, but just get me started. Just get me to know how.

He also told of not receiving the proper support by being pushed into something he did not think he could do instead of starting with smaller steps to build up to it, with his communication and physical skills. Regarding communication, he reported:

JD: More on my breathing and my (um) just loudness. And rather than at [hospital

name] they kept emphasizing on sentences. So (they they had me walking before) they had me running before I can walk.

Interviewer: Okay. So here it sounds like they're working on building <blocks>.

JD: <Basics>. The basics.

He had the following experience with treatment for his physical impairments:

(I think) I think (the most) the worst thing is to be pushed. (if like) Like in physical therapy, (they would they) I had instances where I was forced to do something that I didn't think I could do, and I couldn't do. But still they said, "Keep trying, keep trying" rather than to work (work) up to it. They just said, "Do that". (and I) To me (it became) it became (a) a stop sign. (I I) I didn't want to do it, I didn't think I could do it, and I can't do it. So, you know, (they) they took all my confidence away.

Similarly, S.U. felt she knew her body best, but she was willing to relinquish control to a certain healthcare provider who did provide the proper level of support. She reported:

. . . I know my body better than anybody else knows my body. I respect [clinician's name]. I really respect what she does so I will step back and let her have control when I really [pause] not feeling that I want her to have control. But it hasn't proven to be the wrong thing to do.

D.F. suggested how professionals can provide the correct level of support in the following excerpt:

. . . I love it cause I'm very goal-oriented person, so boom. Boom. Boom. Now, if someone wasn't so goal-oriented, I think what happens here is that (it's um they can) they can see how they're progressing. And I think maybe if they're not as goal-oriented as me (I think) the counselor maybe needs to be aware of that. And maybe be

more (um) affirming. And (more) more coaching. Because they can be overwhelmed by the goals.

Likewise, J.D. discussed what the proper level of support did for him:

I think just getting out. Having someone to help you get out. Not maybe force you out, but give you the right kind of nudge to get you out and (get) get you seeing more things and (get back into the) get back into living. I think for me, {long pause} was the best.

He was able to participate more in life because of the support he received. In the following exchange, he talks about the changes in his speech and that participation has impacted his confidence for communication:

Interviewer: Do you think your actual speech quality has changed a lot or it's more your confidence, how you deal with things?

J.D.: I think my speech has (im*) gotten a lot better. Like the flow is a lot better, and I have tonation[intonation] now (and um) but I think the biggest change is my confidence.

Interviewer: Okay. What made the confidence change?

J.D.: Just getting out.

Discussion

The discussion that follows will first review the role of self-efficacy in communicative participation for participants according to these qualitative interviews. Then, it will focus on what influenced self-efficacy from their perspective. Next it will consider the advice participants gave to other stroke survivors and whether or not this advice was related to self-efficacy. The clinical implications of this line of research will be examined. Finally,

the limitations of this study and future directions will be discussed.

Research Questions

1. *What role does self-efficacy play in communicative participation for adults across a variety of speech or language disorders?*

Despite being asked specifically about confidence in certain communicative situations, the majority of participants denied it being a part of their conscious choice to participate in life roles involving communication. Only one participant, J.D., mentioned confidence having a positive influence regarding communicative participation. He reported that his speech characteristics had improved, but it was his confidence that had changed the most. It is difficult to determine, based on the limited number of interviews conducted during this phase of the research project, whether self-efficacy for communication does not heavily influence a person's decision to participate in communicative interactions, or if self-efficacy just does not rise to a conscious level when the person is making that decision.

Additionally, the homogenous nature of the speech and language disorders demonstrated by the participants precluded any discussion about similarities or differences across a variety of disorders within this study. When compared to the literature regarding self-efficacy in people with a broad range of speech or language disorders as examined in the literature review above, some of the findings appeared to be supported while others were not.

For example, the study by Langevin et al. (2006) with adults who stuttered demonstrating increased self-efficacy after treatment is consistent with J.D.'s self-reported increase in confidence for conversational interactions after receiving treatment which included practice situations. It is difficult to compare the results found by Ornstein and Manning (1985), which indicated adults who stuttered had higher confidence for entering

into situations than maintaining fluent speech during the situation. The participants of the current study were not asked to rate their self-efficacy for entering into specific situations, but they were asked to describe their confidence regarding communicative interactions. As reported in this section, most of the participants did not state that self-efficacy was part of their decision to participate in a communicative situation. However, it is unclear whether having a concrete list of situations, as in the rating scale used by Ornstein and Manning (1985), would have altered the results.

Regarding the literature about adults with voice disorders, there was no particular terminology used by clinicians that emerged as having consequences for self-efficacy in the current study. However, the importance of what healthcare professionals said was confirmed by the message *progress continues long after one year post-stroke*. When healthcare workers indicate progress is limited to the first year post-injury, that has implications for the patient's self-efficacy for behavior change.

Of the broader rehabilitation literature discussed in the literature review, this study's results were most similar to the study by Dixon et al. (2007). Those researchers investigated a more diverse neurologically impaired population with regards to self-efficacy for participation in neurological rehabilitation. Two themes that emerged from their interviews resembled sub-messages from the current study: "external reassurance" (p.234) and *encourage me*, "setting goals" (p.235) and *set attainable goals*.

2. *What factors influence self-efficacy for communication from the perspective of people with speech or language disorders?*

While most of the participants did not acknowledge purposeful consideration of confidence, or self-efficacy for communicative situations in those specific terms, the

experiences they talked about did contain elements of Bandura's (1977) theoretical agents of change of self-efficacy. According to Bandura, and as reviewed in the introduction, self-efficacy might change based on accomplishing a task, based on observing someone else accomplish the task, or based on verbal persuasion. There were examples of each of these factors in these interviews. For example, performance accomplishments refer to successfully completing a behavior that the individual was not confident that he or she could perform. This is exemplified in this study in the message to other stroke survivors of *progress requires hard work and effort*. Many of the participants set up practice situations of tasks which they were not able to complete during the acute phase of recovery but are currently able to do. It is possible that their confidence for completing these tasks during the acute phase was low, and now is higher because of the accomplishment brought on by practice. One participant, N.C., discussed portraying confidence during communicative interactions even when she does not feel confident. She felt this influenced the outcome of the communication. Having a professional set up situations that would lead to successful completion of a behavior encouraged one participant to increase his communicative participation. Prior to beginning volunteer work in a nursing home, J.D.'s mental health counselor set up practice interactions with interns at the clinic. This preliminary finding about the importance of practice is similar to the study by Babbitt and Cherney (2010), discussed in the literature review, which showed increased confidence in a person with aphasia after treatment of rehearsing personalized scripts.

Another factor influencing self-efficacy, as described in the literature review, is vicarious experience. Two participants mentioned groups they attend where they hear about other survivors' experiences. Listening to other group members talk about their successful

participation in communicative interactions may unknowingly influence the confidence of the interview participants. This is consistent with the results from Dixon et al. (2007) where interviews with adults who received inpatient rehabilitation revealed the theme of “vicarious experience” (p.234). As those participants observed other patients improving physically, their own beliefs changed.

Verbal persuasion is a third way that self-efficacy can be influenced. In their messages to family and community members, one of the ways to help was *encourage me*. Encouragement takes many forms. Most of the participants discussed verbal encouragement regarding the recovery process in general, but it may also be inferred that they received encouragement for participation in specific situations. Dixon et al. (2007) also found that social persuasion was notable since it was mentioned by most participants.

3. *What advice would people with communication disorders give to others in a similar situation regarding communicative participation and does their advice relate to the construct of self-efficacy?*

The messages that emerged for other stroke survivors did not contain information related explicitly to the construct of self-efficacy. As described above, the advice under the subheading of *Progress requires hard work and effort* where participants set up practice situations is similar to performance accomplishments. However, the participants were not suggesting that other survivors engage in these practice situations in order to gain confidence, but instead to improve their communication skills at the impairment or activity level.

Clinical Implications

Because of the limited number of participants, the role of self-efficacy in

communicative participation remains unclear. However, treatments increasing self-efficacy for people with other chronic diseases (e.g., arthritis) have been shown to improve outcomes (Marks, Allegrante, & Lorig, 2005). Marks, Allegrante, and Lorig (2005) summarized the important characteristics of treatment strategies to increase self-efficacy for people with chronic diseases. Some of these characteristics were discussed by the participants of this study who have a chronic communication disorder. The similar messages included setting goals, utilizing small steps, and involving significant others.

A message only loosely related to self-efficacy that has implications for healthcare professionals appeared under the heading *Progress continues long after one year post-stroke*. Professionals need to find the balance between informing stroke survivors that the greatest opportunity for spontaneous recovery may be shortly after the stroke, and encouraging them that there is continued potential for growth and improvement in the long-term. Perhaps focusing on encouragement for long-term growth may improve self-efficacy for clients by helping them to remain motivated to continue working on their communication and communicative participation.

Study Limitations

Several factors contribute to the limitations of the present study, including the number of participants and the type of participants. Because of feasibility issues, interviews with only five participants were completed, which restricts the ability to determine overarching themes for this topic. Saturation has not yet been achieved. Additionally, all of the participants were stroke survivors in the chronic stage of recovery, and were older than age 50. The original intent of the study was to incorporate participants with various communication disorders, but people who responded to recruitment efforts were all stroke survivors. Given that these

stroke survivors were also in the chronic stage of recovery, the current study is unable to provide a comparison of messages from survivors in the acute stage. While most strokes tend to occur in the older population, younger stroke survivors were not represented in this study. One participant acknowledged explicitly that young survivors have unique struggles in part because their social structure is more severely impacted. Additionally, all participants were recruited from clinics associated with one university, which may have skewed the results.

Future Directions

Future studies, including the continuation of this present study, should seek to reduce the limitations explained above. This can be accomplished by intentionally recruiting participants with communication disorders other than aphasia and dysarthria, those who are younger than 50, and those in an acute stage of the disorder. Efforts should also be made to recruit participants from more diverse clinics or community organizations. Interviews should continue until saturation is reached.

Conclusion

In conclusion, the current study provided preliminary results of qualitative interviews investigating the nature of self-efficacy for communicative participation in people with communication disorders. While these initial interviews suggested that self-efficacy, or confidence, for communicative participation did not necessarily consciously shape participants' experiences, the experiences reported by participants did reflect factors contributing to self-efficacy according to Bandura's theories. With continued research along these lines, the role of self-efficacy in people with communication disorders may become more apparent.

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Appendix A

Literature Review Table of Evidence

<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Aben, et al. (2011)	Stroke	136	Cross-sectional	First & only stroke, min. 18 months post-onset	Progressive neurological disorders, excessive drinking/ drug abuse, insufficient grasp of language, subarachnoid hemorrhage or subdural hematoma	Memory SE measured by Metamemory in Adulthood questionnaire	Participants who were younger, had increased depression, lower memory SE more frequently reported complaints about memory. Participants with lower memory SE had no partner, left-side stroke, increased depression, less word production on word fluency test.

* SE= Self-Efficacy

<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Babbitt, et al. (2010)	Aphasia	1	Case study; single subject pre- post-trial	Not provided; Participant was 41 years old, 19.1 months post-stroke	Not provided.	Communication Confidence Rating Scale for Aphasia (CCRSA)	Results regarding SE were measured using rating scales and unstructured interview with client and partner. There were significant gains in performance on the script (in terms of script-related words per minute and content) and participation in life activities measured via Communicative Effectiveness Index (CETI) and Communication Activities of Daily Living, 2nd edition (CADL-2) and these were related to an improved score on the CCRSA and associated with improvements on self-confidence. Her score for the Burden of Stroke Scale (BOSS) decreased, which means she was feeling less burdened by the stroke. Qualitative reports also reflected an increase in SE.
Babbitt, et al. (2011)	Aphasia	47 participants completed scale 94 times	Rating scale development	Aphasia: either fluent or non-fluent	Not provided.	CCRSA	There was one item that did not fit as well as the others. This item was then re-worded. Person reliability was .81

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<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Cicerone, et al. (2007)	Traumatic Brain Injury	97 adults, convenience sample	Correlational study using multiple regression	At least 6 months post-injury, adequate reading comprehension, living in community	Not provided.	TBI Self-Efficacy Questionnaire (TBI-SE) adapted from scale for other health condition for this study	SE for management of cognitive symptoms made the greatest contribution to predicting quality of life in both measures used (24% & 40% of variance).
Cicerone, et al. (2008)	Traumatic Brain Injury	68 adults	Randomized controlled trial: Effectiveness of two treatments	Independent with basic self-care, at least 3 months post-injury, age 18-62, adequate verbal language	Active psychiatric illness, substance abuse, or pain considered to prevent treatment compliance	TBI-SE	For treatment condition receiving intense cognitive rehabilitation, a statistically significant improvement on measures of self-efficacy. The other treatment condition did not demonstrate a significant impact on self-efficacy.
Dixon, et al. (2007)	Stroke, Traumatic Brain Injury, Monophasic Neurological Impairment	24 adults	Qualitative, semi-structured interviews	Inpatient care on Rehab Unit, age 16-65, monophasic neurological impairment, difficulties with mobility/self-care	Severe cognitive, psychiatric, or linguistic problems	Participants were asked open-ended questions about SE for participation in neurological rehabilitation	11 main themes divided into 3 domains: Self (self-reliance, determination, independence, recognizing own improvements, pushing your limits); Others (external reassurance, vicarious experience, working with professionals); Process (setting goals, information needs, making time for rehabilitation).

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<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Dumont, et al. (2004)	Traumatic Brain Injury	53	Cross-sectional, single measurement, exploratory correlational study	TBI, received treatment, finished intensive treatment at least 1 year prior	Any other major health impairment	SE Scale	Approx. half the variance in societal participation explained by dynamism, perceived self-efficacy, and will.
Eccles & Simpson (2011)	Multiple Sclerosis (MS), Parkinson's Disease (PD), Motor Neuron Disease (MND)	44 articles	Systematic review of literature	Peer-reviewed studies in English, adult participants	Treatment articles	Various, including specific and general SE	No articles about SE in PD or MND. For MS, inconsistent relationships between psychological state, quality of life, general self-efficacy. Some evidence for positive association between MS-specific SE and wellbeing.
Gillespie & Abbott (2011)	Voice Disorders, Self-perceived "voice problem"	14	Randomized controlled trial	Teachers	Any prior evaluation or treatment for voice problem	Voice SE Questionnaire	'Phonotrauma/muscle tension' group improved SE scores on pre- vs. post-test. 'Abuse/misuse' group showed no difference.

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<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Hellstrom, et al. (2003)	Stroke: right hemisphere, left hemisphere, brainstem, cerebellum	37	Group data comparison	Stroke less than 8 weeks prior, only 1 stroke, "able to communicate & understand questions"	Not provided.	Falls Efficacy Scale, Swedish version	Significant improvements on all measures from admission to discharge. Falls efficacy scale was a better predictor of independence with ADLs at 10 months post-discharge than the more objective measure (balance scale). Participants with higher SE had greater improvements than participants with lower SE.
Jones & Riazi (2011)	Stroke	22 articles	Systematic review of literature	Primary population was stroke, any age of participants, any rehab setting	Greater focus on general chronic disease self-management, self-efficacy not fully defined, poorly described methods	Various	Evidence SE is important variable for post-stroke outcomes.
Jones, et al. (2005)	Stroke	40	Rating scale development	First stroke	Not provided.	Stroke SE Questionnaire (physical & self-management tasks)	Scale has good internal consistency.

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<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Jones, et al. (2008)	Stroke	Stage 1: 15 Stage 2: 40 Stage 3: 57	Rating scale development	2-24 weeks post- first stroke	Unable to read, difficulty understanding 2-step instructions	Stroke SE Questionnaire	Stage 1: development of questionnaire items, participants completed rating scale: good face validity. Stage 2: refinement of the items using statistical analysis. Stage 3: good internal consistency, criterion validity, feasibility.
Jones, et al. (2009)	Stroke	10	Multiple participant 2-phase single subject	12-18 months post- first stroke	Severe memory and language impairments, depression	Stroke SE Questionnaire	Statistically significant change in SE scores after intervention began. Measures of activity, mood, participation had no statistically significant change.
Jones (2006)	Stroke, Arthritis, COPD, Diabetes, Heart Conditions	n/a; theoretical paper	Literature review & theory	Literature since 1995	Not provided.	various	Strong evidence to support interventions of self-management influence SE and health outcomes.
Langevin, et al. (2006)	Stuttering	41	Group data comparison	Received treatment of ISTAR Comprehensive Stuttering Program either in Netherlands or Canada, had 2-year follow-up	Not provided.	SE Scaling by Adult Stutterers	Statistically significant improvement in SE "approach" score at 2-year follow up.

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<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Laplante-Lévesque, et al. (2011)	Hearing Impaired	139	Group data comparison of 3 intervention options	Age 50 or older, 1 st time requesting assistance with hearing impairment	Not provided.	SE for Situational Communication Management Questionnaire	Participants with higher SE were significantly less likely to choose hearing aids for intervention; they may use internal resources or strategies instead.
Neubert, et al. (2011)	Stroke	11	Pilot test of 3 groups of educational modules facilitated by psychologist	Enough cognitive skills to participate in group education	Impairments hindering participation in group (e.g., severe aphasia), memory deficits, psychiatric disorders	not measured quantitatively	Education program included strategies to enhance SE. Intervention was subjectively noted to be "well accepted" by participants.
Ornstein & Manning (1985)	Stuttering	40	Rating scale development	Experimental group: diagnosed with stuttering & receiving treatment. Control group: no history of speech or language disorder	Not provided.	SE Scaling by Adult Stutterers (SESAS)	Scores for the persons who stutter (PWS) on SESAS were statistically significantly lower than for people who do not stutter (PWDNS). Additionally, PWS had higher 'approach' scores than 'performance' scores while the PWDNS had the opposite. This means that PWS had more confidence in entering the speaking situation than maintaining fluency once the interaction began. Moderate negative correlation between the SESAS and the ratings of stuttering severity. This indicates the SESAS does not assess stuttering severity.

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<i>Author (Year)</i>	<i>Population, Site of Lesion</i>	<i>Sample Size</i>	<i>Design</i>	<i>Main Inclusion Criteria</i>	<i>Main Exclusion Criteria</i>	<i>Method of measuring SE*</i>	<i>Relevant Outcomes</i>
Pang, et al. (2007)	Stroke: left & right hemispheres	63	Group data comparison using multiple regression	1 stroke, at least 1 year post, age 50 or older, score of 22 or higher on mini-mental state exam	Other neurological conditions or serious diseases	Activities-Specific Balance Confidence Scale (ABC)	Balance SE scores were independently associated with community reintegration scores.
Robinson-Smith, et al. (2000)	Stroke: right hemisphere, left hemisphere, brainstem, unknown	63	Longitudinal descriptive correlational	Admission to in-patient rehab within 2 weeks of stroke, score greater than 23 on mini-mental state exam	Any neuromuscular conditions, psychiatric disorders	Self-care SE via Strategies Used by People to Promote Health Questionnaire	SE for self-care increased after stroke; strongly correlated with quality of life measures and depression scores at 1 and 6 months post-stroke.
Smith, et al. (2011)	Hearing Impaired	169 older, w/ hearing loss 56 young, no hearing loss 32 older, no hearing loss	Rating scale development	No self-reported comorbid conditions that would cause them to require assistance to complete questionnaires.	Prior hearing aid experience	Listening Self-Efficacy Questionnaire (LSEQ)	Older listeners with hearing loss had relatively high SE for quiet situations but low SE for complex listening situations. Significant & fair to moderate correlations between LSEQ and audiologic measures. Listeners with normal hearing = high SE for listening.
Sweetow & Sabes (2010)	Hearing Impaired	85 hearing impaired, 57 normal hearing; 547 clinical patients	Rating scale development	Not provided.	Not provided.	Communication Confidence Profile	Communication Confidence Profile has good test-retest reliability, internal consistency, construct validity, and concurrent validity.
van Leer, et al. (2008)	Voice Disorders	N/A; theoretical paper	Theoretical paper	N/A	N/A	N/A	N/A

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Appendix B

Interview Questions

Please note: these questions are examples of the types of topics that we would like to include in the interview and will be used as a guideline if the participant does not bring up the topic spontaneously.

1. Tell me about experiences that have (and have not) gone well regarding communicating with others, and why do you think they turned out as they did?
2. Could you share some examples of situations in which you thought you might have difficulty participating because of your communication disorder, but things turned out very well?
 - a. Why do suppose things went well?
 - b. Was it something you did or something else?
 - c. How have things changed over time?
3. Could you share an example of a situation when things did not go very well?
 - a. Why do you think things did not go well?
 - b. How did your communication style affect the situation?
 - c. Was it something you did or something else?
 - d. How have things changed over time?
4. Tell us about a time when you felt confident about having a conversation with someone.
 - a. When do you feel unsure of yourself when entering into a conversation?
 - i. For example, what is it like for you at home versus the doctor's office?
 - ii. How confident are you about speaking to someone over the telephone?
 - b. What do you think influences your confidence about participating in situations where you are expected to converse?
 - i. What makes you more confident?
 - ii. What makes you feel less sure of yourself?
 - iii. Does the outcome of the situation have any relationship to how confident you are that you can participate?
5. What advice did you receive from others, for example a friend or healthcare provider, that helped you overcome difficulties in daily interactions such as having a conversation with a friend or debating the news?
 - a. What do other people do that make it easier to listen and be listened to?
 - b. What suggestions were unhelpful to you?
 - c. What suggestions or advice do you have for other people with communication problems?
6. With so many strategies and treatment options available to you, how do you decide what is worthwhile to try?
 - a. Where do you focus your efforts?
7. What help do you wish you could have received?
 - a. In what format would these strategies best be provided?
 - i. Would you prefer to have read about someone else's experiences?
 - ii. Would it have been helpful to meet another person with the same communication disorder?

- iii. Would it have been helpful to have someone work with you to pre-plan and role-play specific situations?
 1. Who would you suggest would be good to do that?
8. We are planning to create a program to help people with communication disorders overcome obstacles they face trying to participate in their daily activities. What advice do you have for us in creating that program?
 - a. What kind of information would be helpful?
 - b. What format would be best?
 - i. Video
 - ii. In-person
 - iii. Lecture
 - iv. Workbook
 - c. What wouldn't you want to see?
 - i. Is there anything specific that would make you uneasy about it?

Appendix C

Preliminary Code Dictionary

<i>Code</i>	<i>Definition</i>
Advice	Insight, suggestions, etc., meant for other people with communication disorders.
Challenging Situations	Situations that were difficult.
Communication Partners	Any person other than self.
Communication Strategies	Any method, successful or not, used to modify a communicative situation. (Subcategories might be Self, Listener)
Family	Discussion of family members (both immediate and extended).
Feelings/Emotions	Any reference to feelings or emotions felt in past or present (e.g., hopelessness).
Goals	Any reference to long or short-term goals.
Good Quotes	Any quotes that represent a participant's viewpoint particularly well, in order to make these quotes easier to locate in the transcript.
Other Therapies	Any other treatment mentioned, besides SLP (e.g., physical therapy, occupational therapy, mental health, etc.).
Participation	Any reference to participating in societal or familial roles, including hobbies, job, etc., following the WHO model.
Personal Characteristics/Attitudes	Description of distinguishing quality, attribute, personal trait, or own attitude.
Practice	Situations which allowed for communication practice (not with therapist or in clinic room).
Reflections on Change	Any reflection on personal progress or changes pre-/post-stroke.
Resources	Available resources in the community.
Salient Messages	Participant's important, key messages. Includes activities participant felt were beneficial to recovery.
SLP Treatment	Description of what occurred during SLP treatment past or present, positive or negative, including hypothetical changes desired.
Symptoms/speech Characteristics	Reference to changes in bodily functions (including speech/language) as a result of neurological lesion.
Timeline	Reference to length of time of recovery, including recovery progress during that time.