“THE SECRET INGREDIENT”: SPEECH-LANGUAGE PATHOLOGISTS’ PERSPECTIVES ON CONFIDENCE IN COMMUNICATION FOR PEOPLE WITH APHASIA

by

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Abstract

Background: Confidence, particularly in the domain of communication, has recently emerged as a factor which may influence people with aphasia’s (PWA) psychosocial well-being. However, PWA’s psychosocial needs, including their confidence in communication, are often neglected. Moreover, increasing confidence post-stroke has been identified as a research priority by stroke survivors, including PWA. Therefore, investigating how to increase confidence in communication for PWA is of clinical importance to speech-language pathologists (S-LPs) and their clients with aphasia.

Aim: The purpose of this study was to explore the perspectives of S-LPs on the meaning of confidence in communication for PWA, factors which help with it, factors which detract from it, and what SLPs’ role in this area might be.

Methods and Procedures: Based on the constructivist paradigm, and using a qualitative descriptive approach, semi-structured in-depth interviews were conducted with 15 S-LPs who had worked with PWA for at least one year. Qualitative content analysis was used to derive codes and categories from the interview transcripts in relation to each of the four research aims. To increase rigour, member-checking and peer debriefing were used.

Results: Analysis of the semi-structured interviews generated the following: 56 codes for the meaning of confidence in communication for PWA, grouped into 12 categories (e.g., PWA being willing to put themselves out there and participate/try to communicate); 93 codes for factors which help with it, grouped into 14 categories (e.g., PWA practicing communication and experiencing success/improvement in the clinic and beyond); 62 codes for what detracts from confidence in communication for PWA, grouped into 13 categories (e.g., lack of social/communication support for PWA); and 88 codes for the role of S-LPs in working on this with PWA, grouped into 14 categories (e.g., educating others about aphasia and training communication partners on how to support PWA’s communication).
Conclusion: S-LPs perceive working on confidence in communication with PWA to be part of their clinical role. Factors such as communication and social support from others may be important for SLPs to consider in relation to PWA’s confidence in communication and could ultimately have an impact on PWA’s life participation and psychosocial well-being.
**Lay Summary**

Aphasia is an acquired language disorder caused by brain damage, usually from a stroke. It can impair a person’s ability to use and understand language: speaking, understanding others’ speech, writing, and reading. The experience of living with aphasia can have a negative impact on a person’s psychological and social health, such as their confidence in communication. The purpose of this study was to explore speech-language pathologists’ perspectives on confidence in communication for people with post-stroke aphasia: its meaning, what helps with it, what detracts from it, and their role in working on it with people with aphasia. The results from this study can be used to inform future speech-language pathology assessment, treatment, and management of adults with aphasia.
Preface

The work presented in this thesis was produced by A. Tonello, under the supervision of Dr. T. Howe, and co-supervision of Dr. P. Colozzo and Dr. J. Small. A. Tonello participated in development of the study topic and design, generated accompanying documents, and was responsible for all data collection and analysis.

This study was reviewed and accepted by the Behavioural Research Ethics Board of the University of British Columbia on August 16, 2017, under the project title “Confidence in Communication for People with Aphasia: Speech-Language Pathologists' Perspectives” [certificate # H16-02831].
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To my grandmother, Lois M. MacFarlane
Chapter 1: Introduction

The topic of this research project is S-LPs’ perspectives on confidence in communication for PWA: the meaning of confidence in communication for PWA, what helps with it and what detracts from it, and what S-LPs’ roles are in working on this area with PWA. This investigation is motivated by findings that increasing confidence has been identified as a priority for stroke research by stroke survivors, including PWA (Pollock, St George, Fenton, and Firkins, 2014); that PWA have reported decreased confidence in social situations (Horne, 2016); and that increased confidence has been reported by S-LPs to be an important outcome of intervention (e.g., Cruice, Isaksen, Randrup-Jensen, Eggers Viberg, and ten Kate, 2016; Rose and Attard, 2015; Shrubsole, Worrall, Power, and O'Connor, 2016; Simmons-Mackie and Holland, 2011; Wallace, Worrall, Rose, and Le Dorze, 2016), as a factor involved in living successfully with aphasia (Brown, Worrall, Davidson, and Howe, 2011), and as an area that S-LPs have a role in addressing by supporting improvements in language ability (Northcott, Simpson, Moss, Ahmed, and Hilari, 2017). However, PWA have frequently been excluded from research on post-stroke confidence and related psychological health factors. Moreover, there is no research to date on how S-LPs might address confidence in communication in working with PWA. This study serves as an initial step to address this research gap in order to inform clinical speech-language pathology services for people with post-stroke aphasia.

In this chapter, the communication disorder of aphasia is described, and confidence and related constructs (i.e., self-esteem, self-concept and identity, and self-efficacy) will be defined. In addition, an overview of the literature on confidence and related constructs is provided, along with an explanation of their importance for PWA. Finally, the definition of confidence used in this study is presented, followed by the specific research aims and rationale.

1.1 Aphasia

Aphasia is “a communication disorder that results from damage to the parts of the brain that contain language (typically in the left half of the brain)” (American Speech-Language Hearing Association [ASHA], 2016). All modalities of language can be impacted, including speaking, understanding what others say, reading, and writing; nonverbal modalities such as
gesturing may also be impaired (Hilari et al., 2016). Estimates of the incidence of aphasia resulting from stroke have varied from 20 to 38% across studies (Dickey, Lindsay, Fang, Rowland, and Black, 2010). In Canada, it has been estimated that the incidence of aphasia after a first acute ischemic stroke is 30% (Flowers, Silver, Fang, Rochon, and Martino, 2013), whereas the incidence of aphasia symptoms identified in stroke survivors at the time of discharge was reported to be 35% in another study (Dickey et al., 2010).

1.2 Confidence and related constructs in literature on stroke survivors

Stroke can have a negative impact on psychological and social functioning, which may include confidence and participation in life activities (Horne, Lincoln, Preston, and Logan, 2014). In the literature on stroke survivors, confidence has been associated with other psychological concepts such as self-esteem (Babbitt and Cherney, 2010; Horne, 2016) and self-efficacy (Horne, 2016). In addition, self-esteem has been linked to self-concept and identity. For instance, self-concept has been used by some researchers to explore challenges to identity (e.g., Ellis-Hill and Horn, 2000). The concept of identity in PWA has received some attention in the aphasia literature, and has been used interchangeably with the term “self-concept” (e.g., Babbitt and Cherney, 2010; Shadden, 2005). The following discussion will explore these constructs as they pertain to stroke survivors (with and without aphasia) and other populations with neurogenic disorders.

1.2.1 Confidence

In a qualitative study of stroke survivors' perspectives on confidence (including PWA), Horne (2016) conceptualized this term as a combination of self-esteem, self-efficacy and information from the environment which influences beliefs about what one can do. Babbitt, Heinemann, Semik, and Cherney (2011) have defined “communication confidence” as “a feeling about one's power to participate in a communication situation, one's sense about one's own skills and/or ability to express oneself and to understand the communications of others” (pp. 727-728). This construct was introduced in light of findings that PWA's communication skills as well as their confidence in using these skills has repercussions for their quality of life. The authors
suggested that improving confidence in PWA can increase their participation in life activities, which will in turn increase autonomy and self-determination, leading to further increases in communication confidence. However, this concept has received little attention in the aphasia literature to date (Babbitt and Cherney, 2010; Babbitt et al., 2011).

1.2.2 Self-esteem

Self-esteem pertains to an overall affective judgment of one's self-worth (Brumfitt and Sheeran, 1999; Horne, 2016; Ponsford, Kelly, and Couchman, 2014). It has been described as having two aspects: state self-esteem and trait self-esteem. State self-esteem is a type of self-judgment which is subject to change depending on the situation or context. In contrast, trait self-esteem is the enduring component which tends to be stable in adulthood. State self-esteem has been found to change post-stroke in a sample of stroke survivors with "no severe hearing impairment" who were "able to communicate" (Chang and Mackenzie, 1998). In a series of studies on stroke survivors without receptive aphasia and/or receptive language difficulties, Vickery and colleagues (Vickery, Evans, Sepehri, Jabeen, and Gayden, 2009; Vickery, Sepehri, and Evans, 2008a; Vickery, Sepehri, Evans, and Lee, 2008b) found that the level and stability of self-esteem was related to and predicted depressive symptoms. Although these studies would have excluded PWA with more severe linguistic impairments, self-esteem is of relevance to PWA at various levels of functioning. For instance, high self-esteem has been identified by SLPs as an indicator of moving towards acceptance of life with aphasia (Brown, Worrall, Davidson, and Howe, 2012). For persons with traumatic brain injury (TBI), Ponsford, Kelly, and Couchman (2014) have argued that interventions for specific domains of self-concept may serve to increase global self-esteem, which may in turn decrease the incidence of mood disturbance. To date, this possibility has not been investigated in individuals with TBI or in other neurogenic disorder populations, such as PWA.

Low self-esteem often co-occurs with depression, and has been found to contribute to depression rather than vice versa (Sowislo and Orth, 2013). This finding may be explained using Beck's (1970) cognitive paradigm of depression, in which negative beliefs about the self are not only a symptom of depression, but are a cause of its emergence and maintenance. Moreover, depressive cognitions are thought to consist not only of negative self-evaluations, but negative
thoughts about the world and the future, as well (Beck, 1970). Broomfield and colleagues (2011) argued that research showing that stroke survivors experience low self-esteem suggests that these individuals may have negative beliefs about themselves. These negative cognitions may serve to maintain depression via a "cognitive feedback loop" (p. 205). Low mood can result in negative thoughts, which can reinforce low mood (and so on). As a result, a person's self-confidence, personal agency, and level of activity are negatively impacted, which may contribute to a slower rate of recovery from stroke. Laidlaw, Thompson, Gallagher-Thompson, and Dick-Siskin (2003) posited a type of cognitive error that stroke survivors may make. "Baseline distortions," in which stroke survivors compare their present functional level with that from before their stroke, instead of immediately after their stroke, can lead to a focus on one's impairments. This may result in a belief that one's post-stroke progress is inadequate, which is discouraging for stroke survivors.

1.2.3 Self-concept and identity

Self-concept has been defined as an assortment of judgments about the self which may belong to distinct or multidimensional domains, such as cognitive competence and physical appearance (Ponsford et al., 2014). Importantly, these judgments, or self-representations, are dynamic: they are continuously shaped through personal experience and interaction with the environment (Ellis-Hill and Horn, 2000). Self-concept is linked to self-esteem, but is differentiated from it in that self-esteem involves a global, emotion-based evaluation of one's self-worth (Ponsford et al., 2014), and it has also been described as the evaluative component of self-concept (Brumfitt and Sheeran, 1999). In a study which excluded PWA, it was found that stroke survivors' self-concepts became more negative post-stroke (Ellis-Hill and Horn, 2000). Self-concept and self-esteem have been found to be associated with one another, with both contributing to levels of anxiety and depression in a sample of individuals with TBI (Ponsford et al., 2014). Self-concept measures have been used to assess challenges to identity in stroke survivors (excluding PWA [Ellis-Hill and Horn, 2000]). Babbitt and Cherney (2010) have conceptualized personal identity for PWA as consisting of personal autonomy, self-efficacy, self-esteem, and communication confidence. Research on PWA has suggested that experiencing aphasia has an impact on identity. Communication disability can compromise personal identity in PWA, which may lead to decreased confidence (Babbitt and Cherney, 2010). According to
Shadden’s application of sociocultural theoretical concepts to PWA’s experiences, two critical aspects of pre-stroke identity for this population are a sense of self-efficacy and a sense of the self as empowered. Post-stroke, PWA are at risk for "identity theft," as these components of identity are threatened by communication impairment (Shadden, 2005). A change in self-concept has been found to be a critical aspect of adjusting to life with aphasia (Hinckley, 2006). Similarly, Shadden (2005) has argued that the renegotiation of one’s identity post-stroke is crucial for PWA, given that quality of life and identity are associated with one another.

1.2.4 Self-efficacy

Self-efficacy has been described as perceived confidence (Jones, Partridge, and Reid, 2008). This construct was introduced by Bandura (1997), who defined it as “beliefs in one's capabilities to organize and execute the courses of action required to produce specific attainments” (p.3). Cognitive appraisal of one's abilities is central to this concept. New self-evaluative judgments are shaped based on one's performance in specific domains, such as post-stroke functional progress (Jones et al., 2008). Improvements in self-efficacy may result from mastering a skill (*enactive mastery experience*), watching others performing tasks (*vicarious experience*), receiving verbal encouragement and feedback from others (*verbal persuasion*), and managing negative *physiological and affective states* (Bandura, 1997). Failing to manage such states may negatively impact self-efficacy beliefs. For instance, a PWA may feel anxiety in communicative situations, which may be interpreted as an inability to manage task demands, thus negatively impacting his/her self-efficacy (Biel, Nitta, and Jackson, 2018). In addition, PWA may experience low self-esteem and mastery resulting from negative social interactions (DuBay, Laures-Gore, Matheny, and Romski, 2011). Participants in Horne's (2016) study commented that successfully mastering skills increased their confidence, which led to a belief that they could achieve more. However, when their efforts did not result in improved skills, participants reported frustration and decreased confidence. This suggests that mastery contributes to beliefs which affect confidence levels in stroke survivors.

Currently, there is no research on the relationship between self-efficacy and quality of life outcomes for PWA. However, self-efficacy beliefs have been associated with post-stroke quality of life in individuals without aphasia. As such, Biel, Nitta, and Jackson (2018) argue that self-
efficacy is important to address in assessment and treatment with PWA, as these individuals tend to overestimate the severity of their communication disability, which negatively impacts their self-efficacy. However, they note that general self-efficacy interventions may not be applicable to PWA, and that the clinician should consider the PWA’s current abilities and prognosis for improvement as well as his or her self-efficacy beliefs.

1.3 Definition of confidence in communication used in the study

As stroke is the most common cause of aphasia (ASHA, 2016), Horne's (2016) definition of confidence will be used to guide this research, as it was derived from qualitative research with stroke survivors, including those with aphasia. Confidence for PWA will be conceptualized as consisting of self-efficacy, self-esteem, and information from the environment which influences PWA’s beliefs about their abilities.

The definition of self-efficacy in this study will follow from Bandura's (1997) theory, as discussed in section 1.2.4. To re-iterate, self-efficacy refers to the belief that one is able to carry out a task in a specific situation. In a communicative context, this would translate to the belief that one is a competent communicator, which is similar to Babbitt and colleagues' (2011) definition of “communication confidence” (as discussed in section 1.2.1).

Self-esteem does not have a universally-accepted definition in psychological research (Vickery et al., 2008b). As discussed in section 1.2.2, it is often conceptualized as an overall judgment of one's self-worth or self acceptance. In other words, it is a positive or negative judgment of the self (Horne, 2016). In sum, confidence in this project is defined as consisting of self-efficacy and self-esteem, and environmental input which affects beliefs about one’s abilities, and will be explored in the context of communication for PWA.

1.4 Importance of confidence in communication for PWA

Confidence in communication for PWA is important for a number of reasons: stroke survivors, including PWA, have indicated that increasing post-stroke confidence should be a research priority (Pollock et al., 2014); PWA have reported feeling less confident in social situations (Horne, 2016), which has implications for their participation in life activities; and S-
LPs have reported that increased confidence is an important outcome of therapy for PWA (e.g., Cruice et al., 2016; Rose and Attard, 2015; Shrubsole et al., 2016; Simmons-Mackie and Holland, 2011; Wallace et al., 2016), that confidence is a factor involved in living successfully with aphasia (Brown et al., 2011), and that S-LPs can address the confidence of their clients with aphasia by helping them to improve their language skills (Northcott et al., 2017). However, PWA have been excluded from much of the research on confidence and associated constructs in stroke survivors (e.g., Chang and Mackenzie, 1998; Ellis-Hill and Horn, 2000; Vickery, Evans, Sepehri, Jabeen, and Gayden, 2009; Vickery, Sepehri, and Evans, 2008; Vickery, Sepehri, Evans, and Lee, 2008) and from psychological health research in general (Brumfitt and Sheeran, 1999; Hackett and Pickles, 2014; Kouwenhoven, Kirkevold, Engedal, and Kim, 2011; Müller, 1993; Sarno and Gainotti, 1998; Townend, Brady, and McLaughlan, 2007). Moreover, where PWA have been included in research in this area, the focus of these studies has been on developing assessment tools (see section 1.6 for a review). In addition, there is a paucity of psychosocial interventions for PWA, and where psychosocial interventions have been used with PWA, they often have not been developed for use with this population (Herrmann, 1997). Finally, there is no research to date on how S-LPs currently manage confidence in communication in working with PWA.

It is currently unknown whether the relationship between low and/or unstable self-esteem and depressive symptoms in stroke survivors without aphasia also exists for PWA. However, targeting self-esteem (which may be considered a component of confidence as per Horne [2016]), especially with regards to communication, may be relevant to interventions which aim to prevent depression in PWA (e.g., Worrall et al., 2016) or treat it (e.g., Thomas and Lincoln, 2006). One possibility emerged from Pearl, Sage, and Young’s (2011) research on volunteering: PWA who volunteered reported increased confidence and self-esteem. It is therefore possible that promoting PWA’s participation in activities such as volunteering may be a way to support confidence-building. Moreover, in research on PWA’s perspectives on goals for rehabilitation, PWA reported that recovering their communication ability contributed to their confidence (Worrall et al., 2011). Increased confidence has also been perceived as a benefit of participating in aphasia groups by PWA and their family members (Rotherham, Howe, and Tillard, 2015; Wallace et al., 2016).
Decreased confidence, especially in communicative contexts, may occur in PWA as a result of challenges to personal identity. For instance, PWA in Horne's (2016) study reported decreased confidence in social situations. This is concerning since, as Sarno (1993) argues, “the primary goal of rehabilitation is to restore the person’s role as a communicator, regardless of whether certain symptoms have been eradicated or particular linguistic skills have improved” (p. 325). If an individual is not confident in their role as a communicator, this may hinder social participation and psychosocial adjustment. Moreover, if PWA are not confident that they can successfully complete therapeutic tasks, this may have a negative impact on their motivation to engage with rehabilitation (Biel et al., 2018).

1.5 S-LPs’ perspectives on addressing psychosocial issues, including confidence in communication

As discussed in section 1.2.2, low and/or unstable self-esteem is associated with depressive symptoms in stroke survivors. Low self-esteem has been found to be a risk factor for depression in the general population, regardless of gender or age, as well as for moderate and clinical levels of depression (Sowislo and Orth, 2013). The rate of depression is estimated to be higher in stroke patients with aphasia than those without (Lincoln, Kneebone, Macniven, and Morris, 2012) and stroke survivors in general often have unaddressed mental health needs (Morris, 2016). Given these findings, one might wonder if S-LPs are addressing this gap in service delivery. However, research has found that although S-LPs in various countries feel that psychosocial functioning and quality of life are important for PWA, they do not feel prepared and/or comfortable addressing these issues in their clinical practice (Cruice et al., 2016; Foster, Worrall, Rose, and O’Halloran, 2016; Gibson and Purdy, 2014; Hilari et al., 2016; Holland and Nelson, 2014; Rose, Ferguson, Power, Togher, and Worrall, 2014; Sekhon, Douglas, and Rose, 2015). A study by Simmons-Mackie and Damico (2011) has demonstrated ways in which psychosocial issues brought up by clients may be left unaddressed by S-LPs.

Recently, there has been a call for collaboration between mental health professionals and S-LPs in addressing the psychological needs of stroke survivors with communicative impairments (Brumfitt and Barton, 2006; Doughty Horn, Crews, Guryan, and Katsilometes, 2016; Lincoln et al., 2012; Townend et al., 2007). In Canada, it is within the scope of practice of
S-LPs to address psychosocial issues which pertain to clients' communication. Speech-Language and Audiology Canada (SAC [2016]) outline the role of S-LPs in counselling clients: “prevention, counselling and education services to patients or clients, families, caregivers, other professionals and the public regarding all aspects of communication and swallowing function” (p. 3). This is therefore a role which needs to be considered by S-LPs in working with PWA.

1.6 Research on confidence in communication in PWA

Although confidence and related constructs such as self-esteem and self-efficacy appear to be clinically important considerations in working with stroke survivors, there are few assessment tools and interventions available to address these components of psychosocial well-being with stroke survivors, including PWA.

Jones, Partridge, and Reid (2008) developed the “Stroke Self-Efficacy Questionnaire” (SSEQ) to measure perceived self-confidence in functional abilities post-stroke. Preliminary investigation of its psychometric properties suggests good validity. However, individuals who were not able to read or who were unable to understand a two-step instruction were excluded from this study, so the sample may not have been representative of PWA. Moreover, none of the questionnaire's items were specifically related to communication or interaction with others in general, a domain which is highly relevant to PWA.

The “Daily Living Self-Efficacy Scale” (DLSES; Maujean, Davis, Kendall, Casey, and Loxton, 2014) was designed to differentiate between stroke survivors’ confidence in their ability to complete functional tasks independently of physical impairments. It consists of two subscales: self-efficacy for psychosocial functioning and self-efficacy for activities of daily living. The DLSES has been found to have high internal consistency, test-retest reliability, and convergent and divergent validity. However, individuals with language impairments were excluded in the development of the questionnaire, so it is unknown whether the DLSES is valid for the assessment of PWA’s self-efficacy.

In order to overcome language difficulties in the assessment of self-esteem in PWA, the “Visual Analogue Self-Esteem Scale” (VASES) was developed by Brumfitt and Sheeran (1999). The scale consists of 10 bipolar pictorials with seven-point scales. Items include constructs such
as “competent/incompetent,” “confident/unconfident,” “self-critical/not self-critical,” and “talkative/quiet.” Although the sample size of PWA was small, the VASES was found to be a reliable and valid measure of self-esteem for this population. The authors suggested that the VASES could be used to assess psychological adjustment in PWA over time, or as an outcome measure for psychological and linguistic interventions.

The “Communication Confidence Rating Scale for Aphasia” (CCRSA) was designed (Babbitt and Cherney, 2010) and subsequently revised (Babbitt et al., 2011) to assess the personal identity, attitudes, and feelings of PWA in relation to communication. Overall, the psychometric properties of the CCRSA have been shown to be adequate, although further research is needed to determine test-retest and inter- and intra-rater reliability (Babbitt et al., 2011). Although there are other aphasia-friendly self-assessment measures, none of these addresses communication confidence.

Horne, Lincoln, and Logan (2017) developed the “Confidence after Stroke Measure” (CaSM), a 27-item questionnaire intended to comprehensively evaluate confidence post-stroke. The scale has three sub-scales: self-confidence, positive attitude, and social confidence. Psychometric evaluation revealed high internal consistency among all scale items and between each subscale and a high correlation with the SSEQ, indicating good internal validity and convergent validity. The CaSM was also found to have high test-retest reliability. A small number (6%) of participants in the study in which the CaSM was developed had aphasia. The authors note that the scale may be appropriate for use with some PWA, but further research is needed to determine the minimum level of communication ability required to complete it.

A recent social, emotional, and communication intervention for people with aphasia has used the CCRSA as an outcome measure. This program, “Aphasia Action, Success, and Knowledge” (Aphasia ASK; Ryan et al., 2017) was developed in response to the lack of evidence-based psychosocial interventions for PWA post-stroke. The purpose of this intervention is to address and prevent emotional problems secondary to communication disability. It consists of six sessions for the PWA and his/her family member(s) in which participants are educated about the emotional impact of aphasia, aphasia rehabilitation, and strategies for communicating and connecting with others and staying positive. A phase one trial of Aphasia ASK demonstrated that this intervention resulted in improved communication confidence and mood; these outcomes were found to persist three months post-treatment. These findings show promise for Aphasia
ASK as a psychosocial intervention for PWA which may increase their confidence in communication.

1.7 Research aims and rationale

Confidence in communication is a component of post-stroke experience, which is particularly relevant to PWA, as confidence has been identified as an important factor in intervention according to PWA, their family members, and S-LPs. In particular, confidence in communication has been identified as a component of living successfully with aphasia.

There is an identified need for psychosocial interventions for PWA, yet this need does not appear to be sufficiently addressed by mental health professionals or S-LPs. Aphasia can have a negative impact on the way a person thinks and feels about him- or herself as a communicator. Targeting confidence in interventions has been suggested to decrease the prevalence of mood disturbance in stroke survivors in general (Lincoln et al., 2012). Confidence in communication may be one aspect of PWA’s psychosocial needs which may be addressed by S-LPs while staying within their scope of practice. However, little research has been conducted on this topic to date, and it is unknown whether and how S-LPs address confidence in communication in their clinical practice with PWA.

In sum, PWA’s confidence in communication may be a crucial component of post-stroke psychosocial health, quality of life, and rehabilitative success. As discussed above, confidence and related psychological factors such as self-esteem and identity may have a role in mental health and life participation for stroke survivors. Confidence in communication is of particular importance to PWA due to the negative psychological sequelae of living with communication impairment. The paucity of research on this topic was addressed in this study by providing a rich, thorough description of S-LPs perspectives on confidence in communication for PWA. This study has advanced the understanding of this concept through semi-structured, in-depth, qualitative interviews. Moreover, this study has advanced prior research by investigating confidence in communication for PWA specifically, informed by theories of social psychology and interpersonal communication. Therefore, the aim of this study was to explore the concept of confidence in communication for adults with post-stroke aphasia from the perspective of S-LPs. Specifically, the study addressed the following specific research aims:
1. To explore the perspective of S-LPs on the meaning of confidence in communication for adults with aphasia post-stroke.
2. To explore what helps confidence in communication for adults with aphasia post-stroke from the perspective of S-LPs.
3. To explore what detracts from confidence in communication for adults with aphasia post-stroke from the perspective of S-LPs.
4. To explore the role of S-LPs in working on confidence in communication for adults with aphasia post-stroke from the perspective of S-LPs.
Chapter 2: Methodology

2.1 Research paradigm

The position of inquiry for this research was constructivism. This paradigm emphasizes the importance of deep reflection to bring meaning to the surface. Reflection may be achieved through a dialogue between researcher and research participant. Through dialogue, these interlocutors co-construct an interpretation of reality (Ponterotto, 2005). The aim of constructivist inquiry is to understand and reconstruct phenomena (Guba and Lincoln, 1994).

2.2 Study design

As little is known about the topic for this research, a qualitative approach was deemed to be appropriate (Strauss and Corbin, 1990). In particular, a qualitative descriptive approach was used, as the purpose of this study was to answer a clinically relevant question and to summarize S-LPs’ experiences (Sandelowski, 2000). Qualitative description contributed to obtaining a comprehensive understanding of S-LPs’ perspectives. The goal of this approach is to summarize the data in order to best fit its informational content without interpreting it through the lens of a particular theory (Sandelowski, 2000). This allowed the findings of the study to answer questions which are relevant to S-LPs’ clinical practice.

2.3 Ethics

This study was reviewed and accepted by the Behavioural Research Ethics Board of the University of British Columbia (UBC) prior to its commencement.

2.4 Participants

The inclusion criteria for participation in this study included individuals who had had at least one year of experience working with PWA as a registered S-LP based on self-report. This criterion ensured that the participants had sufficient involvement with clients with aphasia in
order to provide an insiders’ perspective on the topic. Exclusion criteria included individuals who were unable to participate in a qualitative interview in English.

2.4.1 Sampling

Maximum variation sampling, a form of purposive sampling (Simmons-Mackie and Lynch, 2013), was used to recruit participants who had a variety of characteristics representing a diverse array of experiences in order to increase the richness and depth of the data (DiCicco-Bloom and Crabtree, 2006). In this investigation, variation within the sample was sought for the following characteristics: years working as a S-LP with PWA, work setting (e.g., acute care, private practice, inpatient rehabilitation, outpatient/community rehabilitation), and gender.

2.4.2 Recruitment

Participants were recruited through the British Columbia Association of Speech Language Pathologists and Audiologists (BCASLPA; now, Speech and Hearing BC) and the Community of Practice Aphasia Group. A total of 15 eligible participants were recruited through these special interest groups.

2.4.3 Participant demographics

Fifteen S-LPs were interviewed to represent their perspectives on confidence in communication for PWA. These participants are referred to as (P#) (e.g., P7 refers to participant number seven). Fourteen participants were female, and one was male, with a mean of 15.2 years of experience working with PWA (SD = 11.51, Range = 5-40 years). Participants had experience in work environments across the continuum of care, with many working or having worked in more than one type of workplace. See table 2.1 below for further detail.
Table 2.1 Participant Demographics

<table>
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<th>Number of participants (n = 15)</th>
</tr>
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<tbody>
<tr>
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<td>Male</td>
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</tr>
<tr>
<td>Female</td>
<td>14</td>
</tr>
</tbody>
</table>

*Years of experience as a speech-language pathologist (range = 5-40 years, mean ± SD = 19.40 ± 11.482)*

<table>
<thead>
<tr>
<th>Experience</th>
<th>Number</th>
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</thead>
<tbody>
<tr>
<td>1-5 years</td>
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</tr>
<tr>
<td>6-15 years</td>
<td>7</td>
</tr>
<tr>
<td>&gt;15 years</td>
<td>7</td>
</tr>
</tbody>
</table>

*Years of experience as a speech-language pathologist working with people with aphasia (range = 5-40 years, mean ± SD = 15.214 ± 11.5154)*

<table>
<thead>
<tr>
<th>Experience</th>
<th>Number</th>
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</thead>
<tbody>
<tr>
<td>1-5 years</td>
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</tr>
<tr>
<td>6-15 years</td>
<td>9</td>
</tr>
<tr>
<td>&gt;15 years</td>
<td>4</td>
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<tr>
<td>Unsure/not reported</td>
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<tr>
<td>Variables</td>
<td>Number of participants (n = 15)</td>
</tr>
<tr>
<td>---------------------------------</td>
<td>---------------------------------</td>
</tr>
<tr>
<td><strong>Current work environment</strong></td>
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<tr>
<td>Private practice</td>
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</tr>
<tr>
<td>Inpatient rehabilitation</td>
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<tr>
<td>Outpatient/community rehabilitation</td>
<td>8</td>
</tr>
<tr>
<td>Retired</td>
<td>1</td>
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<tr>
<td>Other</td>
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<tr>
<td><strong>Workplace experience with PWA</strong></td>
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<tr>
<td>Acute care</td>
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<tr>
<td>Private practice</td>
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</tr>
<tr>
<td>Inpatient rehabilitation</td>
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</tr>
<tr>
<td>Outpatient/community rehabilitation</td>
<td>10</td>
</tr>
<tr>
<td>Other</td>
<td>2</td>
</tr>
<tr>
<td><strong>Proportion of the caseload devoted to aphasia management at time of interview (range = 0-100%, mean ± SD = 31.167 ± 32.778)</strong></td>
<td></td>
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<tr>
<td>≤25%</td>
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<tr>
<td>&gt;25-50%</td>
<td>3</td>
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<tr>
<td>&gt;50-75%</td>
<td>2</td>
</tr>
<tr>
<td>&gt;75%</td>
<td>2</td>
</tr>
</tbody>
</table>

Notes: *A number of participants worked across multiple environments.*
2.5 Data collection method

This project consisted of face-to-face and telephone interviews with S-LPs who were working with or had worked with PWA. Semi-structured in-depth interviews were used to organise the dialogue with participants about their experiences with and perceptions of providing services to PWA. Open-ended questions which were derived from the research aims (see Appendix A) were used to co-construct the dialogue between the researcher and the participant. Due to the semi-structured nature of the interviews, the researcher followed the participant’s lead in exploring the topics pertaining to the research aims. Follow-up questions and prompts were used to clarify participants’ comments and/or to explore them further in a non-leading manner (DiCicco-Bloom and Crabtree, 2006).

Interviews explored S-LPs' experiences with confidence in communication for PWA at different time periods post-stroke, and their perspectives on the meaning of confidence in communication for PWA, what helps or detracts from confidence in communication for PWA, and the role of S-LPs in focusing on confidence in communication with PWA. Interviews were conducted at a location of the participant's preference, if local. If the participant lived outside of the Greater Vancouver area, or preferred a telephone interview, the interview was conducted over the telephone. Similar data can be obtained from face-to-face and telephone qualitative interviews (Sturges and Hanrahan, 2004). The same amount and depth of responses may be obtained regardless of whether the interview is conducted over the telephone or in person. Moreover, in conducting interviews over the phone, a wider variety of participants may be interviewed (Sturges and Hanrahan, 2004), which is consistent with the sampling method used in this study. Brown and colleagues (2011) used telephone and face-to-face interviews for their qualitative study on S-LPs' perspectives on living successfully with aphasia, demonstrating that this method of data collection is suitable for interviews with this population.

Individual interview sessions, which consisted of rapport-building and the interview itself, ranged from 36 minutes to 71 minutes in length (Mean = 58 minutes, SD = 9.1). All interview sessions were audio-recorded using a Marantz recorder.
2.6 Data analysis

Verbatim transcriptions were made from the audio-recordings of the interview data, based on Poland’s (2003) notation conventions and quality maximization strategies. Subsequently, qualitative content analysis (Graneheim and Lundman, 2004) was used to analyze the transcripts. First, the researcher immersed herself in the data by reading and rereading the transcripts while listening to the audio recordings. She then identified four units of analysis based on the four-specific research aims. Content that was outside of these research aims was not analyzed. Within each content area, relevant meaning units were identified and condensed (shortened while still preserving their core meaning). Similar meaning units within each transcript were assigned an initial code to describe words or statements that had the same core meaning. Initial codes that were similar across transcripts were aggregated and assigned a revised code that captured the core meaning of all the meaning units. Similar codes were then aggregated into higher-level categories. As data analysis progressed, new codes were added as required and categories were modified to accommodate new findings from the data (Sandelowski, 2000). An example of how a meaning unit was identified and assigned a code is provided in Table 2.2 below.
Table 2.2 Data Analysis Example

Meaning unit
I: Mmkay. Okay, thank you…so thinking again across the continuum of care, how would the role be different at different stages, or how might it be…

P3: The S-LP helping with confidence? (interviewer nods “yes”)
Yeah, y’know, in acute care, nobody…is, the, the person with aphasia isn’t thinking about “oh I wanna order, or I wanna read a book, or I wanna make a phone call.” Y’know, they’re, they’re still adjusting to this major change. So I think there it’s really about validating their, humanity, their intellect, saying “you are, you are still you,” that sense of self that crumbles after a stroke…

Condensed meaning unit
P3: …in acute care, nobody…is, the, the person with aphasia isn’t thinking about “oh I wanna order, or I wanna read a book, or I wanna make a phone call.” Y’know, they’re, they’re still adjusting to this major change. So I think there it’s really about validating their, humanity, their intellect, saying “you are, you are still you,” that sense of self that crumbles after a stroke…

Code
S-LPs in acute care validating PWA’s humanity and intellect, saying “you are still you”

Category
Codes such as: S-LPs in acute care validating PWA’s humanity and intellect, saying “you are still you” AND Others recognizing the PWA and still connecting and communicating: having a connection that is not contingent on language compiled into the category labelled: Others’ recognition of PWA’s identity/personhood/sense of self

2.7 Rigour

Peer debriefing and member-checking were used to minimize researcher bias and increase the credibility of the data and the analysis process (Curtin and Fossey, 2007; Graneheim and Lundman, 2004). In addition, a reflexive journal entry was written after each interview.
2.7.1 Member-Checking

Member-checking involved providing the participants with a written summary of the initial analysis of the deidentified data from all the interviews. Participants were asked to provide written feedback on this initial summary within three weeks of receiving the summary. Five participants provided comments about this initial summary to the researcher. Participants’ comments from the member-checking process were incorporated into the final analysis.

2.7.2 Peer debriefing

The peer debriefing process involved the interviewer (AT) consulting with the supervisor of the project (TH) and supervisory committee members (PC and JS) to reach a consensus on the analysis of the data.

2.7.3 Reflexivity

In qualitative research, it is vital to acknowledge that the researcher is an active participant in the research process (Curtin and Fossey, 2007). As an S-LP student with an undergraduate degree in psychology, the primary researcher’s academic background may have influenced her approach to this study. In order to better reflect participants' perspectives instead of her own, the primary researcher engaged in member-checking (see section 2.7.1) and kept a reflective journal. This journal allowed her to examine the influence of her subjective experience particularly in relation to her background in counseling in which there is often a tendency to focus on emphasizing addressing personal factors more than addressing both personal factors and the communication behaviours and attitudes of those people who interact with them on the development of the research and her interactions with the participants (Curtin and Fossey, 2007). For instance, initially, the researcher tended to focus on internal processes instead of focusing on changing others’ behaviour to make interactions more successful for the client; this was considered during data analysis. In contrast, S-LP intervention may seek to improve interpersonal interactions, for example, through training PWA’s communication partners how to better support their language expression and comprehension.
Chapter 3: Results

Qualitative content analysis of the interviews revealed the following results:

1. Meaning of confidence in communication for PWA: 12 categories of 56 codes
2. What helps with confidence in communication for PWA: 14 categories of 93 codes
3. What reduces confidence in communication for PWA: 13 categories of 62 codes
4. Role of S-LPs in working on confidence in communication for PWA: 14 categories of 88 codes

Results are presented in the order listed above. Direct quotes from participants are provided to illustrate findings throughout this chapter. Quotes will be attributed to participants as follows: P# (e.g., P7 for participant number seven). All categories and codes which arose from data analysis are provided in Appendices B through E.

It should be noted that the reflective journal, peer debriefing, and member-checking processes reported in Chapter 2 had an impact on the data collection and analysis. For example, journal entries were used to acknowledge the researcher’s initial conclusions about what concepts might emerge in subsequent interviews. In identifying these after each interview, the interviewer was able to be mindful of not leading subsequent participants to express similar ideas. Peer debriefing resulted in the primary researcher adding clarification to the reporting of the results to better distinguish between categories, and in one case, a code was re-assigned to a different category. Finally, the participants who returned comments about the initial, de-identified results of the study generally indicated agreement with the findings, although some participants indicated the need for clarification on certain matters (e.g., distinguishing between similar categories). At one participant’s suggestion, it should be clarified that the thought processes presented in the results reflect S-LPs’ interpretations thereof, and may not necessarily reflect how PWA would present their experiences.

3.1 Meaning of confidence in communication for PWA

All codes pertaining to the meaning of confidence in communication for PWA are displayed in Table 3.1. Fifty-six meaning codes were identified during data analysis, which were grouped into 12 meaning categories, and subdivided into four higher-order categories:
behaviours of PWA associated with confidence in communication; attitudes of PWA associated with confidence in communication; characteristics of confidence in communication in PWA; and “other.” Behaviours of PWA associated with confidence in communication included the following six categories: PWA being willing to put themselves out there and participate/try to communicate; PWA taking risks with communication; PWA being comfortable to communicate with anybody/anywhere; PWA using/being open to using different communication modalities; PWA sharing more information, joking around in conversation groups; and PWA persevering/persisting. Attitudes of PWA associated with confidence in communication consisted of two categories: PWA’s beliefs/perceptions/knowledge about communication and PWA accepting themselves and their communication abilities. Characteristics of confidence in communication in PWA contained two categories: PWA’s lack of and variation in confidence and PWA’s personal factors. The “other” higher-order category was comprised of two categories: confidence is elusive and ephemeral and overconfidence in Wernicke’s aphasia. Each subsection below serves to describe each of these categories in detail.

3.1.1 Behaviours of PWA associated with confidence in communication

3.1.1.1 PWA being willing to put themselves out there and participate

Many participants reported that PWA being willing to put themselves out there and interact with people despite the aphasia and “not letting their insecurity about their communication stop them from interacting with people and participating in life” (P2), even if the interaction is not through language, reflects confidence in communication. Other comments included PWA’s participation in life, accessing their community freely, and “getting out there and doing what they need to do” (P7). PWA making an effort to regularly attend conversation groups and being confident in pointing out what they want to say with AAC (augmentative and alternative communication; e.g., a TouchChat system) were other components mentioned. One participant elaborated on the relationship between PWA’s confidence and their communication with others:

“I’ve often wondered…what it is about people that drives them, to such different outcomes…I had a patient who was a man who lived alone, and he was very chatty, and
he made huge gains in his aphasia recovery, because he would talk to anyone, everywhere. And I’ve had other…patients who just don’t have that and their progress is so much slower…And I think that might be the, the secret ingredient. The man who made great recovery, he was just confident enough to go out and talk to people. And the people who’ve, didn’t progress didn’t have the confidence to try” (P3).

3.1.1.2 **PWA taking risks with communication**

PWA being comfortable “to participate, to take a risk, to try” (P1) was a common thread in this category. The risks described were communicative in nature (e.g., “maybe this phrase “I want coffee” is not gonna come out correctly” [P4]), and PWA still having the confidence to try was equated with confidence in communication. Two participants mentioned PWA not being afraid as evidence of confidence in communication (e.g., “it’s what they’re not afraid of doing anymore…not being afraid of jumping in somewhere, and if they can’t communicate, they always know they can bail themselves out somehow” [P11]). Finally, PWA being experimental and creative through being willing to “try things and fail and be okay with it” (P7) was also thought to indicate confidence in communication.

3.1.1.3 **PWA being comfortable to communicate with anybody/anywhere**

Some participants indicated that PWA communicating with people who aren’t “aphasia-friendly, who don’t know about aphasia” (P5), and “being comfortable talking to anybody, anywhere” (P9) are components of confidence in communication. One example of this was PWA initiating interactions in the community.

3.1.1.4 **PWA using/being open to using different communication modalities**

Several participants reported that PWA initiating interactions and being willing to communicate in any modality, and/or with the use of strategies, demonstrates confidence in communication (e.g., having “the kind of confidence that they can use certain strategies” that are “gonna work most of the time” P11)). This may include PWA “welcome[ing] assistance” from a
partner to “continu[e] to try to communicate in whichever way possible” (P5). Strategies and modalities that participants discussed included writing, gesturing, drawing, using an iPad, and using AAC (e.g., a communication board). Creativity of PWA in communicating was also mentioned (e.g., a PWA who “just whips something out and tries it” [P7]).

3.1.1.5 PWA sharing more info, joking around in conversation groups

PWA in conversation groups being comfortable, sharing, and joking with one another was also thought to demonstrate confidence in communication. One participant indicated that this was shown by how PWA appear and carry themselves in groups: “it’s not that…scared look” (P11).

3.1.1.6 PWA persevering/persisting

A few participants mentioned that when PWA keep trying to communicate and advocate for themselves and what they want/need, this demonstrates confidence in communication. According to one participant, when PWA “initiate or persist, or assert…you get a sense that they feel strong” (P8). Examples of this included PWA “who will keep trying and trying and trying and don’t care how, fully they’re communicating in terms of typical communication” (P5), PWA who “demand that others give [them] the time to get that out, or work with [them] to figure out the message” (P3), and PWA who accept “it’s not perfect” but make “multiple attempts. Or just persist or make people wait. Or…say “it’s okay. Let’s keep going” (P8).

3.1.2 Attitudes of PWA associated with confidence in communication

3.1.2.1 PWA’s beliefs/perceptions/knowledge about communication

This category contains a range of cognitions that participants thought signified confidence in communication for PWA. Beliefs included PWA having a “base level of…faith in [their] own ability” (P13), “believing they have a right, to speaking their mind. A right to choice. A right to be respected” (P8), believing that they can impact their own healthcare, and having a
sense of hope (e.g., this trust that…it’s worth struggling because it’ll get better” [P13]). In addition, PWA knowing certain things about themselves and their communication was thought to convey confidence in communication (e.g., being “secure in their knowledge that they’ll be able to interact with people” [P2], “knowing that [they] have something important to say, and that [they] want to get it out” [P3], “knowing that if they fail…it doesn’t mean that they’re a failure” [P13] and “the knowledge that, “I’ve come through this, so I can…do a lot of things” [P11]).

3.1.2.2 PWA accepting themselves and their communication abilities

Several participants reported that PWA being able to “resolve that old self with the new self” and “find some sort of harmony between that old and new” (P1), being willing to “just say…“yeah, I know you can’t understand me, I had a stroke”…admitting it and accepting it” (P12), being “proud of how far they’ve come” (P11), feeling good about themselves, and having trust in themselves conveys confidence in communication. One participant elaborated on the process of self-acceptance, speaking of PWA resolving the tension between what one used to be able to do but now cannot and what one is trying to do now, negotiating identity to become more settled in one’s new identity, and “progress[ing] from, that chaos piece to more of a...peaceful state.” (P1). Another participant indicated that building confidence is a lifelong process for PWA, and that as their speech and communication improves, so will their confidence. However, a different participant indicated that sometimes PWA’s aphasia has not improved, but that their confidence has grown from becoming “better-functioning people with aphasia” by “bridging the gaps to barriers of communication that they face maybe initially” (P6).

3.1.3 Characteristics of confidence in communication for PWA

3.1.3.1 PWA’s lack of confidence/variation in confidence

Many participants described the meaning of PWA’s lack of and/or or variation in confidence. Lack of confidence was reported to be demonstrated by PWA not communicating and making comments such as “I can’t communicate” (P12) or “I don’t feel like I can” (P6), or showing frustration “if they can’t get their point across” (P14). Some participants thought that
confidence in communication for PWA varies based on the severity of their aphasia. One participant had observed a variation in PWA’s confidence across settings (e.g., in an aphasia group or in a therapy environment, where “they’re doing really well” [P3] and out in the community, where they do not do as well for lack of trying to communicate, and/or deferring to someone else to speak for them.

3.1.3.2 PWA’s personal factors

Some participants indicated that confidence in communication for PWA may involve their personality (e.g., having a “super shiny” [P12] very outgoing personality) and not letting severe aphasia stop them from communicating. One participant commented on PWA who had confidence prior to entering a community-based aphasia program, and who were looking for “challenges and ways to push themselves” (P13). Others mentioned that confidence in communication is internal, or that it is “something that you create for yourself” (P7). For instance, “there is definitely something internal…we [S-LPs] don’t put it there” (P13).

3.1.4 Other aspects of confidence in communication for PWA

3.1.4.1 Confidence is elusive and ephemeral

Two participants commented on challenges in defining or measuring confidence (e.g., “the confidence thing is really elusive” [P1]; “confidence isn’t a percentage…it’s not a worksheet…it’s very much…part of human life, that is a bit more ephemeral” [P2]). One of them noted that “it's impossible to say whether the service you’re providing is what's creating the increased confidence, because you don't see [PWA] in a vacuum” (P1).

3.1.4.2 Overconfidence in Wernicke’s aphasia

One participant described PWA who are overconfident, particularly in the case of Wernicke’s aphasia: “their feedback loop is broken. So they’re not getting what they’re saying”
(P15). This was thought to lead to overconfidence in one’s own abilities, “especially if that insight piece isn’t there” (P15).

3.2 What helps with confidence in communication for PWA

Codes relating to what helps with confidence in communication for PWA are presented in Table 3.2. A total of 93 codes of what helps were identified during analysis, which were grouped into 14 categories of what helps: PWA practicing communication and experiencing success/improvement in the clinic and beyond; PWA’s use of communication strategies with communication partners; S-LPs’ and other communication partners’ use of supported communication techniques; accepting, supportive social networks/environments to participate in; others’ recognition of PWA’s identity/personhood/sense of self; support from other PWA; opportunities to participate in their communities (e.g., aphasia-friendly resources, programs, volunteering); S-LPs providing client-centred care for PWA; S-LPs providing counseling and education to PWA; others providing positive reinforcement, encouragement, and feedback to PWA; S-LPs supporting independence and self-advocacy for PWA; PWA’s personal factors; PWA having goals and challenges; and PWA having routines/knowing what to expect. The subsections below provide detail on each of these categories.

3.2.1 PWA practicing communication and experiencing success in the clinic and beyond

Most respondents indicated that PWA experiencing success in their communication is a confidence-builder. As one participant noted, “the most important type of reinforcement is, the client with aphasia communicated something successfully and they got what they asked for or, the other person was able to understand their, their message” (P4). Moreover, clients noticing when they’ve successfully communicated, such as by using a strategy, was suggested to help build confidence by making them think, “hey, wait a minute, I can actually do this” (P1). Similarly, one participant proposed that PWA “having a background of success…really helps them to, think that they can be successful in future endeavours” (P4). PWA experiencing improvement in different communication modalities (e.g., auditory comprehension, verbal expression, and use of AAC), was thought to be important in building their confidence – “with
all of those things comes, confidence and independence” to “not be afraid of breaking down and not being able to communicate” (P11).

S-LPs were also considered to be contributors to PWA’s ability to have successful experiences (e.g., S-LPs working at PWA’s “optimal level” [P6] so that PWA are successful in therapy activities but still working hard, and using errorless learning techniques). In addition, S-LPs reducing PWA’s barriers to success (e.g., by identifying necessary strategies or tools necessary to complete a task and equipping PWA with them), was suggested as a way to support PWA’s confidence in communication.

PWA practicing their communication was described as helpful for confidence in communication by several respondents. For example, PWA practicing speaking on the telephone to gain more confidence in having phone conversations was mentioned by some participants. However, most of the content in this category referred to S-LPs practicing communication with PWA and/or setting up opportunities for them to do so. For instance, in the acute care setting, having S-LP resources for communication, not dysphagia, so that PWA are treated and S-LPs are not “just getting people out the door” (P2). With the support of S-LPs, PWA practicing their communication with different people, such as different members of the healthcare team in a hospital, and in different environments, such as a grocery store or a coffee shop, were suggested as ways to aid confidence-building in communication. In addition, S-LPs doing “staged practice” (P8) of scenarios such as giving a wedding speech or making an emergency phone call with PWA were also considered to be helpful. Finally, two participants mentioned that working on the impairment level, by S-LPs doing exercises with PWA, for example, and helping clients or patients “to have more fluent speech” (P7) are helpful for confidence in communication. In inpatient rehabilitation, a particular focus was to “facilitate natural recovery as the brain is still healing. And in that stage it’s, I think about, giving them that confidence that they can keep working and they can keep improving. To try to, push that depression away, that’s so common” (P3).

3.2.2 PWA’s use of communication strategies with communication partners

While practicing communication skills in general was thought to be important to confidence in communication by many participants, there was also a specific focus on PWA’s
use of communication strategies with others as a helpful factor. Some participants indicated that by teaching PWA communication strategies and equipping them with AAC tools (e.g., a communication support app such as TouchChat, communication books and boards) that work for them, S-LPs can help to build PWA’s confidence. Moreover, PWA gaining trust in their ability to use these tools was considered to be important, including for the purpose of training communication partners in the community. PWA using partner-assisted communication strategies was thought to help PWA “really open up” and be less “self…criticizing” (P5), and improve their quality of life. In the community setting, three participants discussed PWA presenting a communication alert card that describes aphasia and/or includes helpful communication strategies for that individual before talking with a member of the public. This was thought to be a good way to “erase the initial barrier of, “what will people think of me?”” (P2), to “dispel that stereotype that comes from…talking to a client with aphasia” (P4), and to facilitate “the client helping the communication partner” (P15).

Other comments highlighted the impact of encouraging and cueing PWA to use all modalities of communication, including non-verbal or alternative methods of communication. This was noted by some participants to be particularly significant in acute care, to “to help PWA “feel heard and seen and valuable” (P1).

3.2.3 S-LPs’ and other communication partners’ use of supported communication techniques

Most participants highlighted the use of communication strategies with PWA, including Supported Conversation for Adults with Aphasia (SCA™). Many participants described using strategies consistent with this approach in their clinical practice with PWA, including writing down keywords, using pictures, encouraging the use of gesture, and giving PWA more time to communicate; “anything that can promote success” (P9).

Nearly all participants described PWA having communication partners who are equipped to support them as being a helpful for confidence in communication. This included S-LPs training PWA’s healthcare team (e.g., in the use of SCA™), providing training sessions and workshops for PWA’s family members on supporting their significant others’ communication, and PWA learning strategies from peers and having a trained communication support person.
with them in the community. According to one participant, “training partners facilitates, or builds confidence, in clients because…success encourages more trial” (P2). Several participants discussed S-LPs educating and modeling for PWA’s family members on including and supporting their significant other with aphasia in their communication. Some comments referred to increasing helpful behaviours, such as verifying PWA’s messages and giving PWA the chance to communicate by waiting and listening, while others targeted the decrease of unhelpful behaviours, such as jumping in, or trying to “interpret” the PWA’s intended message (e.g., “What he wants to say is…” [P8]). The goal of this was described by one participant as creating “a culture of confidence” for PWA, in which “the people that surround the client…understand what aphasia is and they have the right expectations of that client. They know how to properly support them, to again, build…a successful environment for the client, which is gonna build confidence for them.” It should be noted that one participant who provided member-checking feedback indicated that S-LPs need to have received SCA training themselves in order to use this method with clients and their communication partners.

3.2.4 Accepting, supportive social networks/environments to participate in

PWA having access to people and environments that are understanding of how they communicate was reported by most participants to be beneficial to PWA’s confidence in communication (e.g., PWA knowing that “the therapist is on their side, is trying to support them, and wants them to do as well as they can” [P3]). PWA being more comfortable with their S-LP due to “greater safety” and the fact that S-LPs “can really facilitate their expression” (P8) was also mentioned.

Some participants indicated that S-LPs building places and social networks where PWA have access to people who understand how they communicate and can support them is important, so that “PWA have opportunities to interact where they feel safe” (P2). According to one participant, “in the safe environment of a therapy or an aphasia group, or camp, or cruise…they have a lot more confidence because they feel safe” (P3). Similarly, another participant commented that communication partners in an aphasia group setting having SCA™ training can contribute to the group being “a safe space…if they don’t get their message out…there’s support there” (P7).
Other comments focused on the importance of PWA having supportive friends and family, so that PWA “[feel] like they’re accepted and…have friends that understand them and support them in their communication” so that “they’re able to…re-engage in those…relationships” (P6). In addition, the community being aware of aphasia and being supportive of PWA and how they communicate, so that they are included in community life, was mentioned by some participants as helpful for confidence in communication. Specifically, a supportive community was described as having “people who are around to give you what you need” and who are “willing to…look at what the person is doing to communicate and build on that” (P13). This could involve an “at-easeness” (P11) of a person in interacting with PWA (i.e., having patience, and “an attitude that you’re trying, really trying” [P11]).

3.2.5 Others’ recognition of PWA’s identity/personhood/sense of self

Approximately half of the respondents indicated that acknowledgment of a person with aphasia’s personal self facilitates confidence in communication. PWA’s communication partners acknowledging and revealing competence (e.g., via acknowledgment and inclusion of PWA’s strengths in interaction), and people being honest and not pretending that they have understood PWA were examples of this. In addition, S-LPs were considered to facilitate this recognition when providing services that help others view PWA as competent, and that help PWA see themselves as competent (e.g., by helping clients with aphasia to feel like contributors through storytelling). S-LPs helping PWA “to recognize that a lot has changed but not everything” by “pointing out the parts of the person that are still the same” (P1) was also mentioned.

Four participants mentioned the importance of acknowledging personhood in acute care on the part of S-LPs and/or other staff (e.g., the medical team in acute care) showing a PWA that “they are still… a worthwhile person who should be involved in their care, involving them more in those decisions, to the amount that they can be, depending on the lethargy and whatever else is going on medically” (P3). PWA having a positive experience in acute care so that “they feel like they’re part of the process and that they have a voice even though they may feel like they don’t” was noted as “key” (P6). One participant indicated that a positive healthcare experience as a PWA can “positively impact your later sense of self and your later journey” (P1). Additionally, the development of PWA’s post-stroke identity was considered to promote confidence in
communication, either through S-LPs providing opportunities for this or through PWA creating a new identity by finding a purpose (e.g., by volunteering and/or helping other PWA).

3.2.6 **Support from other PWA**

“Safety and trust” (P5) was described as an important aspect of aphasia groups, which is cultivated by members encouraging and supporting each other to communicate, the knowledge that the group is nonjudgmental, and people taking the time to help them get their messages across. Several respondents emphasized the value of peer support, particularly from participating in aphasia groups. PWA being with others who are going through similar experiences was thought to be a source of psychosocial support, and it was suggested that members of the group “make up for the friends that they’ve lost” (P11) due to their communication impairment. In addition, learning from peers by seeing how other PWA communicate was thought to facilitate confidence in communication. As one participant put it, “the power of groups is when they’re in a group and they see other people also have deficits… and they see how other people work through it…it gives them the confidence to work through it.” (P12).

3.2.7 **PWA having opportunities to participate in programs and in their communities**

PWA having community services for PWA’s growth and development, such as conversation groups and setting up opportunities for community re-integration, was suggested by some participants to be helpful to their confidence in communication. This included S-LPs creating programs that “allow people to grow and develop” (P1) and using approaches to facilitate participation for PWA (e.g., through making changes to PWA’s environment, as per the Life Participation Approach to Aphasia [LPAA]). The Living with Aphasia: Framework for Outcome Measurement (A-FROM) was also indicated as a useful approach in facilitating PWA’s participation. Some specific examples of PWA participating in their communities included PWA going on community trips with an S-LP or other multidisciplinary team member (e.g., a recreational therapist), and volunteering (e.g., for an aphasia group that they were once members of).
3.2.8 S-LPs providing client-centred care for PWA

This category contained a variety of ways in which S-LPs can provide client-centred care to facilitate confidence in communication for PWA. Some respondents commented on adjusting the amount of support provided based on the needs of the patient or client (e.g., for individuals who are more shy, doing a lot more encouraging, practicing, and coaching, and not fading support as quickly during S-LP sessions or outside of the therapy room). Two participants mentioned using the A-FROM; according to one, S-LPs using the A-FROM to “[look] at all factors to make the greatest impact for PWA” (P1) as helpful for confidence in communication.

3.2.9 S-LPs providing counseling and education to PWA

“Fostering a sense of hope” (P1) in their patients or clients was highlighted by a few participants as a role for S-LPs to increase their confidence in communication. This included giving PWA “a chance to, express themselves in whatever way they can…addressing any emotions that come up, giving them…control to communicate” (P6). Some participants commented on the importance of “showing PWA what they can do” for those “who are really not confident in their skills and just focus on what they can’t do” (P12), showing PWA that communication can work outside of a quiet, controlled environment with a trained person, as well as debriefing with PWA when a communication interaction was not successful. In addition, S-LPs supporting PWA to take risks when there is a possibility of failure was mentioned, as “you can only get confident if you take the risk and you don’t fail” (P13).

3.2.10 PWA getting positive reinforcement and feedback

Two-thirds of participants indicated that PWA getting positive feedback about their communication from others, particularly from S-LPs, was helpful for confidence in communication. S-LPs giving PWA reinforcement when they try using a communication strategy, encouraging them to try again, and talking to PWA about how much they’ve improved since first meeting the S-LP, were described as ways of doing this. PWA receiving positive
reinforcement from family members, and getting encouragement from “other people in the same boat” (i.e., other PWA) was also thought to help with confidence in communication.

3.2.11 S-LPs supporting independence and self-advocacy for PWA

Supporting independence for PWA in outpatient and community settings was indicated by approximately half of participants to be a factor that helps confidence in communication. This included S-LPs giving more independent clients homework “to put [themselves] out there, [their] communication out there” (P12), encouraging self-advocacy, (e.g., by having a page in a communication book with suggestions for communication partners to support a PWA), or helping PWA to develop skills to initiate communication, look for opportunities to get their turn in conversation, and do things themselves (e.g., booking a taxi). In addition, helping PWA to know that they have agency in their recovery was thought to be helpful (i.e., “that they’re the ones who, can, build their own confidence through the successes that they’ve worked hard for [P5]). Finally, S-LPs “letting go” (P13) of telling PWA how they should and should not communicate (e.g., when PWA are preparing a workshop for students) was also mentioned.

3.2.12 PWA’s personal factors

Several participants discussed that having certain characteristics can facilitate the confidence in communication of PWA. This included PWA’s baseline personality, such as being “willing to make mistakes” and “being able to laugh off their errors and keep plugging away” (P11), as well as being outgoing or an extrovert, and “putting themselves out there in a group by being willing to contribute and participate” (P1). PWA finding the internal motivation to communicate, having a sense of hope, “accepting that this is [their] new communication style” (P12), and trusting their clinician to not ask them to do something that they could not do were also thought to be helpful personal factors. One participant noted that “Whatever gives people their own confidence…depends on who they are” (P13) (e.g., time, lots of encouragement, or an “in your face” [P13] approach).
3.2.13 **PWA having goals and challenges**

Three respondents indicated that having a goal or challenge to work towards assists PWA in gaining confidence in their communication. Examples included PWA setting a goal to increase their talk time and monitoring it through a wearable tracking device (e.g., the ComFit, which is currently in development), or by someone challenging them to try public speaking.

3.2.14 **PWA having routines/knowing what to expect**

Three participants mentioned that routines are helpful to PWA’s confidence in communication as, according to one participant, “they anticipate success, due to the routine supporting the communication” (P5). This could be through S-LPs helping PWA “to get over the fear” of communicating on the phone for, example, so that “it becomes more of a routine than a risk” (P8), or participating in a conversation group, where there is “just a bit of a rhythm to it,” so that PWA know what to expect.

3.3 **Detractors of Confidence in Communication for PWA**

Detractors of confidence in communication are presented in Table 3.3. Analysis resulted in 62 codes of detractors, grouped into 13 categories: PWA’s failure in communicating in the clinic and beyond; PWA’s lack of improvement in communication; lack of social/communication support for PWA; others not helping with, respecting, or accepting PWA’s communication; PWA experiencing negative thoughts and feelings about communication breakdowns and others’ perceptions of them; PWA having unrealistic expectations; PWA “being perfectionists” and avoiding risk; PWA’s focus on deficits and comparison to pre-stroke function; PWA’s learned non-use of communication; others’ perceptions/expectations undermining PWA’s confidence; others’ lack of knowledge of aphasia; and PWA’s personal factors. Further detail on these categories is provided in the subsections below.
3.3.1  PWA’s failure in communicating in the clinic and beyond

PWA experiencing failure in communication was mentioned by many respondents as something that minimizes confidence in communication. As one participant stated, “failure’s a lot more powerful than success” (P3). Another participant indicated that when failure happens, PWA letting “that person or that environment control their life, and dictate what they can and can’t do” (P3) detracts from confidence in communication. In addition, situations where PWA’s failed communication attempts result in consequences (e.g., not being able to make their choice known, so that they are “stuck” (P8) with something they did not want) were mentioned. Another participant described S-LP therapy sessions that aren’t “designed with appropriate step-downs, cues, and supports, and the PWA keeps failing and failing and failing,” so that the PWA “might start thinking, “I can’t do this, because I keep failing” (P6). However, S-LPs and family members finding a balance between protecting PWA from failure and exposing them to it was also a concern: “we have to stand back and let them, maybe fail…on the other hand, we can’t let them go to certain failure” (P13).

3.3.2  PWA’s lack of improvement in communication

A lack of improvement in communication ability was discussed as a detractor of confidence in communication, either due to PWA not grasping onto the use of communication strategies, reaching a plateau in their progress, or being “so severely affected that it’s very difficult to improve to a point where they can develop confidence” (P11). Finally, PWA having skilled communication partners without seeing improvement in their own abilities was indicated to minimize confidence in communication.

3.3.3  PWA having a lack of social/communication support

Many participants mentioned PWA having a lack of support in communicating as a detractor of confidence in communication. Two participants indicated that social isolation is related to feelings of depression; according to one of them, this results in PWA being “less confident about their ability to participate socially” (P2).
PWA being “pushed out the door because of hospital bed pressures, and not getting training and support” (P9) was another area of neglect for PWA. PWA not being supported in their transition from hospital to home was considered to be “where the big gap is” (P6) in aphasia services, which was thought to result in “limited carryover because, y’know they don’t have that transition piece. Like, we don’t have any support for them as they re-integrate into the community” (P6). Similarly, one participant commented that PWA not having enough therapy to give PWA the confidence to communicate is a potential issue (e.g., if they are not provided with education on the use of communication strategies). Finally, PWA not having family or caregiver support to encourage them to use communication strategies or other communication modalities was thought to detract from confidence in communication.

3.3.4 Others not helping with, respecting, or accepting PWA’s communication

Others’ negative communicative behaviours were thought to have a diminishing impact on confidence in communication for PWA by most participants. This category included situations where others know that a person has aphasia but communicate with that person in a less than ideal manner. The most commonly mentioned situation was PWA having negative experiences in acute care as a result of being “overlooked, not spoken to, left lying there with no idea of what was going on” (P1). Another participant remarked that “if you’re a client in acute care, with…no communication difficulty, your confidence will be challenged. So add on top of that the fact that no one’s listening to you, no one’s taking the time, no one’s got…appropriate strategies to, to facilitate you [as a PWA]” (P8). In addition, S-LPs and medical professionals telling PWA “that they’re not going to get better past a certain mark, or that they will never get back to their old selves, or they will likely never return to work” was described as “devastating” (P3) for PWA. Two participants also mentioned patronizing feedback from S-LPs (e.g., “Good job! Good talking, Joe!” [P2]) as a detractor of confidence in communication for PWA.

PWA’s spouses were mentioned by one participant as detracting from PWA’s confidence in communication when they do not accept non-oral communication or correct them when they have “made a good effort” (P2), or ask them questions that the spouse already knows the answer to. Other detractors included communication partners who aren’t patient, who don’t make an effort to communicate with PWA, or who don’t allow room for PWA’s turn. In addition, PWA
knowing that certain situations will be “a bit rushed or a failure” (P5), or interacting with someone who is uncomfortable communicating with them, can also have a negative impact. One participant summarized PWA’s negative experiences with others as “a vicious cycle sometimes of, maybe not being successful, in a communication interaction. Not being supported or just having…communication breakdowns” (P7).

3.3.5 PWA experiencing negative thoughts and feelings about communication breakdowns and others’ perceptions of them

PWA having negative thoughts and feelings about potential communication breakdowns and/or how others might perceive them when they try to communicate was indicated by many respondents to have a negative impact on confidence in communication. For example, some participants mentioned PWA’s perception of others thinking that they are “dumb” (P4), “stupid” (P1, P4, P12), or “mentally incapable” (P10). As one participant put it, PWA may be “afraid to try to communicate because they don’t want to be perceived as less than they are” (P3). In addition, PWA not wanting to use “an app, or a piece of paper, or a communication tool because that makes them look different” (P3) was thought to be an issue. Others commented on emotional aspects, such as “dealing with anxiety and fear around a communication breakdown happening again” (P7) and “the demand capacity aspect of it…I mean people have strategies that they might not use in those situations because they’re overcome” (P5). PWA blaming themselves for communication breakdowns instead of thinking of communication as a “two-way street…to make this a good communication experience” (P5) was also thought to be a detractor of confidence in communication. Another participant noted that for some PWA, there is a “self-fulfilling prophecy” in that they anticipate having difficulty, resulting in them “getting their nervous system up so they are so stressed they can’t get the words out” (P12).

3.3.6 PWA experiencing a loss of sense of self and of function

Most participants expressed that PWA’s post-stroke experiences of loss detract from their confidence in communication. Some respondents indicated that these experiences have a
negative impact on PWA’s sense of self (e.g., “PWA not being happy with where they are post-stroke, wanting to get back to “the old me,” being less accepting of “the new me,” feeling shame in how they now talk” [P3]), such as not feeling comfortable returning to an enforcement/protection profession due to feeling as though they do not have any authority anymore. Some participants highlighted the importance of communication to PWA’s sense of self (e.g., “the MORE communication was your thing, the more of yourself you’ve lost” [P2]). According to another participant, “even if they’re not as much affected because communication is not part of their personality…it goes to their role…because of the importance of communication” (P11). Other participants described emotional consequences of PWA’s change in function, including “being in a huge grief process right after their stroke, being very angry and upset” (P4), “having feelings of depression” (P7), and “being frustrated about the loss of function” (P6). Such feelings can be brought forth when PWA are “out there, in the big, bad world…it’s a scary place for them because, they can be…exposed…every time they’re exposed…it’s like a blow about what’s happened to them and how much they have lost” (P11). Moreover, for some PWA, “family support…can also illuminate their deficits, or their…areas of loss” (P8) (e.g., a loss in family roles and relationships). Finally, one participant indicated that the impact of loss of communication function on confidence in communication “depends on how severe the aphasia is” (P14); if very severe, and/or if there is an additional apraxia, this was thought to decrease PWA’s confidence in communication.

3.3.7 PWA having unrealistic expectations

One participant discussed the issue of PWA having unrealistic expectations, in which a person is in denial about where their communication abilities are, and have expectations that are too high. In addition, PWA who are early in the rehabilitative process may be “waiting to get better…waiting for something that [is]n’t gonna happen”, which may be demonstrated by saying, “you can’t ask me to do that because I can’t” (P13; i.e., the person may decline to perform a communicative task under the assumption that their impairments prohibit them from doing so). These unrealistic expectations were thought to mean that “you’re likely always gonna fail” (P13) in communication.
3.3.8 PWA “being perfectionists” and avoiding risk

Several participants commented that PWA resisting risk could minimize their confidence in communication. Most of the comments in this category linked this to PWA having unrealistically high self-expectations (e.g., “PWA being perfectionists, and being less willing to put themselves out there and take risks” [P7]). Some participants remarked upon the consequences of this for rehabilitation (e.g., “PWA resisting risk, so they won’t be able to use what the S-LP is offering” [P8]; “PWA who have to be perfect sometimes won’t say very much, and they won’t get very much practice, and they won’t improve at a very good rate” [P11]).

3.3.9 PWA’s focus on deficits and comparison to pre-stroke function

Some participants reported that PWA being focused on their loss of function is a detractor to their confidence in communication (e.g., “being stuck on what they are missing” [P8] and being “too focused on their lack” [P13]). PWA comparing their communication to how it was pre-stroke (e.g., “saying, ‘no, it’s just not that good,’” even if they are able to have a conversation with someone [P11], or PWA “being shy about communicating because they can’t do it in the way they used to” [P5]) was mentioned by some participants. Similarly, PWA saying or thinking “I just can’t do that” (P8) or “I can’t do this” (P13) was contrasted with PWA “looking at what they are able to do, or looking at a way they could do it differently” (P8) and “making the transition to say, “yes, but I can do this…”” (P13). Finally, having a mindset of wanting to “get better” (P5), in that PWA are focused more on a stimulation approach, rather than a life participation approach, was thought to detract from confidence in communication.

3.3.10 PWA’s learned non-use of communication

One participant introduced the concept of “head-turning syndrome” (P3), in which PWA turn their head towards a partner when asked something, demonstrating that they are “expecting their partner to speak, or answer for them.” This behaviour was thought to be the result of PWA learning not to attempt to communicate “if something complicated comes their way” (P3),
because someone else will take their turn. This participant also explained the concept of “learned non-use,” in which “PWA…[think] that not using their abilities is the way things are” (P3).

3.3.11 Others’ perceptions/expectations undermining PWA’s confidence

The influence of other people’s perceptions of PWA on PWA themselves were reported by some participants to minimize their confidence in communication. Comments included others expecting less of PWA, and S-LPs being overprotective of PWA (e.g., “when [we] see things through our S-LP lens, we risk, we risk seeing more of the impairment than, than maybe we should…But, over-protective is probably just as undermining to confidence as under-protective…equally risky to, to damaging people’s confidence is, is not allowing people to fail” [P13]). One participant described the impact of this as “the battle between others’ view that PWA are not competent, versus PWA’s belief that they are competent, impacting self-worth and identity,” and others’ perceptions of PWA’s competence overpowering PWA’s sense of self by creating uncertainty and insecurity.

3.3.12 PWA’s personal factors

A few participants mentioned pre-stroke factors as potentially having an impact on confidence in communication for PWA. One factor was pre-stroke personality, such as PWA being shy, introverted, and or reserved before their stroke, or having a temperament that causes them to not try again “if it’s too difficult” (P5). One participant commented on PWA’s mental health (i.e., “if they had mental health issues before, they might have negative self-talk” [P6]).

3.3.13 Others’ lack of knowledge of aphasia

“PWA having a communication impairment in a community that doesn’t know how to work with it” (P1) was considered to be a detractor of confidence in communication for PWA by nearly all participants. The public’s lack of knowledge of aphasia was cited as a reason for PWA worrying about what others think of them and not getting the communication support that they need in order to participate. For instance, “the person at the grocery store maybe has no idea how
to interact with that person [with aphasia], [the PWA] has mustered up the confidence to actually

go into this grocery store and they’re probably tired, because it’s a lot of work, and now they’ve
gotten to the till, and the person behind the till maybe ruins the experience for them and now
they have no confidence to ever do it again” (P6).

3.4 Role of S-LPs in working on confidence in communication for PWA

Codes pertaining to the role of S-LPs in working on confidence in communication with

PWA are listed in Table 3.4. Eighty-eight codes were revealed during analysis, which were

subsequently grouped into 14 categories: increasing PWA’s confidence in communication;

practicing communication skills/strategies with PWA so they can experience success in relation
to communication; giving PWA encouragement, positive reinforcement, and feedback; providing

client-centred care for PWA; counseling and educating PWA about aphasia and their

communication; addressing PWA’s emotions and mood and helping them get treatment from a
counseling or mental health professional if need be; educating others about aphasia and training
communication partners on how to support PWA’s communication (e.g., family, other health
professionals, individuals in public service, community workers); recognizing PWA’s
identity/personhood/sense of self and targeting it in interventions; supporting PWA’s
generalization of skills across people and environments; supporting PWA to find appropriate
opportunities for life participation and identifying barriers to participating; supporting PWA’s
independence; supporting PWA and/or their family members in self-advocacy about aphasia;
advocating for more time for S-LP services for PWA at every stage in the continuum of
recovery; and challenges to role fulfilment. The subsections below describe each category in
detail.

3.4.1 Increasing PWA’s confidence in communication

Nearly half of participants reported that one role of S-LPs is to work with PWA on
increasing their confidence in communication. This included assessment (e.g., with the CCRSA
or the ALA), treatment (e.g., making it a therapy goal), and education (e.g., “educating
everybody about confidence: the [healthcare] team, the family members, the client with aphasia, who might not even know that they don’t have confidence in communicating” [P4]).

3.4.2 Practicing communication skills/strategies with PWA so they can experience success in relation to communication

Several participants indicated that S-LPs have a role in practicing communication with PWA (e.g., working with scripts, practicing AAC in a safe setting, practicing gestures and written words, and practicing activities such as booking taxis, giving wedding speeches, and making emergency phone calls). Many participants believed that helping PWA to use diverse ways of communicating in order to enhance their ability to express themselves and understand others is a role for S-LPs in supporting PWA’s confidence in communication. This included S-LPs practicing communication with PWA in different environments. However, if S-LPs are not able to work one-to-one with clients every day (e.g., in an inpatient rehabilitation program), having volunteers, caregivers, and an S-LP assistant practicing PWA with them “would be the ideal…situation” (P15).

The importance of using communication strategies in acute care to reveal PWA’s competence and allow them to experience success as soon as possible post-stroke was highlighted. Other participants indicated that finding appropriate communication strategies and tools for PWA and cueing them to use them is a role for S-LPs in working on confidence in communication for PWA. One participant introduced the idea of “prosthetic flexibility,” in that communication strategies become a “routine compensation” (P8) so that PWA are more flexible about whether or not they are using verbal communication.

Other participants commented that working on language abilities with PWA is a role for S-LPs in working on confidence in communication. One participant indicated that sufficient, appropriate speech and language therapy resulting in “progress no matter how small…will add confidence” (P10), with another mentioning work on higher-level language (e.g., literacy, problem-solving, memory) with PWA who want to go back to work. Finally, building awareness and insight with PWA who have deficits in those areas was thought to be important in ensuring they know about their communication difficulties and that they need to use communication strategies “in order to get their message across” (P15).
3.4.3 Giving PWA positive reinforcement and feedback

Most participants indicated that giving positive reinforcement and encouragement to PWA is a role for S-LPs in working on confidence in communication. Comments included S-LPs telling PWA that they believe in them, letting PWA know that interactions with others “might not be successful, and that’s okay,” (P4) but to keep trying, and talking about how much PWA have improved and supporting them in feeling good about their progress. Providing positive reinforcement to PWA (e.g., when they achieve a goal, or when they try very hard to use a communication strategy, even if it did not work) was also mentioned. S-LPs providing “pep talks” (P5) for and being “unconditionally positive” (P8) with PWA were also thought to support confidence in communication. Pointing out PWA’s communication improvement to them was mentioned as a role by some participants (e.g., “when you first started, you couldn’t do this, and now you can do THIS” [P14]).

3.4.4 Providing client-centred care for PWA

S-LPs respecting PWA’s goals, choices and what they want to do in therapy was thought to be a role in working on confidence in communication by some participants. This included talking about goals with a spouse or caregiver, and setting up a plan for PWA to keep working intensively on their communication while “adjusting to life at home, adjusting to this new you” (P3). Others mentioned tailoring their interactions with PWA depending on the client (e.g., for “clients who are a bit more shy or have a bit more, a, a different personality, I find…as a speech pathologist we have to do a lot more coaching, a lot more encouraging, a lot more practice. A lot more repetition…Just, a lot, a, a bit more support. So I don’t…fade the support as quickly, I guess, in our sessions or outside of the therapy room” [P4]). Two participants commented that the WHO’s ICF model and the A-FROM are relevant in working with PWA (e.g., S-LPs “creating programs that really look holistically at the, the client and puts them right at the centre…how are we targeting each of those four domains.” [P1]). Finally, one participant highlighted the importance of knowing whether and when to address confidence in communication with PWA (e.g., when they reach “the accepting phase…of the grief process” [P4]).
3.4.5 **Counseling and educating PWA about aphasia and their communication**

A broad range of comments focusing on educating and counseling PWA about aphasia and their communication, starting in acute care, were identified (e.g., “What is aphasia? What does your aphasia look like? How does it affect your day? Like, how has it changed from before? What did you do before that you can’t do now? Let’s talk about that and why” [P12]). In acute care, according to one participant, in “that little window of opportunity” post-stroke, “the biggest role we [S-LPs] can give people is a solid foundation to understand that, that, y’know, this is, that whatever their communication is like now is not how it’s going to be.” (P13). Additionally, counseling PWA about what they can expect in the future was also thought to be a role in working on confidence in communication (e.g., “counseling is…all about helping PWA to come to terms with the change in their life, and grieving the loss of their previous communication person, and trying to accept what their communication future looks like” [P12]). Several participants mentioned the role of S-LPs in “fostering a sense of hope” (P1) and “keep[ing] PWA hopeful and focused on a brighter future” (P3) through education and counseling. A related idea that emerged in some interviews was “showing them that it’s not too late…we need to, build that confidence in “I’m not done recovering”” (P3). The concept of “teachable moments” was introduced by one participant, which refers to helping PWA understand that there will be “peaks and valleys… in their performance,” and “how to set [themselves] up for success” (P6). S-LPs counseling PWA around communication breakdowns, building the expectation that “it’s not gonna go perfect” (P8), discussing how they feel about them and/or identifying what they could do differently next time, was discussed as a role by some participants. Finally, S-LPs making PWA “aware that their recovery is not dependent on [S-LPs]” was highlighted by one participant.

3.4.6 **Addressing PWA’s emotions and mood and helping them get treatment from a counseling or mental health professional if need be**

Two participants indicated that if PWA have depression, the S-LP’s role is to assist the PWA in getting treatment for this. In reference to emotions and mood, one participant stated that “it’s important to know when it’s outside of your scope or too much for, y’know, you to handle.
as a clinician, and with the client’s permission, y’know maybe exploring whether they want to talk about this with another professional who’s more suited to the role of, say a counselor or a psychologist or a psychiatrist or whatever it may be. To address some of those other issues, and, you know probably reaching out to that clinician and asking them if they would like support with supported communication, or other ways so that the person with aphasia would have confidence to speak about those issues with that other clinician” (P6). On the other hand, other comments indicated that “there is no harm in an S-LP calling an emotion what it is” (P6), and that “sometimes, you, you are one of the few people that the person with aphasia can communicate with… so, you can, you can actually help them, sort of, communicate and actually get out some of the emotions and feelings they have” (P11).

3.4.7 Educating others about aphasia and training communication partners on how to support PWA’s communication (e.g., family, other health professionals, individuals in public service, community workers)

Most participants indicated that communication partner training and education is a role for S-LPs in working on confidence in communication for PWA. Comments in this category touched upon this role across the continuum of care, from acute care to community, and with a variety of communication partners (e.g., family members, friends, other professionals who work with PWA, and members of the community at places that PWA frequent). In acute care, S-LPs providing education to PWA’s families was thought to be important (e.g., to help them to be confident in communicating with PWA so that the confidence of the PWA can improve). Ensuring other staff in acute care know how to successfully communicate with PWA through modeling and the provision of communication resources was thought to be important in supporting the PWA to be involved and engaged in their own care (e.g., by posting over-bed signs of what works and what does not when communicating with a particular PWA). Similarly, in the rehabilitation setting, S-LPs providing education sessions about aphasia and how to increase PWA’s confidence in communication to other staff was recommended. In the community, supporting people in PWA’s environments to cue them to use communication supports so that they can be more successful was mentioned as a role for S-LPs. This included S-LPs modeling for other professionals in joint sessions with PWA, and providing education about
aphasia and how to better communicate with PWA to colleagues. The importance of educating PWA’s communication circles was emphasized to create “a culture of confidence” (P12) in which PWA’s communication partners have appropriate expectations of them and know how to support them so that they can communicate in a successful environment. Training those close to PWA was emphasized so that PWA can experience success with “their own important people” (P2). Three participants also mentioned increasing the confidence of PWA’s communication partners in communicating with PWA as an S-LP role.

Nearly half of participants mentioned that S-LPs raising awareness about aphasia and providing education to the public, including all levels of public service, is a role for them in working on confidence in communication for PWA, so that they understand that “because somebody can’t express themselves or can’t express themselves quickly, or has trouble understanding, doesn’t mean that they’re stupid, or doesn’t mean that they can’t make decisions on their own” (P12). As one participant explained, this may have an impact on confidence in communication for PWA: “training and education is a big piece and I think that can help the person with aphasia have confidence, to know that…people understand (P7). Some participants mentioned specific ways to educate the public, such as S-LPs doing an aphasia campaign so that aphasia would be in “everyone’s eyes and ears” (P10) and S-LPs supporting PWA in using communication alert cards with the public.

3.4.8 Recognizing PWA’s identity/personhood/sense of self and targeting it in interventions

Acknowledging PWA’s personhood, particularly when they are in acute care, was identified as a role for S-LPs in working on confidence in communication. According to one participant, “it starts from the moment you meet the client” (P6) because “you can instill confidence in someone just by the way you interact with them. So, y’know, just being respectful and understanding what they might be, experiencing without putting words in their mouth, so to speak. Letting them tell their story in their own way.” Similarly, another participant commented that “it’s really about validating their, humanity, their intellect, saying “you are, you are still you” (P3). Identifying ways of fostering PWA’s sense of self throughout assessment, treatment, and discharge was also highlighted, including helping PWA get to their “new normal” (P1). Addressing PWA’s personal sense of self in therapy included S-LP programs which are “gonna
make people just feel better about themselves” (P1), S-LPs helping clients feel like contributors through storytelling, and acknowledging change in the PWA while pointing out what has remained the same.

3.4.9 Supporting PWA’s generalization of skills across people and environments

Several participants indicated that S-LPs assisting PWA in using their communication skills “in the outside world” (P14) (i.e., outside of the clinic) is one of their roles in working on confidence in communication. This may be supported through talking to family members about how to help PWA with transferring skills to an everyday environment (e.g., a restaurant), and providing more independent clients with homework to “put yourself out there, your communication out there” (P12), and following up to see how it went. Some participants commented on S-LPs supporting PWA in practicing skills across environments and functional situations (e.g., “just getting outside of the therapy room. So, like I said, if we would practice something like “I want coffee” in my therapy room, we wouldn’t do it every single day, we would try to get out and generalize it as soon as possible” [P4]).

3.4.10 Supporting PWA to find appropriate opportunities for life participation and identifying barriers to participating

Most participants commented on S-LPs having a role in helping PWA to re-engage in community life and/or facilitating their participation in activities involving communication. Comments included S-LPs supporting PWA in getting out into the community (e.g., going out for coffee with them), using the LPAA approach to guide therapy for PWA, and “helping PWA to find opportunities to communicate in safe environments” (P3) (e.g., where they have communication support that facilitates their success). Two participants highlighted the importance of supporting PWA in participating in their lives and “get[ting] them back to what they want to be doing” (P7). Some participants thought a role for S-LPs is to identify barriers to PWA’s participation so that they can be addressed. Moreover, building opportunities for PWA’s success in daily interactions, using concepts of SCA™, was thought to be important. For PWA
living in long-term care facilities, looking for opportunities for them to participate in
programming and activities at their facilities (e.g., using AAC) was suggested as a role for S-LPs
by two participants. In the community, S-LPs, with the assistance of social workers, arranging a
job or volunteer position in a supportive setting, was thought to help them see that they are “still
capable of doing many things” (P12).

3.4.11 Supporting PWA’s independence

Encouraging PWA to be independent communicators and to be accountable for their own
rehabilitation was also reported to be a role for S-LPs. Some comments suggested that S-LPs
identify and set goals with PWA and hold them accountable to practice, so that PWA are
creating their own “action plan” (P6), then following up on it. In addition, S-LPs identifying
PWA’s learned non-use, and setting goals to eliminate it, was also thought to be a role for S-LPs
in working on confidence in communication. Finally, one participant mentioned “dignity of risk”
(P1): encouraging PWA to take chances and try new things.

3.4.12 Supporting PWA and/or their family members in self-advocacy about aphasia

Three participants indicated that a role for S-LPs in working on confidence in
communication for PWA involves advocacy, or self-advocacy. Encouraging PWA to educate
others about their communication impairment (e.g., by using a communication alert card, or
working closely with family members to support them in advocating for their loved ones with
aphasia), were some of the ideas expressed in this category.

3.4.13 Advocating for more time for S-LP services for PWA at every stage in the continuum
of recovery

Several participants commented that S-LPs having more contact with PWA and their
family members in acute care, and having more time with PWA across the continuum of care,
would be ideal for S-LPs as a way to support confidence in communication. Two participants
believed that a role for S-LPs is to advocate for more time with PWA at all stages of recovery so that they have more opportunity to receive S-LP services and support: “not just like, “sorry, y’know, we see you for six months and you’re out the door”” (P13).

3.4.14 Challenges to role fulfilment

Three participants mentioned that performing communication screens or assessments, and setting goals to address basic needs, are prioritized in acute care; according to one of them, “confidence gets way less priority” (P4). The comments in this category highlighted S-LPs’ role in working on communication in acute care, as opposed to confidence in communication for PWA, with an indication from two participants that the former made focusing on the latter more difficult (e.g., “increasingly in the inpatient population it’s all about discharging clients as quick as possible and not having the time” [P15]). S-LPs not being aware of confidence as part of the therapeutic process was also mentioned as an issue: they may be “tuned into a very limited style of interaction, in a very set environment”, such that a client may not be able to reproduce a communicative behaviour outside of the clinic. This was attributed to S-LPs’ education being focused on an impairment-based model, in which they are taught to “scientifically word [their] goals and interventions…Confidence doesn’t really fit into that model” (P3).
Chapter 4: Discussion

In this chapter, I will discuss S-LPs’ perspectives on confidence in communication for people with post-stroke aphasia. Participants’ definitions of the meaning of confidence in communication for PWA, factors they believe help with or detract from it, and what they perceive S-LPs’ role to be in working on confidence in communication with this population will be synthesized. This study aimed to address the gap in the literature on confidence in communication for PWA. This was driven by findings such as increasing confidence being identified as a research priority by stroke survivors, including PWA (Pollock et al., 2014). Moreover, PWA have reported reduced confidence in social situations (Horne, 2016), and some authors have argued that low self-efficacy may decrease PWA’s engagement with rehabilitation (Biel et al., 2018), which may have implications for their recovery. This study highlighted perspectives which are consistent with Bandura’s (1997) self-efficacy theory, as well as speech-language pathology literature on the impact of aphasia on identity and self-concept (e.g., Shadden, 2005; Hinckley, 2006).

4.1 Meaning of confidence in communication for PWA

Although the definition of “confidence” in this study consisted of self-esteem, self-efficacy, and input from the environment that influences beliefs about one’s capabilities (Horne, 2016), self-esteem did not feature largely in participant’s comments about facilitating confidence in communication for people with aphasia. Rather, several of the identified categories are consistent with Bandura’s (1997) self-efficacy theory. This may be due to the fact that S-LPs were interviewed in the present study, as opposed to PWA themselves, as was the case in Horne’s (2016) study. Moreover, Horne (2016) interviewed stroke survivors with and without aphasia, and asked participants about daily activities post-stroke in general, without a focus on communication.

Several of the categories in the topic area of the meaning of confidence in communication were concerned with behaviours that participants thought indicated that PWA are confident in their communication. For instance, many participants indicated that PWA being willing to put themselves out there and participate demonstrates confidence in communication. This appears to
be consistent with a component of Babbitt and colleagues’ definition of communication confidence: “a feeling about one’s power to participate in a communication situation” (2011, p. 727-728). As previously discussed, the authors posit that improved communication confidence can result in greater life participation. Although their definition refers to a *feeling* as opposed to a *behavior* (i.e., participating in a communication situation), it may be that the feeling precedes or accompanies the action.

Participants also commented on cognitive and affective indicators of confidence in communication, such as PWA’s beliefs, perceptions, and knowledge about communication. This category encompassed cognitions that suggest a strong sense of self-efficacy in PWA, such as believing in their communicative ability and their ability to impact their own care. In addition, not attributing failure to being “a failure”, but rather to having failed “locally, right here” (P13) is reminiscent of the finding that self-efficacious individuals attribute lack of success to environmental factors or inexperience as opposed to lack of ability (Bandura, 1997).

PWA accepting themselves and their communication abilities is a category in which several comments about identity emerged. Participants suggested that PWA re-negotiating identity by acknowledging post-stroke communicative change and “finding harmony between the old self and the new self” (P1) indicates confidence in communication. This is in accordance with Shadden’s (2005) and Hinckley’s (2006) arguments that re-negotiating identity/self-concept is important to quality of life for PWA. It is also consistent with Babbitt and Cherney’s (2010) definition of identity, which includes self-efficacy and communication confidence; in the present study, however, participants have described identity re-negotiation as a component of confidence in communication.

Some participants had a sense of confidence in communication being an internal factor, such as having an outgoing personality, or as “something that you create for yourself” (P7). These comments suggested that it is something that is intrinsic to the PWA, and may be a pre-existing factor or something that is “found” (e.g., “…finding strength that leads [PWA] to become very independent, very strong people” [P13]). “Confidence” as a pre-existing personality characteristic or as a function which can be impacted by stroke is considered by the World Health Organization's (WHO [2001]) International Classification of Functioning, Disability, and Health (ICF). The ICF is an internationally recognized framework used to guide service delivery, including for PWA. Specifically, confidence is considered a “Personal Factor” when it pertains
to a pre-stroke personality factor. Confidence issues which arise post-stroke (e.g., as a result of aphasia) are classified under “Body Functions” as a “Mental Function”; confidence may also be classified this way if it is linked to a pre-stroke mental health condition, such as depression (Threats, 2007).

Discussion of topics which were not included in the interview topic guide was introduced by some participants. For example, one participant commented on the lack of awareness of one’s difficulties which may occur in people with Wernicke’s aphasia, resulting in overconfidence. In contrast, some participants commented on what a lack of confidence in communication, or variation in confidence in communication, looks like for PWA. Comments reflected what may be considered evidence of a weak sense of efficacy, such as not participating in communication activities (or deferring participation to someone else), or making comments indicating a belief that they cannot successfully communicate. Comments about variation in confidence indicated that PWA appear to be confident in some environments (e.g., an aphasia group) but not others (e.g., in the community). This raises the question of why PWA’s confidence may vary across environments. One factor may be the support available in an environment such as an aphasia group, which were found to help with confidence in communication in this study (see section 4.2.1).

4.2 What helps with and what detracts from confidence in communication for PWA

4.2.1 Communication support, and lack thereof, for PWA

Participants from this study highlighted the following as helpful for confidence in communication for PWA: communication support for PWA, PWA having trained communication partners, and PWA having opportunities to participate in their communities. One participant emphasized that PWA feel particularly comfortable in communicating with their S-LPs due to S-LPs’ ability to facilitate their communication. Examples of communication opportunities included everyday interactions, such as PWA communicating with friends, family and members of their communities. This suggests that PWA’s successful participation in conversation is seen by participants as important to PWA’s confidence in communication. Although a variety of approaches have been described as such, conversation therapy may be
defined as “direct, planned therapy that is designed to enhance conversational skill and confidence using activities that directly address conversation and focus on changing behaviours within the context of genuine conversation (Simmons-Mackie, Savage, and Worrall, 2014, p. 512). A qualitative review of the literature on conversation therapy for aphasia by Simmons-Mackie, Savage, and Worrall (2014), which included communication partner training and group intervention approaches, indicated that there is insufficient evidence to make conclusions regarding outcomes for PWA, as the studies used a broad range of outcome measures, making comparison across studies difficult. In addition, a systematic review on the impact of communication partner training for PWA and their communication partners found that there was not enough evidence to determine whether this training influences psychosocial outcomes, including confidence (Simmons-Mackie, Raymer, Armstrong, Holland, and Cherney, 2010). However, as communication is collaborative in nature, PWA’s success in interaction, as well as their access to social participation, is impacted by how others interact with them (Simmons-Mackie and Damico, 2007).

The finding that PWA having support, understanding, and inclusion from others, such as peers in aphasia groups, is deemed helpful to their confidence in communication is consistent with one study’s findings on PWA’s confidence after receiving group communication treatment. Elman and Bernstein-Ellis (1999a; 1999b) conducted qualitative interviews with participants with aphasia, which revealed that PWA felt more confident in their communication abilities post-treatment. Family members of these participants were also interviewed, and they reported increased confidence and motivation in their significant others with aphasia. This was evidenced by changes in PWA’s behaviour (e.g., a participant with limited verbal expression going to a restaurant by himself and ordering a meal). The authors suggest that these changes were due to the “curative power of the groups” (Elman and Bernstein-Ellis, 1999b) – the communication modeling, practice, and encouragement provided by group members to each other.

Lack of communication support was linked by some participants to others’ lack of knowledge of aphasia. Comments in this category reflected the difficulties PWA may have in interacting with members of the public that do not know what aphasia is and do not know how to accommodate PWA in their communication. This, in turn, was thought to contribute to PWA’s concerns about how others view them, as well as PWA having unsuccessful interactions in their communities (e.g., while trying to check out at a grocery store).
Related to PWA’s experience of failure is others not helping with, respecting, or accepting PWA’s communication. Central to the comments in this category was the notion that other people not making accommodations for PWA to participate, especially in acute context regarding their own care, is deleterious to confidence in communication. Such lack of accommodation indicates people’s beliefs about the competence of PWA, which may impact PWA’s beliefs about their abilities.

PWA’s self-esteem may be impacted by negative interpersonal interactions. The influence of contextual and interpersonal factors on interlocutors’ perceptions and reactions to an interaction has been addressed by Communication Accommodation Theory (CAT; Giles, Mulac, Bradac, and Johnson, 1987). This theory posits that speakers adjust their communicative behaviour based on judgments of their interlocutors’ communicative traits, as well as contextual factors such as intergroup history, interpersonal history, and social norms and values (Dragojevic, Gasiorek, and Giles, 2015). Speakers tend to have an “accommodative stance” to interactions, in which they adapt their communicative behaviour to meet the needs of their communication partner.

In spite of an intention to accommodate the other person, speakers may use inappropriate communication strategies in some situations. Communication partners of PWA may overaccommodate to them based on assumptions about their abilities without determining what accommodations would be helpful for the individual (Burns, Baylor, Dudgeon, Starks, and Yorkston, 2015). Overaccommodative behaviours may include interrupting PWA, speaking for them, or correcting them (Blom Johansson, 2012; Simmons-Mackie, 2018). These strategies may be accommodative; however, they undermine the competence of PWA and constrain their role in the interaction, which may have negative emotional consequences for the PWA.

Overaccommodation of older adults has been explained by the Communicative Predicament of Aging Model (CPAM; Ryan, Giles, Bartolucci, and Henwood, 1986; Ryan, Hummert, and Boich, 1995), which is derived from CAT. This model proposes that patronizing communication directed toward elders reduces their opportunities for quality interactions, which negatively impacts their self-esteem, social identity, and physical and mental health. Moreover, this communication style may reinforce negative age stereotypes for both younger and older adults, framing elders as incompetent and dependent on others, which causes the cycle of patronizing communication to continuously recur (Ryan et al., 1995). Although the CPAM has
not been specifically applied to older adults with aphasia, it may inform negative interpersonal interactions experiences by PWA.

Underaccommodative behaviours may also occur when people without aphasia interact with PWA, which involves not changing, or even exaggerating one’s communication style (Simmons-Mackie, 2018). In health care settings, clinicians have been found to over- or underaccommodate PWA (Burns et al., 2015; Burns, Baylor, Dudgeon, Starks, and Yorkston, 2017). With regards to under-accommodation, one study found that family members of PWA reported that their loved ones with aphasia had difficulty understanding physicians whose speaking style was too fast for them to understand. Both PWA and their family members reported physicians being either unaware of the impact of PWA’s communication difficulties on patient-client interactions, or unwilling to attempt to adapt their communication style to support the PWA. Health care providers in general may not be aware of communication disorders such as aphasia or how to accommodate people with these disorders (Burns et al., 2017). Other behaviours on the part of health care staff which may cause difficulty for PWA include the use of close-ended questions and restricting turn-taking (Burns et al., 2015). Blackstone (2015) has highlighted that communication access for all patients, including those who experience communication difficulties, is vital to prevent adverse medical events and improve patient safety, satisfaction, and engagement with and outcomes from treatment.

4.2.2 Self-efficacy: enactive mastery experience

Put simply, “success builds a robust belief in one’s personal efficacy” (Bandura, 1997, p. 80), which is a form of enactive mastery experience. This is consistent with most interviewees reporting that PWA experiencing and recognizing success and improvement is helpful to their confidence in communication. Importantly, a strong sense of self-efficacy is developed through succeeding in challenges that require tenacious effort; if tasks are too easy, then success is the expected outcome, and encountering difficulty becomes discouraging. This is also consistent with some participants’ comments that PWA having goals and challenges are helpful to their confidence in communication, as this is a means of achieving something (e.g., successfully performing a communication task) through continuous effort. Pearl, Sage, and Young (2011) found PWA who participated in volunteering opportunities reported increased confidence, self-
esteem, and “feel good factor” (p. 1812). It is therefore possible that purposeful activities such as volunteering may help to build confidence in PWA. It should be noted that although supporting communicative success for PWA was identified as a helpful factor, some participants commented on the importance of “dignity of risk” (P1), and that S-LPs and family members need to find a balance between being overprotective, and not allowing PWA to take risks, while also preventing situations where they will experience “certain failure” (P13).

4.2.3 Self-efficacy: vicarious experience

The finding that PWA having support from their peers was thought to be helpful to confidence in communication is relevant to self-efficacy in that peer modeling can impact efficacy beliefs. Specifically, seeing people like oneself carry out tasks successfully (i.e., vicarious experience) can increase beliefs that one can achieve similar things (Bandura, 1997). In addition, observing how similar others cope can be a way to learn how to use better strategies, while increasing one’s self-efficacy beliefs. Observing someone succeeding after persevering can reduce the negative of impacts of one’s failures by demonstrating that, if one fails, it may be due to not exerting enough effort, or lack of experience, as opposed to incompetence – “coping modeling, in which people like themselves of limited competence achieve progressive mastery by stick-to-itiveness can help build a stronger sense of learning efficacy than mastery modeling” (p. 100). As such, aphasia groups in which there is the opportunity for PWA to learn from peers’ successful use of communication strategies and management of communication breakdowns may be a means of building self-efficacy in communication.

4.2.4 Self-efficacy: verbal persuasion

As a factor that facilitates confidence in communication for PWA, PWA receiving positive reinforcement, encouragement, and feedback is also likely to support the development of self-efficacy. Verbal persuasion, particularly when it highlights gains that have been made, can be effective in increasing efficacy beliefs. Importantly, individuals who have been persuaded of their efficacy are increasingly likely to trial various strategies and exert sufficient effort in a task when compared to those who doubt their efficacy (Bandura, 1997). This may be relevant for
PWA during communication breakdowns, in which a strong sense of self-efficacy may lead to the PWA persisting in repairing the breakdown by using different communication strategies or supports.

Alternatively, where participants discussed PWA anticipating or perceiving negative feedback from others, this was thought to detract from their confidence in communication. For example, in the category of others’ perceptions/expectations undermining PWA’s confidence, some comments explicitly link others’ perceptions of PWA’s competence to PWA’s perceptions of their competence. According to Bandura (1997), this may occur because “social evaluations of capability are often conveyed indirectly and subtly toward people believed to be of limited aptitude…the individuals at the receiving end of such indirect appraisals are generally well-practiced in seeing through thinly-veiled devaluations…such practices tend to lower recipients’ judgments of their capabilities” (p. 102). Given participants’ comments about PWA’s worries about others thinking they are “dumb” (P4), “stupid” (P1, P4, P12), or “mentally incapable” (P3), it is likely that in situations where PWA perceive this to be the case, their own perceptions of efficacy are threatened.

4.2.5 Self-efficacy: managing negative physiological and affective states

Participants’ belief that the use of SCA/communication supports, tools, and techniques by PWA are helpful to confidence in communication is compatible with the finding that individuals who believe that they can cope with a situation use strategies to change their environment to reduce the risk of having a negative experience. Exercising control over one’s environment therefore reduces stress and anxiety resulting from negative experiences, and is thus a way of managing negative physiological and affective states (Bandura, 1997). S-LPs educating PWA about communication strategies and tools and encouraging their use may be a way to support PWA in exerting control over their communication environments.

PWA having routines and knowing what to expect as a factor that helps their confidence in communication is consistent with the finding that predictable situations reduce stress and anxiety and increases one’s ability to cope with difficulties (Bandura, 1997). The routine of an aphasia group, for example, may provide a framework for lower anxiety and better coping with
communication breakdowns. In addition, the greater the extent to which situations can be predicted and controlled, there is a lesser impact of unfamiliar elements has on anxiety levels.

PWA experiencing negative thoughts and feelings about breakdowns and others’ perceptions of them was another factor that minimizes confidence in communication according to participants. Notably, participants often described the *anticipation* of a negative event as a detractor of confidence in communication (i.e., PWA worrying about having difficulty in communicating prior to attempting to do so). Bandura (1997) defines anxiety as “a state of anticipatory apprehension over possible deleterious happenings” (p. 137). Such arousal can be caused by thoughts about one’s perceived inefficacy to cope with a particular situation. Unfortunately, the anxiety resulting from such thoughts can have a negative impact on performance. This is consistent with one participant’s comment about a “self-fulfilling prophecy” (P12) PWA may experience when they think about potential communication difficulties (e.g., not being able to answer an unanticipated question at the doctor), which results in physiological arousal that reduces their ability to communicate effectively.

4.2.6 Identity, loss, and self-efficacy beliefs

Several participants’ comments were consistent with Shadden’s (2005) concept of “identity theft.” This was most apparent in the category of PWA experiencing a loss of sense of self and of function. PWA grieving the loss of communication ability and being dissatisfied with one’s “new” self were key messages identified in this category. According to self-efficacy theory, people’s beliefs about their inefficacy to successfully perform tasks which are highly valued by them can lead to feelings of sadness (Bandura, 1997). If people experience “irreparable loss” (Bandura, 1997, p. 153), they may become despondent, and stop trying to pursue desired outcomes. In the case of language impairment due to aphasia, preoccupation with loss of ability may contribute to lack of effort to regain communication skills due to the belief that it is not a worthwhile endeavour. In particularly severe cases, this may contribute to feelings of worthlessness and depression (Bandura, 1997).

As discussed above, PWA experience a loss of communicative function after stroke, which can negatively impact their identity. Related to this is PWA’s focus on deficits and comparison to pre-stroke function. This has been referred as a “baseline distortion” by Laidlaw
and colleagues (2003), and can contribute to beliefs that the progress one has made post-stroke is insufficient. Such negative thoughts, combined with the anticipation of failure, can have a negative impact on motivation and function (Bandura, 1997). Those who believe they are inefficacious are likely to interpret unfamiliar contexts as perilous, and may see themselves as likely to fail. The impact of these thoughts on performance may therefore further contribute to negative beliefs about one’s efficacy – a bidirectional relationship (Bandura, 1997). This is of concern for PWA’s participation in communication, as the expectation that one cannot successfully communicate could result in the PWA constraining their own opportunities to do so, thereby reducing their chances of experiencing communicative success which could aid in the development of their sense of efficacy as communicators. However, one participant noted that PWA having unrealistic expectations (i.e., being in denial about their abilities, or waiting for their communication to improve) may eventually detract from confidence in communication, as frequent failure is likely in that case.

4.2.7 S-LPs fostering a sense of hope in PWA

S-LPs providing counseling and education to PWA included the idea that that helping clients or patients maintain a sense of hope assists in PWA’s confidence in communication. Although there is a paucity of research on hope in PWA, there is some literature indicating that it is important to this population (e.g., Bright, Kayes, McCann, and McPherson, 2013). One study in which PWA were interviewed about their experience with hope post-stroke found that participants who experienced a greater loss of identity also had a more difficult time maintaining an active sense of hope (i.e., orienting themselves toward the future [Bright et al, 2013]). It is therefore possible that supporting PWA in having hope for the future plays a role in the renegotiation of identity. This category also contained comments about educating PWA about their communication future with aphasia, with an emphasis on telling PWA that their communication will improve, which appears to be related to the concept of fostering hope.
4.2.8 PWA’s personal factors

PWA’s personal factors were indicated to have an impact on their confidence in communication. PWA having personality characteristics such as extroversion and being willing to take risks were associated with facilitation of confidence in communication. It may be that those who take on opportunities to use their communication also have more opportunities to experience success and progressive mastery – as one participant put it, PWA “who are successful at rehab, who seem to improve the most, are not perfectionists, they’re willing to make mistakes and are able to laugh off their errors and keep plugging away” (P10).

Personal factors are also a consideration in the minimization of confidence for some participants. In contrast to some participants’ comments that PWA being extroverted is helpful for confidence in communication, others indicated that being shy, introverted, or reserved since before their stroke is a detractor of confidence in communication. In addition, one participant indicated that pre-stroke mental health concerns, such as “negative self-talk” (P6), may negatively influence post-stroke confidence in communication.

The duality of the influence of PWA’s personal factors on their confidence in communication can be explained by Threats’ (2007) discussion of how pre-stroke personality traits may interact with a person’s response to disability limitations. For example, one person may have grown up with a “can-do spirit” (p. 75), while another person may not have, which impacts how each person may advocate for themselves. However, pre-stroke personality may change in response to the experience of having a stroke and living with aphasia, and prior methods of coping in response to adversity may not persist post-stroke. Therefore, Threats (2007) recommends that clinicians take into account their clients’ Personal Factors in assessment and interventions, as each individual’s past life experiences and current personality traits will influence how they respond to the functional impact of their disabilities.

4.2.9 PWA’s acute care experiences

Many participants perceived that PWA’s experiences in acute care often have a negative impact on confidence in communication. A common experience which was highlighted was PWA being overlooked as communicators: not being spoken to directly about their own care, not
being facilitated in their expressive communication, and not being listened to. This is consistent with the findings discussed above regarding healthcare professionals’ underaccommodation of PWA in interacting with them (see section 4.2.1). In turn, participants indicated that it is very important to help support PWA’s confidence in communication in this healthcare setting by supporting them in the use of multiple modalities of communication, including compensatory strategies, and involving them in decisions impacting their care as much as possible. Some participants indicated that S-LPs training healthcare staff on how to support PWA’s communication would assist in increasing their confidence in communication. Ultimately, these helpful factors were thought by some participants to reveal PWA’s competence and allow them to experience success in the early post-stroke period, which could be beneficial to their sense of self as they proceed to adapt to life with aphasia.

4.3 Role of S-LPs in working on confidence in communication for PWA

The finding that increasing PWA’s confidence in communication was considered to be a role for S-LPs is consistent with the findings from a study on S-LPs’ goal-setting for PWA and their families, in which interview participants indicated that increasing the client’s confidence was a common goal set for PWA (Sherratt et al., 2011). This therapy target aligns with a social model of S-LPs working with PWA. According to Simmons-Mackie (2000), “a social model of aphasia management is designed to reduce the social consequences of aphasia and promote social communication within natural contexts. Furthermore, a social model is designed to promote the individual’s participation in a social world and reduce barriers to participation” (p. 162). Indeed, other categories in the topic area of S-LPs’ role in working on confidence in communication for PWA were reflected by this definition. One way to achieve this is to focus on conversation therapy, which is “direct, planned therapy that is overtly designed to enhance conversational skill and confidence” (Simmons-Mackie, 2000: p. 170). The individual’s communicative skills and strategies are built upon in this approach to assist the PWA in experiencing successful social interactions. Critical to this therapy approach is the client’s perspective in determining what participation and communication look like for them (Simmons-Mackie, 2000). This relates to the category of providing client-centred care for PWA, in which participants highlighted the importance of integrating PWA’s values into the therapeutic process,
including all four A-FROM domains in developing programs. The A-FROM (Kagan et al, 2008) is based on the World Health Organization’s International Classification of Functioning, Disability, and Health (ICF) and aims to assist in the planning of interventions for PWA, which target domains of living with aphasia in order to support quality of life. An approach which was mentioned as important to confidence in communication for PWA was the LPAA (Duchan, Garcia, Lyon, and Simmons-Mackie, 2001), which emphasizes the goals of PWA and re-engagement in their preferred activities. Both the A-FROM and the LPAA are consistent with the concept of client-centred care, which has been defined in the context of speech and language therapy as: “having a primary focus on the person as opposed to the task, recognizing and valuing personal knowledge and experience as well as the person’s autonomy and competence in terms of decision-making and problem-solving related to both physical and emotional needs” (DiLollo and Favreau, 2010, p. 91). The A-FROM and LPAA each address the importance of individuals’ life experience, goals, and values.

S-LPs counseling and educating PWA about aphasia and their communication was also highlighted as a role for S-LPs in working on confidence in communication. This pertained to the provision of factual information and to addressing negative thoughts and feelings related to communication disability. Counseling and education are both roles for S-LPs outlined in SAC’s (2016) and ASHA’s (2016) scopes of practice. While SAC’s (2016) scope of practice does not define counseling, or the activities of which it consists, ASHA (2016) indicates that this includes providing support (including peer-to-peer groups) to persons with communication disorders and their family members, and discussing, evaluating, and addressing negative thoughts and feelings pertaining to the communication disorder. Other counseling activities which are consistent with participants’ perspectives on S-LPs’ role in working on confidence in communication for PWA include promoting self-advocacy for clients/patients and their family members through building skills in this area and referring patients/clients to other professionals when the need for counseling extends beyond matters related to the communication disability.

As previously discussed, self-concept is closely related to identity, and has been found to be a critical factor involved in adaptation to living with aphasia (Hinckley, 2006). Babbitt and Cherney (2010) included communication confidence in their definition of personal identity for PWA. It is therefore not unexpected that participants commented on identity in the context of
facilitating confidence in communication for PWA, and targeting it intervention as a role for S-LPs.

“Advocacy for the profession of speech-language pathology” (SAC, 2016, p. 3) is another role for S-LPs outlined in SAC’s scope of practice. Some participants discussed this, specifically with regards to advocating for more time for S-LP services for PWA across the continuum of care. This is consistent with findings from a study in which Australian hospital-based S-LPs were interviewed regarding barriers and facilitators to practicing in accordance with aphasia guideline recommendations (Shrubsole, Worrall, Power, and O’Connor, 2018). It is perhaps not surprising, then, that participants indicated that having little time with PWA and their family members, particularly in acute care, is a challenge to fulfilling their role in working on confidence in communication. Related to this was the issue of confidence receiving less priority in acute care than basic and/or short-term communication needs. This finding is consistent with prior research citing insufficient time and/or challenging caseload demands as barriers in the application of clinical practice guidelines for aphasia rehabilitation, particularly in acute care (e.g., Shrubsole et al., 2018). However, clinicians’ perceptions of difficulties and/or lack of ability in successfully implementing clinical practice guidelines have also been found to correlate with a decrease in the uptake of these guidelines in a survey of practices of Australian speech-language pathologists (Young, Shrubsole, Worrall, and Power, 2018).

The results of this investigation could be used to guide speech-language pathology practice in the area of confidence in communication for PWA. In particular, the consideration of self-efficacy and the impact of the environment on PWA’s beliefs about their communicative abilities may inform how S-LPs can best support PWA in their rehabilitation and mitigate factors which impede development of confidence in communication, and therefore psychosocial wellbeing and life participation.

4.4 Study limitations

Measures to increase the rigour of this investigation (i.e., member-checking, peer debriefing, and reflexivity) were used. However, this study has limitations which must be recognized. Self-selection bias may have been an issue, as participants may have elected to be interviewed based on an interest in the research topic. This is an inherent issue with interview
studies, which future research of a different design may be able to circumvent. In addition, information about participants’ cultural and linguistic backgrounds, as well as the geographic region of their service provision, was not collected. Moreover, the results of this study reflect the perspectives of S-LPs on working with PWA, and not the perspectives of PWA. For instance, S-LPs may have inferred certain thoughts and feelings from behavioural observations of their clients. Therefore, the findings of the current study should be interpreted with caution, and subsequent interview research with PWA should be conducted.

4.5 Future directions

Subsequent interview research on this topic may be conducted with PWA, and also their family members, in order to obtain a more comprehensive account of confidence in communication for PWA. Interviews with PWA should include communication supports (e.g., encouraging the use of gesture, writing, drawing, etc. in responding to interview questions), with questions being presented in an aphasia-friendly manner (e.g., avoiding complex syntax, providing questions in written format). As previously discussed, PWA have historically been excluded from research on post-stroke quality of life and psychosocial health, and it is therefore vital to incorporate their perspectives of and experiences with life with aphasia. This will help to inform S-LP services with the goal of improving clinical practice in work with PWA.
Confidence in communication for PWA is considered by S-LPs to be a part of their clinical practice. Factors which help with, and which detract from confidence in communication should be considered in supporting confidence-building for PWA. It may be a not-so-“secret ingredient” (P3) that influences PWA’s life participation and psychosocial functioning.
References


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Appendices

Appendix A: Interview Topic Guide

Experiences with PWA and their confidence in communication:
e.g., Tell me about your experiences with PWA and their confidence in communication.
Meaning of confidence in communication for PWA:
e.g., What does confidence in communication for PWA mean to you?
What helps confidence in communication for PWA:
e.g., What do you think helps PWA with confidence in communication?
What reduces confidence in communication for PWA:
e.g., What do you think minimizes/reduces confidence in communication for PWA?
Role of S-LPs in working on confidence in communication for PWA:
e.g., What do you see as the role of S-LPs in relation to confidence in communication for PWA?
e.g., Have you addressed confidence in communication in your work with PWA?
   If yes, how?/Can you give me some specific examples of how you have done this? How could it be addressed by S-LPs?/What would be the ideal ways in which S-LPs could address confidence in communication when working with PWA?
   If not, should it be addressed by S-LPs? If it should be, how could it be addressed by S-LPs?/What would be the ideal ways in which S-LPs could address confidence in communication when working with PWA?

Additional comments:
e.g., Do you have anything else you would like to add on this topic?
Probe questions will include questions such as:
- Can you tell me more about that?
- Can you give an example of that?

During the discussion of each topic, participants will be asked about differences across the continuum of care, as different care settings have different focuses (Cameron & Gignac, 2008).
Appendix B: Codes and Categories: Meaning of Confidence in Communication for PWA

Behaviours of PWA associated with confidence in communication

**Category**  PWA being willing to put themselves out there and participate/try to communicate

**Codes:**
- PWA being “able to get out there...being able to access their community freely:”
  - social interactions
  - meaningful relationships
  - initiating conversation
- PWA being willing to try to communicate with a variety of people that they used to communicate with before
  - e.g., their family members, food service people, the bus driver, the doctor
- PWA’s willingness to put themselves out there and interact with people despite the aphasia
- PWA not letting their insecurity about their communication stop them from interacting with people and participating in life, even if the interaction is not through language
- The degree to which PWA are going to participate:
  - if they have confidence, then they will participate, and they will be “as active as they’re able to be”
  - when they have less confidence, they are “almost a non-participant”
- PWA getting out there and doing what they need to do:
  - “I gotta go to the bank. So I’m gonna make this work and...hope for the best...And if it doesn’t work, oh well, then I guess I’ll get my wife to come and help me.”
- Conversation groups: PWA showing up regularly and making an effort to be there
• PWA being more confident in pointing out what they want to say
  o e.g., with a TouchChat system
• Confidence might be the “secret ingredient” that drives people to such different outcomes:
  o the PWA who “made a great recovery, he was just confident enough to go out and talk to people”
  o the PWA who “didn’t progress didn’t have the confidence to try”

**Category** PWA taking risks with communication

**Codes:**
• PWA being comfortable in taking risks, participating, and trying
  o e.g., PWA being comfortable enough to trust others (e.g., in an aphasia group), but also being willing to risk failing
    ▪ e.g., at a public speaking exercise
  o “It’s what they’re not afraid of doing anymore:” PWA in groups not being afraid of jumping in somewhere, and if they cannot communicate, they always know they can “bail themselves out somehow”
• PWA being experimental and creative: trying things and failing and being okay with it

**Category** PWA being comfortable to communicate with anybody/anywhere

**Codes:**
• “Being comfortable talking to anybody…anywhere”
• PWA communicating with people who are not aphasia-friendly, who do not know about aphasia
  o e.g., being able to start an interaction in the community

**Category** PWA using/being open to using different communication modalities

**Codes:**
• PWA self-initiating, and being open and willing to use “a whole bunch of different communication modalities”
  o e.g., an iPad app, gestures, writing
• Creativity: PWA “whip[ping] something out and tr[ying] it,” and being “open to using all different…ways of communicating”
• PWA’s communication is similar years later, but their manner is totally different:
  o not being as afraid, and having the confidence that they can use certain strategies that are going to work most of the time
• PWA who use AAC being independent with their AAC strategies or device
• PWA welcoming assistance from a partner to continue to try to communicate in whichever way possible

**Category**  PWA sharing more info, joking around in conversation groups

**Codes:**
• Conversation groups: PWA feeling comfortable and sharing more information and stories with each other, and joking around
• How PWA look and carry themselves in groups:
  o “it’s not that…scared look”

**Category**  PWA persevering/persisting

**Codes:**
• PWA advocating for themselves and what they need
• PWA having the confidence to accept that “it’s not perfect,” but will “persevere to be heard:”
  o multiple attempts
  o making people wait
  o directing communication
    ▪ e.g., “let’s just go on to the next thing”
• When PWA initiate or persist, or assert; “you get a sense that they feel strong”
• PWA who “keep trying and trying and don’t care about how, fully they’re communicating in terms of typical communication. Because they wanna communicate what they have to say”

**Attitudes of PWA associated with confidence in communication**
**Category** PWA’s beliefs/perceptions/knowledge about communication

**Codes:**
- PWA having a base level of faith in their own ability
- A PWA who says, “five, outta five, outta five, outta five!” on a scale such as the Communication Confidence Rating scale, who is confident for someone who has a severe expressive aphasia / “who says…one syllable”
- PWA believing they have:
  - a right to speaking their mind
  - a right to choice
  - a right to be respected
- PWA believing that:
  - they can effect change and initiate change impacting their care, and
  - they can question something impacting their care
- PWA having a sense of hope
  - “This trust that…it’s worth struggling because it’ll get better”
  - PWA perceiving things as being “half-full” not “half-empty:” “it’s exactly the same half-glass of water.”
- PWA telling S-LPs what more confident looks like for them: the person, the place, and the context
- PWA being secure in their knowledge that they will be able to interact with people
- PWA feeling safe/secure in the knowledge that people are “going to continue to acknowledge [their] personhood despite the fact that [they’re] not talking”
- PWA knowing that they have something important to say, and that they want to get it out
- PWA “knowing that if they fail it just means that they’ve failed, right now, locally, right here. It doesn’t mean they’re a failure. It just means, that one didn’t go so well.”
- Perseverance, inner strength, and accomplishment:
  - the knowledge that “I’ve come through this, so I can…do a lot of things,” after having lost so much
**Category**  PWA accepting themselves and their communication abilities

**Codes:**

- PWA finding harmony between the old self and the new self
  - developing a sense of acceptance and peace as to who they are and the abilities they have
  - resolving the tension between what one used to be able to do but now cannot and what one is going to try to do now
- Confidence is a lifelong process for PWA, it could take years to build
  - as their speech and communication improves, so will their confidence
- PWA having trust in themselves
  - e.g., to be willing to be the demo person at a conference in front of a whole audience with an expert
- A huge indicator of confidence: people who are willing to “just say it. Just say, like “yeah I know you can’t understand me, I had a stroke, like, give me a second:’”
  - being aware of the issue and talking anyway; admitting it and accepting it
- PWA “being okay with who they are” and being comfortable being “out there:’”
  - “that doesn't mean they have to necessarily be front and centre with jazz hands…being the centre of attention, but being part of a group. You can be the quieter member, but having that…comfort and and security…and being, yourself.”
- Becoming “better-functioning people with aphasia:”
  - sometimes PWA’s aphasia has not improved, but their confidence has grown with:
    - time
    - understanding of their impairment
    - development of some compensatory strategies for improving communication
bridging the gaps to barriers of communication that they face initially

- PWA being proud of how far they have come
- PWA feeling good about themselves

**Characteristics of confidence in communication in PWA**

**Category**  
**PWA’s lack of and variation in confidence**

**Codes:**

- PWA’s decreased confidence in speaking: not talking
  
  - confidence is part of the ICF model, at the participation level: if PWA do not feel confident in participating in conversation with their family members, then they are not going to do it

- Lack of confidence:
  
  - e.g., a PWA saying “I can’t communicate,” even if they can, and it is just “not the same as before”

- Confidence in communication varies by individual and by degree of severity

- PWA’s decreased confidence in speaking:
  
  - showing some frustration if they cannot get their point across

- Variation in confidence of PWA:
  
  - in an aphasia group or in a therapy environment, where “they’re doing really well,” and
  
  - “in the community or on their own, [where] they don’t do nearly as well because they aren’t trying”
  
  - when their family members are there and they defer to the family member, spouse, or partner to talk for them

**Category**  
**PWA’s personal factors**

**Codes:**

- Previous personality:
  
  - e.g., even though a PWA has “severe aphasia with pretty much no speech:”
    
    - having people come over to visit them
“yeah, let’s just go to [grocery store G] and I’ll order my coffee.”

- “It has a lot to do with personality,” (e.g., having a “super shiny,” very outgoing, very social personality), not letting severe aphasia stop you, and “still really communicat[ing]”
- PWA who had confidence before coming into an aphasia program, and are looking for challenges and ways to push themselves
- Confidence is something that you create for yourself
  - S-LPs can coach and help and encourage PWA as much as possible, although a lot of it has to come from within from the client with aphasia
- “There is definitely something internal. We don’t, we don’t put it there:”
  - PWA finding strength that leads them to become very independent, very strong people

**OTHER**

**Category** Confidence is elusive and ephemeral

- Confidence is “really elusive:” “it’s impossible to a measure…To a degree…”
  - “it’s impossible to say whether the service [the S-LP is] providing is what’s creating the increased confidence, because you don’t see [PWA] in a vacuum”
- A “part of human life, that is a bit more ephemeral” than a percentage or a worksheet

**Category** Overconfidence in Wernicke’s aphasia

- PWA who are overconfident especially if they have Wernicke’s aphasia and that insight piece isn’t there:
  - “…their feedback loop is broken. So they’re not getting what they’re saying:”
    - e.g., “I don’t get it,” “I’m confused”
Appendix C: Codes and Categories: Factors which Help with Confidence in Communication for PWA

**Category** PWA practicing communication and experiencing success/improvement in the clinic and beyond

**Codes:**
- PWA succeeding through their own effort, having the success as a reward
  - e.g., ordering a coffee from Starbucks
- PWA being able to self-evaluate/monitor their progress
  - e.g., noticing when they have successfully used a communication strategy
- PWA having successful interactions will build confidence over time
- Over eight or nine or ten years, PWA going from not being able to say anything for the first two years, to starting to vocalize, then being able to express themselves in sentences:
  - with all those things come:
    - confidence and independence, and
    - the ability to not be afraid of breaking down and not being able to communicate
- The ability of S-LPs to be at the correct level with PWA:
  - to help direct their therapy, if they are being successful or whether they encounter a lot of pitfalls along the way
    - e.g., using errorless learning techniques
- S-LPs reducing barriers to PWA’s success
- PWA having a lot of opportunities and practicing
  - “if you don’t use it, you lose it”
- Having S-LP resources for communication, not dysphagia, in acute care, so that PWA are treated and S-LPs are not “just getting people out the door”
- PWA using the phone to work towards getting more confidence to be able to have phone conversations
• S-LPs practicing communication with PWA in different communication environments:
  o e.g., in an outpatient program taking PWA down the hall to a nursing station to have them interact with a “real stranger”
• S-LPs helping PWA to generalize what they have worked on in therapy sessions with other people
  o e.g., in the community, at a grocery store, coffee shop, or restaurant
• S-LPs doing staged practice or role plays with PWA
• S-LPs working on the impairment level with PWA:
  o helping them to have more fluent speech
  o in inpatient rehab: “in that setting we’re still working a lot on stimulating the impairment areas, to try to facilitate natural recovery as the brain is still healing. And in that stage it’s, I think about, giving them that confidence that they can keep working and they can keep improving. To try to, push that depression away, that’s so common.”

Category  PWA’s use of communication strategies with communication partners

Codes:
• S-LPs building PWA’s confidence through teaching them some strategies and equipping them with some of the right tools
• PWA using partner-assisted communication strategies:
  o they “really open up”; are not “self…criticizing”
  o support from another person: PWA realize it improves their quality of life
    ▪ leads to more confidence, more motivation to use communication supports
• PWA having “the tools to communicate in ways other than verbal language”
  o gaining trust and confidence in the ability to use alternate methods of communication (e.g., technology, books) that can be helpful to them in communicating what they want to say
  o having the tools to train communication partners in the community
• S-LPs having PWA be more flexible about whether they use verbal or non-verbal communication
  o e.g., in aphasia groups: using calendars and prompters “if they get in a jam”
• S-LPs encouraging PWA to use “every single [communication] modality” in acute care
  o having communication supports for PWA, so that that the person feels heard and seen and valuable
  o involving the PWA’s family
• PWA presenting a communication alert card before talking with the public (e.g., a Starbucks employee) to:
  o educate them
  o dispel the stereotype that comes from talking to a PWA
  o erase the initial barrier of “what will people think of me?”

**Category**  
S-LPs’ and other communication partners’ use of supported communication techniques

**Codes:**
• S-LPs using Supported Conversation [for] Adults with Aphasia in clinical practice
  o e.g., acknowledging and revealing competence
• Others’ use of supported communication techniques with PWA (e.g., SCA™):
  ▪ using pictures, pictographs, maps, pen and paper, yes/no boards
  ▪ writing down words
  ▪ using props, so PWA can point to them
  ▪ promoting gestures for PWA who do not have too much limb apraxia
  ▪ others giving PWA more time to communicate
  ▪ others verifying with PWA (e.g., “let me make sure I understand what you’re trying to say”)
PWA being shown how to use and being cued to use alternate methods of communication
- e.g., volunteers and S-LPs in aphasia groups handing PWA a pen and saying, “can you write about it?”
- e.g., a barista cueing a PWA to show them if they have a communication board or app if they want to order a drink at a coffee shop

- S-LPs using supported communication strategies in acute care:
  - “you can see the relief on their face, when you explain it to them”
  - posting over-bed signs of what works and what does not when communicating with a PWA

- PWA learning strategies from peers

- PWA having communication partners who have had some training and education so that they are aware of aphasia and how they can best support PWA
  - e.g., S-LPs training partners, friends, family, volunteers in aphasia groups
  - allows PWA to experience success, which encourages more trial

- Partner training of the PWA’s healthcare team

- S-LPs providing education and strategies to train PWA’s caregivers
  - workshops
  - having sessions with the PWA and the family

- S-LPs modeling for PWA’s families (e.g., in family meetings in acute care):
  - including them in discussions
  - making sure they are able to communicate
  - giving them the chance to communicate and supporting them if they are making attempts
  - managing turns
  - asking authentic questions
  - verifying PWA’s messages
o killing “I’m the interpreter” behaviour (e.g., “I think what he means to say is this”)

- PWA in the community having a communication support person with them
- “A culture of confidence;” S-LPs educating PWA’s communication circles, so that they:
  - understand what aphasia is
  - have the right expectations of the client
  - know how to properly support them
    - to build a successful environment for them

**Category** Accepting, supportive social networks/environments to participate in

**Codes:**
- PWA having a network of support: friends, family
  - e.g., conversation partners or caregivers who are willing to “come in and get the education and work [with] the client [on] some of the strategies”
  - e.g., spouses/partners expecting PWA to communicate but “not expecting perfection and not correcting them”
- PWA’s confidence increasing with their clinician because there is greater safety and S-LP is the profession that can really help facilitate their expression
  - “in the therapy environment, they know the therapist is on their side, is trying to support them, and wants them to do as well as they can”
- PWA having places and social networks where they have security to communicate with people who are understanding of how they communicate
  - Feeling safe/being in a safe environment (e.g., in a therapy room or an aphasia group, camp, or cruise)
  - a safe space for PWA: lots of time to communicate, no distractions or pressure
- Education and opportunity: S-LPs in the community building places and social networks where PWA have security to communicate with people who are understanding of how they communicate
  - e.g., efforts at communication access: making businesses more aware of diverse communication needs
- e.g., LPAA environmental domain: S-LPs providing education so that people understand:
  - what aphasia is
  - that the person’s intelligence is not affected
  - their thoughts and feelings are the same as before, they are just not able to express them
- An “at-easeness” of the other person:”
  - e.g., a patience on the other person’s part, and “an attitude that you’re…really trying” to communicate with a PWA
- PWA feeling like they are accepted and having friends that understand and support them in their communication so they are able to re-engage in those relationships
- Inclusion: the community being supportive of PWA so that they are included
  - a willingness to pay attention and notice how people communicate, and doing your best to respond to it and facilitate

**Category** Others’ recognition of PWA’s identity/personhood/sense of self

**Codes:**
- Recognition of PWA’s personhood: “oh okay, you can still see I’m in here. I’m still in here…I’m still me.”
- PWA’s communication partners acknowledging and revealing competence
  - acknowledgment and inclusion of PWA’s strengths in interaction
  - people always being honest and not pretending that they have understood PWA
- Others recognizing the PWA and still connecting and communicating:
  - having a connection that is not contingent on language
- S-LPs providing services to help clients and others see people with aphasia as competent
- S-LPs helping clients feel like contributors through storytelling
- S-LPs in acute care validating PWA’s humanity and intellect, saying “you are still you”
- PWA having a positive acute care experience can positively impact sense of self, post-stroke journey
  - the medical team in acute care showing PWA that they are still worthwhile people who should be involved in their care
- S-LPs fostering opportunities for negotiation and development of PWA’s post-stroke identity
- PWA creating a new identity, navigating new waters:
  - “finding a purpose that really brings them those same kind of joys and…aspects of life that make them feel good and feel who they are”
    - e.g., volunteer work
- S-LPs helping PWA “to recognize that a lot has changed but not everything.” “pointing out the parts of the person that are still the same”
  - e.g., helping PWA feel like they are being themselves, and that they are using their sense of humour by working with them to feel confident in being able to tell a funny story or a joke

**Category**  Support from other PWA

**Codes:**
- Members of an aphasia group where there is safety and trust:
  - PWA being supported in their communication
- PWA in groups knowing that people will take a lot of time to decode and get their message out, and find out what they are saying
- PWA having peer support
  - Psychosocial support from stroke and aphasia group:
    - “people can gain a lot of confidence knowing that there’s other people out there who are dealing with the same thing”
    - meeting someone who might have a more severe aphasia, but more confidence – “hey, well that person’s going out and doing things, so why can’t I?”
- PWA meeting other PWA:
“the power of groups is when they’re in a group and they see other people also have deficits…and they see how other people work through it…it gives them the confidence to work through it”
  - e.g., PWA seeing other PWA who “can’t say a word” trying public speaking: “well if he can do it, I can do it”
- Communication group members becoming friends to make up for the friends that they have lost

**Category** Opportunities to participate in their communities (e.g., aphasia-friendly resources, programs, volunteering)

**Codes:**
- S-LPs having community services for PWA’s growth and development
  - e.g., conversation groups
    - members “become much more confident,” then start to do other things in the community
      - e.g., yoga classes, volunteering, music
  - setting up opportunities for community re-integration
    - e.g., collaborating with the multidisciplinary team
    - e.g., S-LPs, knowledgeable volunteers, or trusted family members facilitating and scaffolding PWA’s first introductions back to their community
- Programs that are specifically designed to facilitate participation for people with aphasia
- The Life Participation Approach to Aphasia directly and indirectly targets confidence
  - e.g., environmental changes and participation in life
- A-FROM: S-LPs getting PWA as more active participants in a program to help members and their family to see what could be achieved:
  - developing a program with follow-through
  - environment: barrier-free/aphasia-friendly resources to show how communication impairment need not necessarily hold you back if the right supports are in place
• PWA getting in the community
  o e.g., going on community trips with S-LPs and members of the multidisciplinary team (e.g., recreational therapist)
• PWA being successful at getting volunteer positions and having a sense of accountability to work to build confidence

**Category**  S-LPs providing client-centred care for PWA

**Codes:**
• For clients who are a bit more shy, or have a different personality, S-LPs:
  o doing a lot more coaching, a lot more encouraging, a lot more practicing, repetition, and support, and
  o not fading the support as quickly during S-LP sessions or outside of the therapy room
• A-FROM: S-LPs looking at all factors to make the greatest impact for PWA

**Category**  S-LPs providing counseling and education to PWA

**Codes:**
• S-LPs providing counseling and education to keep PWA hopeful and focused on a brighter future
• S-LPs giving PWA “a chance to, express themselves in whatever way they can…addressing any emotions that come up…giving them basically control to communicate”
• For PWA who are really not confident in their skills and just focus on what they cannot do:
  o S-LPs doing a lot of counseling and showing them what they can do
• S-LPs showing PWA that communication can work outside of a quiet, controlled environment with a trained person, and addressing what happens when they leave that environment and there is noise and there are strangers
• S-LPs supporting PWA to take risks when there is a possibility that they will fail:
  o “you can only get confident if you take the risk and you don’t fail”
• S-LPs processing with PWA when something does not go well, so they start to accept it themselves
• S-LPs building the expectation with PWA that “it’s not gonna go perfect” so that they get comfortable with failing, with not being successful every time, so that it does not stop PWA from trying

**Category** Others providing positive reinforcement, encouragement and feedback to PWA

**Codes:**
- PWA getting positive reinforcement from the S-LP
- S-LPs providing affirmations/positive reinforcements to foster clients putting themselves out there and trying again
- S-LPs talking about how much PWA have improved, where they were when they first met and where they are now: supporting PWA in feeling good about that
- PWA getting positive reinforcement from family members
- PWA getting encouragement from “other people in the same boat”
  - e.g., “Wow, you’re sounding so much better” – “that is even more than…clinicians going, “you’re better””

**Category** S-LPs supporting independence and self-advocacy for PWA

**Codes:**
- S-LPs supporting PWA’s independence in outpatient and community work
  - e.g., practicing with and supporting PWA for tasks they want to do and fading the support until PWA are able to do these tasks independently
  - e.g., identifying PWA’s learned non-use and trying to set goals to eliminate that and build skills for a successful independent activity
- S-LPs giving more independent clients homework:
  - to “put yourself out there, your communication out there,” then following up on that and seeing how it went
- S-LPs helping PWA advocate for themselves and to advocate that “I have a communication disorder, I’m still the same person, I’m still intelligent, I don’t have a mental, disorder.”
  - for example, in a communication book, having a page about the PWA helping the communication partner, such as:
    - “ask me yes-no questions,” or,
    - “write down key words for me so that I understand.”
• S-LPs giving PWA skills to ask for what they need, to practice to be confident to book taxis and other basic things themselves, especially if they are alone and do not have any family

• S-LPs doing confidence-generating activities with PWA:
  o initiating non-verbally, and
  o looking for opportunities to get their turn

• S-LPs providing patient-/client-centred care in the rehab setting:
  o PWA having the ability to know that they have agency: “they’re the ones who, can, build their own confidence through the successes that they’ve worked hard for”

• Clinicians letting go as the person who is going to tell PWA how they should and should not communicate
  o e.g., in preparing a workshop for students, and PWA trusting in the clinician, who “trust[s] that they’re gonna be able to do this”

**Category**  
PWA’s personal factors

**Codes:**

• PWA who are successful at rehab, who seem to improve the most, are not perfectionists, they are willing to make mistakes and are able to laugh off their errors and keep “plugging away”

• Personality: PWA being internally motivated to achieve things, being outgoing and more of an extrovert, having no problem with public speaking

• PWA finding the internal motivation:
  o wanting and trying to communicate and trying to use every modality possible

• PWA putting themselves out there in a group by being willing to contribute and participate

• Clients having a sense of hope

• “Accepting that this is your new communication style” is “a huge step in being confident”

• PWA knowing that “this has happened to me, but…this is now my job to work on improving what I want to improve and…re-engaging in my life.”
• PWA trusting the clinician to not ask them to do something that they could not do
• “Whatever gives people their own confidence…depends on who they are:”
  o PWA need lots of support – time, for some people, lots of encouragement for other people, “in your face” for other people

**Category**  PWA having goals and challenges

**Codes:**
• Clients working toward achieving a goal
• PWA having an external motivator: setting the goal to increase talk time (e.g., using ComFit, a wearable talk-time registering device), so that PWA talk more, gain more confidence, and have more successful interactions
• PWA who are high achievers needing someone to challenge them/give them a “man shove” (e.g., to do public speaking)

**Category**  PWA having routines/knowing what to expect

**Codes:**
• PWA having routines throughout the week where they anticipate success, due to the routine supporting the communication
• S-LPs helping PWA to “get over the fear” (e.g., of communicating on the phone) so it becomes “more of a routine than a risk”
• Conversation groups – “there was just a bit of a rhythm to it:”
  o routine, PWA knowing what to expect, talking about respect when PWA came into the group
Appendix D: Codes and Categories: Detractors of Confidence in Communication for PWA

**Category** PWA’s failure in communicating in the clinic and beyond

**Codes:**
- Repeated failures removing PWA’s confidence to try to communicate: “failure’s a lot more powerful, than success”
- A therapeutic session that was not designed with appropriate step-downs, cues, and supports, and the PWA keeps failing and failing and failing:
  - the PWA might start thinking, “I can’t do this, because I keep failing”
- When PWA’s failed attempts result in consequences:
  - not being able to make their choice known, so that they are “stuck” with something they did not want
- When failure happens, PWA letting that person or that environment control their life and dictate what they can and cannot do
- “If you’re overprotective then [PWA] can’t get confidence:”
  - clinicians, spouses, whoever have to stand back and let them fail, and “on the other hand…we can’t let them go to certain failure”
- “A careful balancing act:” “if S-LPs let go to soon…and we push people too much where they can’t go, then they risk failing in a way that is maybe damaging to confidence”

**Category** PWA’s lack of improvement in communication

**Codes:**
- If PWA are not grasping onto the use of strategies
- PWA initially seeing the improvement, but then once they plateau, there is a disappointment because they want to keep improving
- PWA who never improve very much:
  - “it’s not that they’re not trying,” they are so severely affected that it is very difficult to improve to a point where they can develop confidence
- PWA simply having facilitated communication without also having the piece where they are improving: it makes them feel “down and depressed”
**Category** Lack of social/communication support for PWA

**Codes:**

- PWA having a lack of support in communicating
  - PWA not having supportive family and friends to give them opportunities to communicate, or being alone, by themselves (e.g., if they live alone) can be very isolating
  - if a PWA has trouble understanding and the other person is going from topic to topic instead of introducing a subject first and then talking about it
  - if the other person is going a mile a minute, not pausing, and not doing “all those kinds of things that help [PWA] understand”
  - when PWA do not have experience with people outside their immediate environment who are not familiar with their history and being able to “fill in the blanks”
- “Out there in the real world,” little knowledge of, and little skills with supported conversation, and patience; busy people who do not have the time to “problem-solve” what a PWA’s message is
- Relationship between confidence and mental health: when PWA are socially isolated and depressed, they are less confident about their ability to participate socially
- PWA feeling not prepared at all, being “pushed out the door” because of hospital bed pressures, and not getting training and support
- Not enough therapy/rehab to give PWA confidence to feel like they can communicate
- The ultimate goal is for people to go home, and it is usually at a different functional level than they were before, and we just send them on their way – “that’s where the big gap is:”
  - not supporting them for their final transition in order to improve someone’s confidence and make sure that they do return to active living
- PWA not having family or caregiver support to encourage them to use their communication strategies, to use other modalities
• If PWA are not being provided education in the use of strategies

**Category: Others not helping with, respecting, or accepting PWA’s communication**

**Codes:**

• PWA’s negative acute care experiences:
  
  o being overlooked, not spoken to, left lying there with no idea of what was going on

• PWA having experiences with communication partners that are not patient or do not help with any supportive strategies:
  
  o that probably increases their frustration level, which causes “a decrease in the boost in confidence”

• A lot of times, healthcare providers and the general public will not speak directly to a PWA, and will speak differently to them, and somewhat disrespectfully
  
  o would probably lead to a lack of confidence in certain situations and environments

• People not making an effort to communicate with PWA

• Others not allowing room for PWA’s turn

• PWA’s choices not being respected

• Someone who is not comfortable – that immediately sends a message to the PWA, and the interaction becomes much more stressful

• PWA knowing that certain situations will be a bit rushed or a failure

• PWA experiencing “outwardly abusive interactions” in the community by people who do not understand about aphasia and communication disorders

• Well-meaning people who pretend they have understood PWA, therefore dismissing their personhood

• Well-intended spouses of PWA not accepting their non-oral (gestured, printed) communication or correcting them when they have made a good effort

• PWA’s spouses asking them questions that the spouse already knows the answer to
  
  o not expecting information from the PWA
  
  o not expecting the PWA to contribute to their knowledge base
- S-LPs’ condescending or patronizing affirmations of PWA’s performance
- S-LPs and medical professionals telling PWA that they are not going to get better past a certain mark, that they will never get back to their old selves, that they will likely never return to work
  - PWA being devastated because they think they cannot go any further
- Negative experiences: a vicious cycle of not being successful in a communication interaction, not being supported, or having communication breakdowns

**Category**  PWA experiencing negative thoughts and feelings about communication breakdowns and others’ perceptions of them

**Codes:**
- PWA being afraid to communicate because they do not want to be perceived as less than they are
- PWA not wanting to use an app, a piece of paper, or a communication tool because that makes them look different
- PWA dealing with anxiety and fear around a communication breakdown happening again
- Demand capacity:
  - PWA not succeeding due to being overcome by emotional aspects of the situation, causing their communication skills to “shut down”
- When PWA blame themselves for communication breakdowns instead of thinking of communication as a two-way street to make a good communication experience
- A self-fulfilling prophecy:
  - PWA knowing that there may be some questions that they have not anticipated (e.g., at the doctor’s office, and thinking “what am I gonna do if they ask me a question?”) – getting their “nervous system up” so they are so stressed they cannot get the words out
**Category**  PWA experiencing a loss of sense of self and of function

Codes:
- PWA’s sense of self being destroyed by the catastrophic medical event of stroke
  - e.g., a PWA not feeling comfortable working in an enforcement/protection profession anymore because they do not feel like they have any authority anymore
- PWA having feelings of depression; thoughts of “in the past this was what I used to do and I’ve lost that now.”
- “Out there, in the big bad world” is a scary place for PWA because they can be “exposed” and every time they are exposed, “it’s like a blow about what’s happened to them and how much they have lost”
- For some PWA, family support can also illuminate their deficits/areas of loss
  - e.g., loss in a relationship, loss in a role
- “It depends on how severe the aphasia is:”
  - if it is a severe aphasia, and the amount of words that they can get out is minimal, or there is an apraxic component with it, that is going to decrease PWA’s confidence in speaking

**Category**  PWA having unrealistic expectations

Codes:
- A PWA who is in that situation of needing to communicate in the world before they are ready to take that on, and their expectations are too high – a person who is in denial about where their abilities are
- PWA who are relatively early in their rehab process who are waiting to get better/waiting for something that is not going to happen:
  - “…you can’t ask me to do that because I can’t.” – the personal factor’s probably unrealistic expectations, which means you’re likely always gonna fail”

**Category**  PWA “being perfectionists” and avoiding risk

Codes:
- PWA being perfectionists, and being less willing to put themselves out there and take risks
PWA resisting risk, so they will not be able to use what the S-LP is offering

PWA who “have to be perfect” sometimes will not say very much, and they will not get very much practice, and they will not improve at a very good rate

**Category** PWA’s focus on deficits and comparison to pre-stroke function

**Codes:**
- “I just can’t do that:” PWA thinking there is only a certain way that you get it, and not looking at what they are able to do, or looking at a way they could do it differently
- PWA holding on to who they were pre-stroke
  - e.g., “I want to be the old me. I want to get back to normal.”
- PWA who always compare themselves to pre-stroke, saying, “no, it’s just not that good”
  - even if they S-LP says to them “look, we’re sitting here, we’re having a conversation, you’ve told me all these things about your life, I know it hasn’t been perfect, but it’s been pretty good.”
- PWA being shy about communicating because they cannot do it in the way they used to
- PWA having a mindset that they want to get better:
  - thinking more of the stimulation approach, rather than a life participation approach

**Category** PWA’s learned non-use of communication

**Codes:**
- “Head-turning syndrome:” the PWA expecting their partner to speak/answer for them
- PWA’s learned non-use
  - thinking that not using their communication abilities is the way things are

**Category** Others’ perceptions/expectations undermining PWA’s confidence
• “They don’t expect anything of us:” people expecting less of somebody with aphasia

• Others’ perceptions of PWA’s competence overpowering PWA’s sense of self by creating uncertainty and insecurity

• As S-LPs, it is possible to be overprotective:

• “when [S-LPs] see things through our S-LP lens, we risk, we risk seeing more of the impairment than…we should,” and not allowing PWA to fail which is probably just as undermining to confidence as being underprotective

**Category** Others’ lack of knowledge of aphasia

**Codes:**

• PWA having a communication impairment in a community that does not “know how to work with that”
  
  o e.g., “The person at the grocery store maybe has no idea how to interact with that person” with aphasia: “they’ve mustered up the confidence to actually go into this grocery store…they’re probably tired, because it’s a lot of work, and now they’ve gotten to the till, and…the person behind the till maybe ruins the experience for them and now they have no confidence to ever do it again…”

• A lack of education about what communication impairments are and what aphasia is on the part of the general public as well as healthcare providers in general can lead to feelings of lacking confidence:
  
  o PWA worrying “what’s this person gonna make of me?”

**Category** PWA’s personal factors

**Codes:**

• Personality: PWA who were “really shy and introverted” before the stroke, and “didn’t get out a lot…and…weren’t active in the community”

• PWA’s personality and temperament: not trying again “if it’s too difficult”

• Independent patient factors: if they had mental health issues before, they might have negative self-talk
Appendix E: Codes and Categories: Role of S-LPs in Working on Confidence in Communication for PWA

**Category** Increasing PWA’s confidence in communication

Codes:
- One of S-LPs’ primary roles should be assessing, treating, and helping with confidence
  - S-LPs addressing confidence directly (e.g., with the CCRSA):
    - looking at PWA’s confidence levels in different situations with different people
  - S-LPs assessing PWA’s confidence (e.g., with the ALA)
    - to get a picture of how confident they are
    - asking if it is one of the goals they would like to work on in therapy, and
    - brainstorming with the PWA how to work on it
  - picking different settings in which the S-LP and the client can build up that confidence
  - S-LPs using the ICF model to assess and treat PWA’s confidence at the participation level
  - S-LPs doing confidence-generating activities with PWA:
    - initiating non-verbally, and
    - looking for opportunities to get their turn
  - S-LPs educating everybody about confidence:
    - the team
    - the family members
    - the client with aphasia, who might not even know that they do not have confidence in communicating

**Category** Practicing communication skills/strategies with PWA so they can experience success in relation to communication

Codes:
- S-LPs scaffolding things with PWA
• e.g., working with scripts so the PWA can practice and get more comfortable

• S-LPs practicing communication with PWA in different environments:
  o e.g., PWA using a script, written down in advance, and practicing with the S-LP verbally, if that is their way

• S-LPs practicing different scenarios with PWA
  o e.g., making an emergency phone call, such as in a conversation group
  o e.g., preparing and practicing activities such as a wedding speech

• If S-LPs are not able to work with the clients one-to-one every day, some volunteers that can do that, so on top of the caregivers, S-LP, speech assistant, and volunteer, PWA get “tons of practice” – “that would be the ideal…situation”

• S-LPs helping PWA to “get over the fear” (e.g., of communicating on the phone) so it becomes “more of a routine than a risk”

• One of S-LPs’ main roles is to help PWA to be able to communicate, whether it is verbally, or using pictures or gestures
  o any way so that they can communicate and get their point across: that will boost their confidence
    ▪ e.g., doing lots of practice with PWA with strategies that are low-tech (e.g., using gestures, written words)
    ▪ e.g., having a page in a communication book about the PWA helping the communication partner
      • e.g., “ask me yes-no questions”
      • e.g., “write down key words for me so that I understand”
  o S-LPs building PWA’s confidence by giving them strategies that work
    ▪ e.g., writing items down on a shopping list and pulling it out when they are not able to say what they want
    ▪ for PWA who are not able to use AAC, the biggest thing that S-LPs need to focus on is supportive strategies
• S-LPs in acute care revealing PWA’s competence, using communication strategies to make sure that they are having an impact and a say in what they want to happen

• In acute care, picture communication boards do not have to be “pretty and nice and laminated:”
  o S-LPs giving PWA a stack of paper and a Sharpie marker, or
  o just writing down a yes/no board, or
  o drawing some picture of pain, or a toilet, etc., or getting family members to do it,
    ▪ to set up the client for success right away and try to get them to use a variety of communication modalities

• S-LPs having PWA be more flexible about whether they use verbal or non-verbal communication

• Whenever possible, S-LPs offering enough therapy, intensive enough and the right kind of therapy, so that people are making changes, because:
  o someone seeing “progress no matter how small…will add confidence”

• S-LPs working on the impairment level with PWA:
  o e.g., helping them to have more fluent speech
  o e.g., working on higher-level language, literacy, problem-solving, memory, etc. with PWA who want to go back to work

• S-LPs building awareness and insight with PWA: making sure that they know that they are having this difficulty, and they need to use some strategies in order to get their message across

**Category** Giving PWA encouragement, positive reinforcement and feedback

**Codes:**
• S-LPs giving positive reinforcement to PWA
  o if PWA succeed, S-LPs telling them, “let’s be proud of ourselves for achieving the goal”
  o giving PWA verbal reinforcement when they observe PWA trying really hard to use whatever communication strategy they had been working on, and if it did not work, what they can work on next time
• S-LPs giving PWA “pep talks:” “You can actually do this…I’ve seen you do this before, give it a try”

• From a clinician’s point of view…we accept everything. So it’s like unconditionally positive.”

• S-LPs telling PWA that they believe in them

• S-LPs giving PWA encouragement to keep going and to continue to increase their confidence:
  o letting PWA know that “it’s okay” to not have successful communication interactions, “but to keep trying”

• S-LPs talking about how much PWA have improved, where they were when they first met and where they are now: supporting PWA in feeling good about that

**Category**  Providing client-centred care for PWA

**Codes:**

• S-LPs respecting what PWA want
  o S-LPs talking with PWA about what they want to work on
    • e.g., word-finding, reading
    • talking about it with spouse or caregiver if they are there, too
  o As PWA get home, S-LPs helping them to
    • identify what they want to be able to do right away, and
    • set up a plan for them to keep working intensively on their rehab while adjusting to life at home and the “new you”

• S-LPs knowing when and whether to address confidence with PWA, depending on the client
  o e.g., when they get to the accepting phase of the grief process

• For clients who are a bit more shy, or have a different personality:
  o S-LPs doing a lot more coaching, a lot more encouraging, a lot more practicing, repetition, and support, and
  o not fading the support as quickly during S-LP sessions or outside of the therapy room
• S-LPs creating programs that look holistically at and centre the client through targeting each A-FROM domain
  o S-LPs looking not only at the skill or impairment of PWA, but the World Health Organization’s ICF model

**Category** Counseling and educating PWA about aphasia and their communication

**Codes:**
• In acute care, S-LPs giving PWA some terminology, acknowledging that they have had a stroke and it is because of the aphasia that they are having difficulties
• S-LPs providing education about aphasia:
  o Firstly, educating PWA about what aphasia is, because “no-one knows what aphasia is”
• S-LPs connecting PWA with resources, because for many PWA, they have never heard of aphasia:
  o starting with education about what a stroke is, what their aphasia looks like, how it affects their day, what they did before that they cannot do now, and why
• S-LPs doing basic counseling with PWA
  o e.g., active listening
  o “Counseling is…all about helping [PWA] coming to terms with the change in their life, and grieving the loss of their previous communication person, and trying to accept what their communication future looks like”
• S-LPs giving PWA the message that they are going to get better, overriding the message PWA get in hospital that they are only going to see change for six months – not giving people false hope by saying “don’t worry”; “it needs to be a balanced hope”
  o The biggest role for S-LPs in the hospital in the little window of opportunity after PWA’s strokes is giving PWA the solid foundation to understand that “whatever their communication is like now is not how it’s going to be”
• S-LPs showing PWA that “it’s not too late,” and building confidence that they are not done recovering

• Teachable moments: S-LPs helping PWA understand that “they’re gonna have dips and peaks and valleys, rather, in their performance,” and how to set themselves up for success

• For PWA who are very hard on themselves, whose perceived deficits are much stronger than their real deficits: S-LPs counseling them with a social worker (e.g., “yes, it’s not like it used to be… but, look at what you can do”)

• S-LPs building the expectation with PWA that “it’s not gonna go perfect” so that they get comfortable with failing, with not being successful every time, so that it does not stop PWA from trying

• S-LPs analyzing PWA’s failures with them to identify:
  o what they could do differently or
  o what they can control
    ▪ so that failure does not happen again or
    ▪ “happens in a different way that’s less bad”

• S-LPs processing with PWA when something does not go well, so “they start to accept it themselves”

• S-LPs making PWA aware that their recovery is not dependent on their interaction with S-LPs:
  o “all we’re trying to do is give them a little push in the right direction…and it’s a direction that they will need to carry on for years and they will continue to get better for years”

**Category**
Addressing PWA’s emotions and mood and helping them get treatment from a counseling or mental health professional if need be

**Codes:**
• S-LPs helping PWA get treatment for depression and facilitating counseling sessions with social workers or psychologists if need be

• Emotions and mood are not necessarily within S-LPs’ scope of practice, but they come up and they are not something you can “brush aside or
ignore,” but there is nothing wrong with “calling a spade a spade:” if a client seems upset, happy, sad, or angry, calling it what it is

- “Sometimes…you are one of the few people that the PWA can communicate with…you’re almost like a psychologist, psychiatrist, counsellor:”
  - taking time, having tools and strategies to help PWA communicate and actually get out some of the emotions and feeling they have, even at the beginning

**Category** Educating others about aphasia and training communication partners on how to support PWA’s communication (e.g., family, other health professionals, individuals in public service, community workers)

**Codes:**

- In acute care, the S-LP educating the clients and the family members about what aphasia is and some strategies that work
  - S-LPs in acute care teaching PWA’s families and support system to be confident in communicating with PWA in order to improve the confidence of PWA in that early-on situation
  - In the hospital, “quick and dirty:” education for the family and patient about aphasia

- S-LPs making sure that other staff in acute care know how to successfully communicate with PWA through modeling and making sure PWA have resources they need to communicate better so that they have the opportunity to be involved in and engaged in their own care
  - e.g., posting over-bed signs of what works and what does not in supporting someone with aphasia

- “A culture of confidence:” S-LPs educating PWA’s communication circles, so that they understand what aphasia is, that they have the right expectations of the client, and know how to properly support them to build a successful environment for them
• S-LPs in the community supporting PWA by getting people in their environment to cue them to use communication supports so that they can be more successful

• S-LPs training communication partners at every stage of the recovery process: volunteers, community support workers, care aides, rehab assistants, family members, friends, so that PWA “feel safe to open their mouth[s], or try to”
  o e.g., S-LPs in a rehab setting delivering education sessions about aphasia and how to increase confidence to all staff (e.g., doctors, nurses, occupational therapists, physiotherapists, recreational therapists, pharmacists, food service people)

• S-LPs modeling for other professionals if they have joint sessions with PWA
  o S-LPs in the community educating their colleagues:
    ▪ e.g., “this person...they have aphasia, and I noticed that, you made...a note...that they were having trouble understanding you...can I show you a little bit about how you can better communicate with them?”

• S-LPs training communication partners to allow PWA to experience success with “their own important people”
  o S-LPs modeling for PWA’s families around including them in discussions, making sure they are able to communicate, giving them the chance to communicate and supporting them if they are making attempts
    ▪ e.g., verifying PWA’s messages, so the power is always with them
  o S-LPs working with PWA’s family members so that they are listening and able to communicate with the PWA
  o Explicitly addressing family members’ communication with the PWA with them and identifying ways of improving it

• S-LPs increasing the confidence of PWA’s communication partners, and giving them the appropriate communication strategies that work
• S-LPs ideally training the community at places where PWA frequent (e.g., banks, restaurants, stores)
• S-LPs providing education for all levels of public service, including federal public servants, police services, and hospital staff
• S-LPs doing a big campaign across Canada, so aphasia would be in “everyone’s eyes and ears” to increase awareness
• Inclusion: S-LPs educating people in the community so that PWA can interact with the community as people
• LPAA environmental domain:
  o S-LPs providing education so that people understand what aphasia is, and they understand that the person’s intelligence is not affected, their thoughts and feelings are the same as before, they are just not able to express them
    ▪ can help PWA have confidence in knowing that people understand; feeling supported

**Category** Recognizing PWA’s identity/personhood/sense of self and targeting it in interventions

**Codes:**
• S-LPs in acute care validating PWA’s humanity and intellect, saying “you are still you”
• S-LPs helping PWA get to their “new normal”
• S-LPs identifying ways of fostering sense of self, throughout assessment, treatment, and discharge
• S-LPs helping PWA feel like they are being themselves
  ▪ e.g., using their sense of humour by working with them to feel confident in being able to tell a funny story or a joke (e.g., at a dinner party)
• A program that addresses the personal self and makes people feel better about themselves
• S-LPs helping clients feel like contributors through storytelling
• S-LPs acknowledging change while pointing out parts of the PWA that are still the same

**Category**  Supporting PWA’s generalization of skills across people and environments

**Codes:**
• S-LPs’ role is to help PWA to generalize what they have worked on in therapy sessions with other people
• When S-LPs are helping a PWA to develop/regain a skill, making sure that they can do it with a certain degree of accuracy, then making sure that they can apply it in a functional situation in new environments
  o e.g., the counter at Starbucks: confidence is a factor that needs to be addressed outside of the clinic
• S-LPs getting outside of the therapy room and in the community with PWA to try to generalize what is practiced in the therapy room as soon as possible
• S-LPs giving more independent clients homework: to “put yourself out there, your communication out there,” then following up on that and seeing how it went
• S-LPs working with PWA’s significant others, and having them work on transfer into everyday situations, like meal time, or going out shopping

**Category**  Supporting PWA to find appropriate opportunities for life participation and identifying barriers to participating

**Codes:**
• “That’s what rehab’s all about:” S-LPs giving PWA the communication skills to integrate into the community
• S-LPs going out into the community with the client, and having more opportunity to do things outside of the clinic with them
  o e.g., going out for coffee, which does not always happen
• S-LPs, with social workers, trying to set PWA up with a job/volunteer job in a supportive setting so they can see that they are “still capable of doing many things”
• S-LPs helping PWA to find opportunities to communicate in safe environments
  o e.g., S-LPs ensuring that PWA have some kind of connection to communication with people who have some training in how to communicate
  o e.g., S-LPs starting more organic, functional communication-based groups in the community
• S-LPs having opportunities for PWA to communicate in acute care or long-term care, possibly using AAC
• S-LPs looking for opportunities for PWA living in long-term care facilities (e.g., in making sure PWA are successfully integrated into the programming of long-term care)
• S-LPs building opportunities for PWA’s success in daily interactions (formal and informal) by using concepts of SCA™
• S-LPs working with PWA at a functional level in their own homes and communities to get them back to what they want to be doing
• S-LPs identifying barriers to participation to break down
• The LPAA: S-LPs using more quality of life-based, participation-based assessment and outcome measures to shift the focus to:
  o “what is the picture like for this person” and
  o “what is holding them back” (e.g., the Communication Confidence Rating Scale for Aphasia)
• S-LPs facilitating meetings for PWA; accompanying discharged people with aphasia to their first LPAA activity

**Category**  Supporting PWA’s independence

**Codes:**  
• S-LPs setting goals with PWA and holding them accountable to practice
  o e.g., identifying a goal and building confidence and skills to make that a successful independent activity for PWA in outpatient and community work
• e.g., helping PWA to pick scenarios to use the skills they have been practicing, so that PWA are pre-planning, creating their own action plan, then following up on it
  • S-LPs identifying PWA’s learned non-use, and trying to set goals to eliminate that in outpatient and community work
  • Dignity of risk and S-LPs encouraging PWA to take chances and to try new things (e.g., to try a new group)

**Category** Supporting PWA and/or their family members in self-advocacy about aphasia

**Codes:**

• S-LPs working really closely with family members and whoever PWA’s support people are to be advocates for those patients, and for PWA to be advocates for themselves

• S-LPs helping PWA advocate for themselves and to advocate that “I have a communication disorder, I’m still the same person, I’m still intelligent, I don’t have a mental, disorder.”

**Category** Advocating for more time for S-LP services for PWA at every stage in the continuum of recovery

**Codes:**

• S-LPs advocating within the acute care system for communication therapy for PWA

• The S-LP profession advocating for opportunities for people with aphasia over the course of their lifetime, and having the opportunity to have contact with S-LPs in and out of their recovery, over years:

  o “not just like, “sorry, y’know, we see you for six months and you’re out the door””

**Category** Challenges to role fulfilment

**Codes:**

• S-LPs in acute care:

  o doing bedside communication assessments to deem if PWA are appropriate for rehab

  o identifying acute or short-term goals
- assessing basic communication needs and how the PWA is able to say “yes/no”
- confidence gets way less priority

- S-LPs in acute care needing time with the PWA and their family members:
  - “increasingly in the in-patient population it’s all about discharging clients as quick as possible and not having the time”

- S-LPs incorporating fears of participation and environment into earlier stages of therapy, although this is not outlined as part of the job, and it is not emphasized when the goal actually ends

- There are roles for S-LPs at all stages of rehab, and the trouble is the system is set up “so that we…don’t get to see…in acute, people just flow by you…and you see them for very short periods of time”

- S-LPs not being aware of confidence as part of the therapeutic process:
  - being tuned into a very limited style of interaction, in a very set environment (“tiny little rooms, in medical buildings”):
    - e.g., hearing that a wife of a client with aphasia “can’t make him do it at home,” showing that it works (in the clinic), and then forgetting about it

- S-LPs’ education: an impairment-based model in which they are taught to scientifically word their goals in interventions; “confidence doesn’t really fit into that model”