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Exploring Posttraumatic Growth in Aphasia: A Qualitative Investigation

Camille Williams

A thesis submitted to the faculty of  
Brigham Young University  
in partial fulfillment of the requirements for the degree of  
Master of Science

Tyson G. Harmon, Chair  
Tami Brancamp  
Shawn Nissen

Department of Communication Disorders  
Brigham Young University

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## ABSTRACT

### Exploring Posttraumatic Growth in Aphasia: A Qualitative Investigation

Camille Williams  
Department of Communication Disorders, BYU  
Master of Science

This study explored posttraumatic growth (PTG) in people with aphasia and is the qualitative arm of a larger mixed-methods study. After an initial experimental session, 23 people with aphasia (PWA; 12 females and 11 males) completed a 60-minute semi-structured interview during which participants expanded on previously-given questionnaire responses and then answered five additional open-ended questions about communication in their daily life. Interviews were transcribed orthographically and coded using reflexive codebook analysis. A stakeholder with aphasia was consulted to gain insight from an insider's perspective about whether codes and themes captured the experiences of aphasia. Reflexive codebook analysis revealed two themes. Within the first theme, "Recovery is a Journey," there were two categories: "Moving Toward Growth" and "Engagement." The second theme, "Having Aphasia is Challenging, but I've Grown," included four categories: "Challenges and Reactions," "Perception of Self," "General Philosophy of Life," and "Relatedness." Findings suggest that PWA experience PTG across all three primary domains: (1) changed perception of self, (2) changed relationship with others, and (3) changed general philosophy of life and that the challenging circumstances associated with aphasia were integral to the development of PTG. Findings also highlight that PTG does not necessarily develop in a linear trajectory for PWA, but that processes such as acceptance and slowing down may contribute to the development of PTG in this population. Future research should quantitatively investigate the trajectory of PTG for PWA, assess interventions that may facilitate PTG, and examine how PTG contributes to overall recovery.

Keywords: aphasia, posttraumatic growth, qualitative, recovery

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## TABLE OF CONTENTS

TITLE PAGE .....	i
ABSTRACT.....	ii
ACKNOWLEDGMENTS .....	iii
TABLE OF CONTENTS.....	iv
LIST OF TABLES.....	vi
DESCRIPTION OF THESIS STRUCTURE AND CONTENT .....	vii
Introduction.....	1
Posttraumatic Growth .....	1
Processes and Factors Related to the Development of Posttraumatic Growth.....	3
Posttraumatic Growth and Aphasia .....	6
Method .....	12
Participants.....	12
Procedures.....	13
Interview Design.....	14
Posttraumatic Growth Inventory-Aphasia Item Selection.....	15
Basic Psychological Need Satisfaction and Frustration Scale Item Selection.....	15
Successfully Living With Aphasia Rating Scale .....	16
Additional Semi-Structured Interview Questions.....	16
Analysis.....	16
Results.....	18
Theme 1: Recovery Is a Journey.....	18
Category 1: Moving Toward Growth .....	18

Category 2: Engagement.....	24
Theme 2: Having Aphasia is Challenging, but I've Grown.....	26
Category 1: Challenges and Reactions .....	26
Category 2: Perception of Self.....	30
Category 3: General Philosophy of Life.....	35
Category 4: Relatedness.....	38
Discussion.....	43
The Challenging Circumstances Associated With Aphasia are Integral to the Experience of Posttraumatic Growth .....	43
Changed Perception of Self .....	44
Changed Relationships With Others.....	46
Changed General Philosophy of Life.....	47
PTG Does Not Necessarily Follow a Linear Trajectory.....	49
Potential Contributors to PTG .....	51
Limitations and Future Directions .....	53
Conclusion .....	55
References.....	56
Tables.....	67
APPENDIX A: Annotated Bibliography .....	72
APPENDIX B: Institutional Review Board (IRB) Approved Consent Form.....	92
APPENDIX C: Institutional Review Board (IRB) Approval .....	97
APPENDIX D: Study Procedure Diagram .....	98
APPENDIX E: Semi-Structured Interview Guide .....	99

## LIST OF TABLES

Table 1	<i>Participant Demographic Information</i> .....	67
Table 2	<i>Posttraumatic Growth Inventory Scores</i> .....	69
Table 3	<i>Quick Aphasia Battery Scores</i> .....	70
Table 4	<i>Categorization of Results</i> .....	71

## DESCRIPTION OF THESIS STRUCTURE AND CONTENT

This thesis, “*Exploring Posttraumatic Growth in Aphasia: A Qualitative Investigation*” is part of a larger, mixed-methods study investigating posttraumatic growth in people with aphasia. It is written in a format which brings together traditional thesis requirements with a journal publication structure. The annotated bibliography is included in Appendix A. Appendix B contains the Institutional Review Board (IRB) approved consent form, Appendix C contains an IRB approval form, Appendix D contains the study procedure diagram, and Appendix E contains the semi-structured interview guide. Two reference lists are included in this thesis format. The first contains citations used in the journal ready-article and the second contains references used in the annotated bibliography.



## **Introduction**

For many people, the events which precipitate aphasia and the challenges that accompany it can be highly distressing. Stroke, the leading cause of aphasia, bears the hallmarks of a traumatic event because it is unexpected, uncontrollable, and potentially life-threatening (Kelly et al., 2018). Beyond its traumatic onset, aphasia can impact long-term social participation and overall well-being. For example, stroke survivors with aphasia participate in fewer activities and report significantly worse quality of life than both stroke survivors without aphasia and neurologically healthy adults (Hilari, 2011; Ross & Wertz, 2003). Furthermore, when compared with 74 other diseases and conditions (including cancer and Alzheimer's disease), aphasia has shown the largest negative relationship with health-related quality of life (Lam & Wodchis, 2010). It is perhaps not surprising, therefore, that up to 60% of people with aphasia (PWA) experience psychopathologies such as depression, the diagnosis of which is the traditional mode of identifying psychological outcomes related to traumatic events (Baker et al., 2018; Code & Herrmann, 2003; Kauhanen et al., 2000; Parr et al., 1997; Zanella et al., 2023). Although identifying and treating psychopathologies related to aphasia is critical, recent evidence suggests that—independent of psychopathologies—many survivors of various traumatic events also experience the phenomenon of posttraumatic growth (Leong Abdullah et al., 2015; Tedeschi & Calhoun, 2004). Posttraumatic growth (PTG) is defined as “significant positive change arising from the struggle with a major life crisis” (Calhoun et al., 2000, p. 521). The purpose of the present study was to qualitatively explore PTG in aphasia.

### **Posttraumatic Growth**

PTG describes the positive psychological changes that can result from one's struggle with highly challenging life circumstances (Calhoun & Tedeschi, 2001). In other words, the construct

captures the psychological growth that may occur because of adversity or traumatic experiences. Positive psychological growth has been identified in people who have survived violent circumstances (combat, assault, natural disasters, plane crash, abuse, etc.), amongst people living with disease (cancer, HIV/AIDS, cardiac disease, arthritis, multiple sclerosis, etc.), in people who have experienced medical trauma (spinal cord injuries, brain injury, etc.), and in those who are mourning the loss of loved ones (Affleck et al., 1987; Evers et al., 2001; Fontana & Rosenheck, 1998; McMillen & Cook, 2003; McMillen et al., 1997; Parappully et al., 2002; Poorman, 2002; Snape, 1997; Updegraff et al., 2002; Weiss, 2002). People who experience PTG not only survive these traumatic experiences but have been found to surpass baseline levels of psychological functioning in certain areas, such as an increased sense of personal strength and more meaningful interpersonal relationships (Tedeschi & Calhoun, 2004).

Although at first glance growth through adversity may be unexpected, PTG has been theorized to develop as people wrestle with their previously held fundamental assumptions during the distressing aftermath of trauma. For PTG to occur, the difficult circumstance a person faces must significantly threaten his or her preexisting assumptive world. In other words, the traumatic event must significantly disrupt the individual's life. One sign of this is whether a person refers to life events as "before and after" the stressful or traumatic circumstance (Tedeschi & Calhoun, 2004). This is certainly true for many PWA. For example, participants with aphasia have made comments such as, "I know it'll never be the same as what I was before I had the stroke ...but I've got to accept it" (Brown et al., 2012, p. 152) and "before my stroke ... deadline ... quickly. And after my stroke .... slow down ...good" (Brown et al., 2010, p. 1284).

While it is likely that some PWA experience positive psychological growth, it is important to emphasize that the presence of PTG does not denote the absence of stress and pain.

Indeed, painful events and chronic conditions which precipitate PTG may continue to cause pain and distress for people even while they experience growth through positive changes. Findings on growth acknowledge both the positive and negative aspects of one's experience because it is the person's struggle with loss and not the loss itself that may be a catalyst for change (Calhoun & Tedeschi, 2001). Those who experience PTG often reflect on both their growth and the challenges which result from their experience. As a client of Calhoun and Tedeschi once remarked, "this hurts too bad for something good not to come of it" (Calhoun & Tedeschi, 2001, p. 169).

### **Processes and Factors Related to the Development of Posttraumatic Growth**

While traumatic events serve as catalysts for PTG, positive psychological growth does not develop for all survivors. The development of PTG is a dynamic process which is influenced by psychological processes, personal factors, and environmental factors. If PTG is applicable to those with aphasia, then it is necessary to not only understand the existence of PTG in PWA, but also to understand how to help PWA experience PTG. Although factors which contribute to PTG development have not been investigated in PWA specifically, a general theoretical model has been proposed. Factors which contribute to PTG have also been investigated across trauma survivors generally and in stroke and traumatic brain injury (TBI) survivors specifically.

A theoretical model, which outlines psychological processes necessary for the development of PTG, was proposed by Calhoun and Tedeschi (Calhoun & Tedeschi, 2001; Tedeschi & Calhoun, 2004). In this model, the authors propose that traumatic experiences function as psychologically seismic events which shatter previous beliefs, goals, purposes, and ways of managing emotional distress (Tedeschi & Calhoun, 2004). As survivors struggle to make sense of what has happened, they engage in ruminative activity. Automatic cognitive

processing of trauma is necessary for the development of schema changes as survivors manage their initial distress. The initial struggle with distress is important because those who come to a quick resolution may not accommodate new perspectives of the world, resulting in less enduring change (Tedeschi & Calhoun, 2004). Ruminative processes that help people gradually accept loss, find meaning, and accommodate new experiences in a positive direction have been shown to be significantly and positively associated with PTG across stroke survivors as well as those who have experienced trauma generally (Calhoun et al., 2000; Gangstad et al., 2009; Joseph & Linley, 2005; Kelly et al., 2018; Linley & Joseph, 2004; Tedeschi & Calhoun, 2004). Processes such as self-awareness of growth and positive reinterpretation of difficult experiences have also been shown to be significantly associated with the development of PTG for a variety of trauma survivors (Cruess et al., 2000; Park et al., 1996; Tedeschi & Calhoun, 2004). One way that this reinterpretation or reconstruction of meaning has been targeted therapeutically is through co-construction of personal narratives about trauma and survival, which can then be shared with others. The construction and disclosure of personal narratives helps survivors to build new schemas and find greater meaning in life (Calhoun & Tedeschi, 2001; Tedeschi & Calhoun, 2004).

In addition to psychological processes which have been shown to impact the development of PTG, personal factors have also been found to play an important role. These factors include age, personality, and religiosity. In relation to age, a number of studies have shown that, while adults of all ages experience PTG, younger adults and females report greater levels of PTG than their older and male counterparts (Calhoun & Tedeschi, 2001; Linley & Joseph, 2004; Park et al., 1996; Powell et al., 2003; Tedeschi & Calhoun, 2004). In relation to personality, several factors have been shown to be important. For example, extraversion, optimism, high self-

efficacy, openness to experiences, agreeableness, and conscientiousness have all been found to be associated with higher levels of growth (Linley & Joseph, 2004; Tedeschi & Calhoun, 1996). Finally, religiosity has also been shown to play a role in PTG in that intrinsic religiousness and degree of openness to religious change have been identified as predictors for PTG (Calhoun et al., 2000; Park et al., 1996).

Environmental factors which are associated with the development of PTG include factors such as social support and time post-trauma. A person's satisfaction with their social support has been shown to be positively associated with PTG (Linley & Joseph, 2004; Tedeschi & Calhoun, 2004). Social support is especially beneficial to survivors when it comes from those who have been through a similar experience. While some studies have not found a clear relationship between PTG and time post-trauma, research investigating PTG in stroke and TBI has found increased levels of PTG following longer amounts of time after the traumatic event (Kelly et al., 2018; Linley & Joseph, 2004; Tedeschi & Calhoun, 1996). For example, Kelly et al. (2018) found evidence of PTG in stroke survivors four to five months after stroke, but the amount of growth significantly increased across the next six months. Additionally, studies examining PTG in TBI survivors found significantly higher levels of PTG in those who were sampled following a longer period of time after their traumatic event (Collicutt McGrath & Linley, 2006; Powell et al., 2007). Although social support seems to clearly relate to PTG, the link with time post-onset seems tenuous.

In sum, the development of PTG has been evaluated across trauma survivors generally and in those who have suffered from stroke and TBI specifically. Psychological processes such as automatic cognitive processing, positive reinterpretation, and self-awareness of growth seem to aid in the development of PTG. Personal factors such as age, personality, and religiosity as

well as environmental factors such as social support, and possibly time post-trauma may also influence the development of positive psychological growth. Because PTG has not been adequately investigated in aphasia, it is unclear whether these same factors and processes are pertinent to PWA. Exploring the experience of PTG for participants with aphasia will provide a necessary first step for identifying factors related to PTG that warrant further investigation for this specific population.

### **Posttraumatic Growth and Aphasia**

In addition to understanding processes and factors related to PTG, understanding PTG as a construct is also important for considering how PTG may apply to aphasia. PTG has been described as encompassing three different categories (i.e., changed perception of self, changed relationship with others, and changed general philosophy of life), which include five separate domains (i.e., personal strength, new possibilities, relating to others, appreciation of life, and spiritual change; Calhoun & Tedeschi, 2006). The first category, changed perception of self, includes the following domains: personal strength and new possibilities. The domain of personal strength captures an increased sense of being stronger than one previously thought and more able to deal with future challenges. The domain of new possibilities describes the emergence of new interests, new activities, and a new path in life. The second category, changed relationship with others, includes the domain of relating to others. Growth in this domain can be identified as an increased sense of compassion, feeling of closeness to others, freedom to be oneself, vulnerability, altruism, and connection to other people. The third category, changed general philosophy of life, includes the last two domains: appreciation of life and spiritual change. The domain of appreciation of life captures gratitude and a change in what is important. This change may be seen through a realization that life is precious, and a shift of greater meaning being found

in intrinsically important priorities (e.g., spending time with one's children) with less meaning found in extrinsic areas (e.g., making a lot of money). The final domain, spiritual change, includes a greater sense of purpose and meaning in life, greater religiosity, and greater satisfaction with answers given to fundamental existential questions (Calhoun & Tedeschi, 2006). Those who report experiencing PTG may experience growth in some but not necessarily all domains.

Although only one study that we know of has formally examined PTG in participants with aphasia (Sherratt & Worrall, 2020), a larger body of aphasia research touches on concepts that relate to PTG and its associated categories of change. In connection with changed perception of self, previous research in aphasiology has addressed related areas such as autonomy, personal narrative construction, and adapted participation in life activities (Brown et al., 2012; Cruice et al., 2010; Ross & Wertz, 2003; Strong et al., 2018). A sense of autonomy or independence is relevant to personal strength because these qualities reflect how a person perceives their ability to think and act for themselves. In one study investigating quality of life in aphasia, Ross & Wertz (2003) found that independence, social relationships, and environmental facets were the best at differentiating quality of life between those with aphasia and neurologically healthy adults. These findings indicate that a loss of independence may be a frequent psychosocial consequence of aphasia which significantly impacts quality of life. Similarly, qualitative research has identified that feelings of independence and autonomy contribute to quality of life and are important for people to feel they are living successfully with aphasia (Brown et al., 2012; Cruice et al., 2010). These findings demonstrate the importance of autonomy for PWA, but do not examine changes in autonomy or psychological growth in how participants with aphasia perceive themselves.

One therapeutic approach that begins to address how PWA perceive themselves is a four-week personal narrative co-construction project (Strong et al., 2018). This approach was used with three participants who engaged in identity renegotiation as they collaboratively constructed personal narratives about life with aphasia with support from a speech-language pathologist. When investigating this project qualitatively, Strong et al. (2018) reported that the three participants developed a more positive view of their identity and greater confidence in themselves. Greater confidence and positive views of self are certainly relevant to changed perception of self as they indicate that the participants have a sense of being stronger than they previously thought and more able to handle future challenges. However, while it appears that these participants experienced this changed perception of self across the four weeks of intervention, pre- vs. post-aphasia changes were not directly investigated. More research is needed to understand how the perceptions of participants with aphasia change following the onset of aphasia and how this may contribute to psychological growth.

The new interests of PWA and the activities that they may engage in are also related to a changed perception of self. One qualitative meta-analysis evaluated what it means to live successfully with aphasia from the perspectives of PWA, speech-language pathologists, and family members of those with aphasia. All three participant groups commented on the value of opportunities for PWA to engage in activities they enjoyed before the onset of aphasia—even when adapting these activities was necessary—and in developing new hobbies or interests (Brown et al., 2012). Additionally, qualitative work examining 30 participants with aphasia identified that engagement in activities was the most influential factor in affecting their quality of life. Some of these participants described that trying new activities and changing the way they



engaged in their preferred activities helped them to achieve better quality of life (Cruice et al., 2010).

Aphasia literature which corresponds to the category of changed relationships with others often highlights the importance of meaningful relationships for PWA (Brown et al., 2012; Cruice et al., 2010; Ross & Wertz, 2003). Both Brown et al. (2012) and Cruice et al. (2010) found that living successfully with aphasia and experiencing good quality of life happens in the context of meaningful relationships (i.e., positive relationships with family, friends, and other people with stroke and aphasia to whom they feel connected). For many participants with aphasia, meaningful relationships with family members may be the most highly valued relationship (Brown et al., 2012). Additionally, satisfaction with support received from friends has also been found to distinguish quality of life between PWA and neurotypical adults (Ross & Wertz, 2003). While supportive relationships with friends and family are crucial for enhanced quality of life, PWA generally experience smaller social networks following the onset of their communication challenges (Davidson et al., 2008; Hilari & Northcott, 2006). The satisfaction that PWA have with their social network, however, has been shown to be more important for psychological wellbeing than the number of social connections within the network (Hilari et al., 2010). These studies identify the importance of meaningful relationships and the negative consequences which may occur in these relationships due to the challenges associated with aphasia. However, positive relationships in aphasia, the patterns which lead to them, and how they might contribute to psychological growth have not been explored explicitly.

Regarding the PTG category of changed general philosophy of life, reassessing life priorities, maintaining a positive outlook, and the effects of spirituality have been examined in the aphasia literature (Brown et al., 2010, 2012; Grohn et al., 2014; Laures-Gore et al., 2018). In

a previous qualitative study, participants with aphasia discussed how reassessing life priorities led to positive life changes for families, such as PWA spending more time with family members following the onset of aphasia (Brown et al., 2012). Participants also described that maintaining a positive outlook helped them to live successfully with aphasia. Practices such as focusing on improvements and celebrating early successes provided these PWA with greater confidence and hope in further successes (Brown et al., 2012). Similar themes relating to positivity such as acceptance of aphasia, perseverance in challenges, focusing on improvements, appreciation of life, setting goals, and maintaining a positive attitude in challenging times have been described as important to living successfully with aphasia by participants with aphasia in other qualitative studies (Brown et al., 2010; Grohn et al., 2014). Additionally, some PWA have reported that their spirituality has helped them better cope with life changes and improve their communication abilities (Laures-Gore et al., 2018). In one qualitative study, questionnaire and interview data related to spirituality were collected from 13 participants with aphasia. Spirituality was defined as “a general feeling of closeness and connectedness to the Sacred,” “the Sacred” being “whatever a person considers central to their spirituality, such as God, nature, humanity, or the transcendent” (Laures-Gore et al., 2018, p. 1877). All 13 participants considered themselves to be spiritual and 11 described that their spirituality and religion contributed to improvements in their recovery and in successful coping of life with aphasia. While all these findings suggest that changes in one’s general philosophy of life can be effective for PWA to cope with aphasia, growth in these areas from before and after the onset of aphasia have not been explored.

To date, relatively little is known about the experiences of PWA related to posttraumatic growth specifically. Research studies investigating PTG following stroke and TBI have discovered evidence of significantly higher positive psychological change in survivors than

healthy controls (Collicutt McGrath & Linley, 2006; Gangstad et al., 2009; Gillen, 2005; Kelly et al., 2018; Kuenemund et al., 2016; Powell et al., 2003). However, due to the exclusion of individuals with language and cognitive impairments in these studies, only a handful of people with mild aphasia were included (Collicutt McGrath & Linley, 2006). Furthermore, we know of only one published study investigating PTG in those with aphasia (Sherratt & Worrall, 2020). In this study, the authors assessed PTG in 13 people with aphasia during their first-year post-stroke by administering the Posttraumatic Growth Inventory (PTGI; Tedeschi & Calhoun, 1996) and conducting semi-structured interviews in the homes of participants at four points in time (3, 6, 9, and 12 months post-stroke). Quantitative results of the study revealed no significant differences in the mean total score of the five domains within the PTGI over time. There was, however, a trend of greater growth over time since the stroke. Comments from participants illustrated qualitative evidence of growth in relationships, positive traits, appreciation of life, and a sense of what is important, leading the authors to conclude that at least some of the participants appeared to experience PTG during the first year post-stroke (Sherratt & Worrall, 2020). More research is needed to understand the experiences of people with aphasia related to PTG and the mechanisms which may contribute to their positive psychological growth.

Although there is research about aphasia which relates to the three categories of PTG, these studies do not directly investigate positive changes within these domains. The studies frequently describe the state of PWA in relation to negative consequences of life with aphasia but do not examine changes that PWA have experienced in a positive direction. And while there has been some evidence that PWA can experience PTG (Sherratt & Worrall, 2020), little is known about this experience and what contributes to this potential growth. Qualitative research investigating PTG across a variety of PWA has the potential to expand upon previous findings

by directly exploring the experiences of those with various degrees of PTG and by identifying contributing factors to their growth across domains. The purpose of the present study was to qualitatively explore PTG in participants with post-stroke aphasia across a variety of types, severities, and times post-onset as well as to explore possible contributors to PTG in a diverse sample of participants with aphasia.

### **Method**

This thesis is part of a larger mixed-methods study being conducted by research teams from five universities: University of Nevada, Reno; Duquesne University; University of Pittsburgh; Brigham Young University; and California State University, Northridge. The larger research project includes both quantitative and qualitative arms. The purpose of the experimental arm was to assess the convergent validity of the Posttraumatic Growth Inventory for Aphasia (PTGI-Aphasia; Brancamp, 2019) with measures of depression, perceived stress, satisfaction of basic psychological needs, and health-related quality of life. The purpose of this qualitative portion was to explore the experiences of people with aphasia related to posttraumatic growth.

### **Participants**

The larger project involved 77 PWA. Participants were recruited from support groups, social media, and word of mouth. All participants included in the study met the following qualifications: (a) 18 years or older; (b) diagnosed with aphasia; (c) at least 6 months post stroke; (d) spoke English as primary language; (e) had no history of degenerative neurological disease, dementia, diffuse brain injury, or brain disease; and (f) had access to reliable Internet and a webcam. One third of individuals who participated in the experimental portion were invited to participate in the qualitative session. These participants were selected based on the order in which their research session was scheduled. For example, every third participant who was

scheduled to participate in session 1 was invited to participate in a qualitative interview. All invited participants completed the interview session except one who was lost to follow-up. The present study was approved by the BYU Institutional Review Board (IRB). All participants provided verbal informed consent prior to participation in the study. Twenty-three participants with aphasia (12 females and 11 males) were included in this study (see Table 1 for demographic information). During an experimental session prior to their interview, all participants completed the PTGI-Aphasia to identify their self-reported growth across PTG domains (see Table 2 for results) and the Quick Aphasia Battery (QAB; Wilson et al., 2018) to evaluate language functioning (see Table 3 for results).

### **Procedures**

Following the conclusion of the experimental session, one third of participants were invited to participate in a semi-structured interview. These sessions took place within a month after the first session. Interviews lasted approximately 60 minutes and were both conducted and recorded over Zoom. The author and one undergraduate student conducted the interviews under the direct supervision of the author's thesis chair who has 11 years of experience working with people with aphasia. Both students had completed introductory coursework regarding aphasia and had participated in a virtual training about using supportive communication techniques for people with aphasia. Participants were never interviewed by the same student who administered the initial experimental session.

During the interview, participants responded to questions about a sample of their responses from the first session and about their experiences with difficult communication situations (see "Interview Design" section). They were encouraged to share specific examples of their experiences. In accordance with semi-structured interview methodology, the wording of

questions was adapted according to the needs of each participant (Britten, 1995). Supportive communication strategies were used to verify responses, acknowledge competence, and aid comprehension. A unique PowerPoint presentation was created for each participant to provide visual support in the form of text and images. All instructions, interview questions, and selected items and responses from the participants' initial session were displayed. The "pen" and "laser" functions were used to draw attention to specific words or phrases to support comprehension. Participants were encouraged to write on paper or type on their phone and then hold their writing up to the webcam when needed. To assist with comprehension, interviewers also wrote and drew on whiteboards and held these up to the camera as needed. When verbal production was limited, open-ended questions were reworded to provide fixed choice options to facilitate responses.

### **Interview Design**

During each interview, participants were asked questions about (a) a sample of responses from the first session, (b) their daily life, and (c) challenging communication situations. Participants' prior responses to the Posttraumatic Growth Inventory-Aphasia (PTGI-Aphasia), Basic Psychological Need Satisfaction and Frustration Scale (BPNSF), and the Successfully Living with Aphasia Rating Scale (SLARS) questionnaires were examined to learn why they answered the way they did and to elicit specific examples from their life experiences. In accordance with the purpose of this qualitative study, question selection was carefully approached to give participants ample opportunity to describe growth they had experienced since the onset of their aphasia. The procedures for question selection from each questionnaire are detailed below.

### ***Posttraumatic Growth Inventory-Aphasia Item Selection***

The PTGI-Aphasia is a modified version of the 42-item paired format Posttraumatic Growth Inventory (PTGI-42; Baker et al., 2008; Cann et al., 2010), which was developed by Brancamp (2019) to accommodate for the communication challenges of people with aphasia. The assessment is comprised of 21 paired items: the first question in each pair queries posttraumatic growth and the second queries posttraumatic depreciation. The items fall under the five domains described in the introduction: relating to others, new possibilities, personal strength, appreciation of life, and spiritual and existential change (Tedeschi & Calhoun, 1996). One posttraumatic growth question from each of the five domains was selected to be discussed in the semi-structured interview. For a question to be chosen, the participant must have answered “yes,” and the question must have been given the highest ranking relative to other questions within its respective domain. If more than one question within a domain was given the highest ranking, a question among these was randomly selected. When there were no eligible questions within a domain (e.g., if a participant answered “no” to all questions within a domain), then the domain was not addressed during the interview.

### ***Basic Psychological Need Satisfaction and Frustration Scale Item Selection***

The Basic Psychological Need Satisfaction and Frustration Scale (BPNSF) assesses the satisfaction and/or frustration of needs within three domains: autonomy, competence, and relatedness (Chen et al., 2014). One eligible question from each domain was selected. Only questions to which the participant responded with a rating of 4 or 5 were considered. The question with the highest ranking within a domain was selected (i.e., rankings of 5 were chosen over rankings of 4). If multiple questions within a given domain were given the highest rating, a

single question was randomly selected. If all questions within a domain were answered with ratings of 3 or lower, then the domain was not discussed during the interview.

### ***Successfully Living With Aphasia Rating Scale***

The Successfully Living with Aphasia Rating Scale (SLARS) is a one-item assessment that measures how successful a person feels they are living with their aphasia (Grohn et al., 2012). This scale was addressed in the semi-structured interview regardless of the participant's response.

### ***Additional Semi-Structured Interview Questions***

The remainder of the interview consisted of questions about daily life and challenging communication situations. Participants were asked to “describe what a good day looks like for [them].” They were prompted to describe what they do, who they are with, the situations they are in, and what it feels like to communicate on a good day. How frequently the participants felt they had experienced a good day was also elicited. Following this discussion, the interviewer stated that “it is normal for people with aphasia to feel like they communicate better in some situations and worse in others.” The participant was asked to describe (a) a situation in which they find challenging to communicate, (b) their reaction when faced with this situation, and (c) the strategies they find helpful. The clinician continued to ask for additional examples about challenging communication situations until the participant could not think of another.

### **Analysis**

Interviews were transcribed orthographically by a team of undergraduate research assistants. Verbal and nonverbal communication from the interviewer and participant were recorded verbatim in the transcripts. The author (a graduate speech-language pathology [SLP] student), her thesis chair (a researcher with 11 years of experience working with PWA), one



undergraduate research assistant, and a stakeholder with aphasia participated in the coding process using reflexive codebook analysis. The author, her thesis chair, and the undergraduate research assistant are all White, middle-class individuals who are active members of a Christian faith. A stakeholder with aphasia was consulted throughout the coding process to gain insight from an insider's perspective about whether codes and themes were accurately capturing the experiences of participants with aphasia. The stakeholder with aphasia read deidentified interview transcripts so as to be familiar with the data prior to consultations.

Coding was performed following the Framework Method in a six-step iterative process (Gale et al., 2013). First, the team familiarized themselves with the data by independently reading and/or viewing all interviews. Notes were taken throughout this step to assist the team in processing the data. Second, the author, her thesis chair, and the undergraduate student carefully read through the first four transcripts, applying codes that described what they found important in the passage. Coding was inductive to invite interpretation from various perspectives. Third, an initial codebook was collaboratively drafted integrating perspectives from all team members. The stakeholder with aphasia was consulted during this process. The codebook contained descriptive codes that expressed the recurring and/or important experiences and comments from the transcripts. Fourth, the transcripts were coded, and the codebook was collaboratively revised by the author and one undergraduate research assistant. These team members began this process by coding interviews while examining unnecessary, ambiguous, and missing codes. The coders met weekly to review discrepancies in coding, ensure the codes were accurately representing the data, and improve reliability. This process was repeated until both coders were satisfied with the codebook. Following this iterative process, the revised draft was taken to the entire team to be finalized. Fifth, the author and undergraduate research assistant coded all interviews using the

revised codebook. The coders met together regularly to compare coding and resolve discrepancies. Consensus was obtained by comparing the codes to codebook definitions and by discussion among team members. Sixth, the finalized codes were collaboratively organized into themes and categories with input from all team members.

## **Results**

Reflexive codebook analysis of the semi-structured interviews revealed two themes: “Recovery is a Journey” and “Having Aphasia is Challenging, but I’ve Grown.” Within the first theme, “Recovery is a Journey,” there were two categories: “Moving Toward Growth” and “Engagement.” The second theme, “Having Aphasia is Challenging, but I’ve Grown,” included four categories: “Challenges and Reactions,” “Perception of Self,” “General Philosophy of Life,” and “Relatedness.” Table 4 depicts the organization of the themes, categories, codes, and subcodes.

### **Theme 1: Recovery Is a Journey**

The “Recovery is a Journey” theme captures the processes whereby participants moved toward growth and the ways in which they engaged in life. Recovery for these participants was expressed as an ongoing journey with highs and lows and not as a linear progression to a final destination. Categories within this theme include Moving Toward Growth and Engagement.

#### ***Category 1: Moving Toward Growth***

The first category under the “Recovery is a Journey” theme captures processes through which participants moved toward growth. Participants discussed (a) grappling with the new reality of having aphasia, (b) coming to terms with it over time, (c) making goals and putting forth effort to meet those goals, and (d) recognizing their improvement as well as the

improvements they still hope to make. Each of these codes represent a process in and of themselves, and together they demonstrate the overall process of moving towards growth.

**Code A: Grappling With New Reality.** Sixteen participants shared comments which illustrated their struggle to come to terms with new life experiences and abilities. These comments included grappling with emotional, psychological, and behavioral implications of their diagnosis. Nine participants described wrestling with emotions during the initial stages of recovery (e.g., uncertainty, sadness, anger, and frustration). This struggle was often the result of not understanding their diagnosis or its subsequent repercussions. For example, P05 explained, “I didn’t think I had a stroke at all, at first. But when I [was] two months out... I would go somewhere, and I would think, ‘I’m okay. I could do that’. Yeah, but I couldn’t.” Six participants described struggles related to losing their jobs. This was captured by P11 who had previously worked as a professor. She said, “my uh- life is teaching- teaching. And I am frustrated.” Part of this struggle involved managing expectations of recovery. This was exemplified by P06 who said, “well I have to do therapy for it, and... when I’m done, I’m going to be better. And uh so, when I’m working on doing therapy for my speech... it was really, really hard.” Difficult questions also emerged for some participants such as “why did the aphasia happen?” (P15) and “why am I still here?” (P08) along with a struggle to live in the present (e.g., P12 wishing “to go back... [but] you can’t”). As explained by five participants, these struggles sometimes led participants to “reevaluate what [was] important” (P03) to them. For example, P22 said, “I couldn’t speak, I couldn’t drive, I couldn’t golf, I couldn’t – I was in a wheelchair. And you know, I said, ‘I got to get more out of life!’” P08 specifically mentioned the process of finding her purpose again. She said, “I had worked so hard to do what I thought my purpose was in life, and now it has been changed... it’s hard to find out what your new purpose was.”

**Code B: Acceptance.** Seventeen participants indicated acceptance of aphasia and other related effects of their stroke. Overall, participants described acceptance as a gradual process that often contributed to their moving forward. This acceptance required them to understand their abilities and limitations while recognizing what was within and outside of their control. Another important aspect of this acceptance process was coming to terms with and/or reframing the consequences of aphasia.

Participants described acceptance as a gradual process that took place over time. Seven participants specifically linked this acceptance to their choice to “move forward.” This pattern was exemplified by P12 who said that after a few years of being angry about his circumstances, he decided to “forget it. I have aphasia and I’m gotta keep going...I’m never gonna go back so I’ve gotta do it forward.” And while P02 talked about how difficult it is for him to have aphasia, he also explained that aphasia was “just the cards that happened to me and that’s what happens. So just do what I’m supposed to do to get through every day. There’s no use sittin’ around and worrying about life.” Three participants described how they learned to gradually accept having aphasia. For example, P22 explained that two years after his stroke, “it was like... a light... bulb went off in my head.” For P08, acceptance was manifest in learning to admit that she might not make as much progress as she had initially hoped. She explained:

I think it was the first two years that I finally got it. It took almost two years to say, ‘Okay, now what do we do with it? Because this is what you have; you’re not going to be—you’re not going to improve like you wanted to. So this is what we got. What can we do with that?’

One participant, P07, acknowledged that she is still in the process of learning to accept her “little baby—little steps” toward gradual improvement. Likewise, P06 said, “it’s going to be a long road, but... I think that it’s just keep working and working and working.”

Understanding their abilities and limitations while recognizing what was within their control seemed important for achieving this gradual acceptance. Nine participants mentioned accepting their current abilities and limitations. For example, P08 explained, “I’m okay where I am now” and P03 said “I learned that it was okay that I didn’t—wasn’t able to do the things I wanted to.” Most participants spoke about accepting their limitations generally, but a couple of participants (P04, P18) mentioned accepting specific limitations including “difficulty with speaking.” Accepting what was within and outside of their control was mentioned by two participants: “What I...cannot control is that of trying to fix things that I’m never going to have control over and focusing more on what I do have control in” (P08); “What I can’t change, I accept” (P23).

Participants described a number of ways in which they came to terms with and/or reframed the consequences of aphasia. This included accepting aphasia as a chronic condition while also recognizing the possibility of improvement (e.g., “I will always have aphasia...but I can work on getting better” [P22]), acknowledging aphasia as a challenge that they could work to overcome (e.g., P16 described accepting aphasia as, “the hardship that I have, and I have to overcome it”), recognizing the social changes that result from aphasia (e.g., P07 described accepting that others don’t understand aphasia, even if she shares her story with them. She has decided that “that’s their loss and I continue to do my thing”), and thinking of aphasia as a new beginning (e.g., P08 described aphasia as “a new life, or my new beginning”). Two participants indicated that they do not let aphasia define them. For example, P20 said, “Aphasia is just

another piece of my puzzle.” Likewise, P04 accepts that he has aphasia but does not let it bother him. He explained, “I am who I am.... unfortunately, I have a stroke, oh well.”

**Code C: Goals and Effort.** Twenty participants spoke about goals and/or commented on their effort toward engaging in life and meeting their goals. Goals that the participants mentioned most frequently included working on their speech and language, educating others about aphasia, and generally “help[ing] other people.” For example, P15 said, “I would like to be in a position where I can go into places and talk to people and let them know that after a stroke there is a life.” Two participants mentioned career goals. For example, P04 said, “my focus is... I am going to medical school. Whether I’m- is true or not true, I don’t know, but right now I am working with a speech pathology.” Four participants reflected on how setting goals has led to improvements in their communication skills. This sentiment was captured by P16 who explained that she feels successful “because of the goals that I’ve set – and I’ve achieved them. I know I have a long way to go, but I feel success in what I’ve done so far.”

Nineteen participants made comments that indicated effort towards meeting their goals and engaging in life including efforts they were taking to improve their speech and language. Examples of these efforts included going to speech therapy, engaging in conversation or support groups, practicing reading and writing, completing homework, and using speech and language apps. In describing these efforts, P06 said, “I won’t quit... it’s going to be a long road, but... just keep working and working.” Participants also put forth effort by “following a routine” (P08), completing daily tasks, working to improve their mental health, and reaching out to friends. For example, P18 said, “I always have a plan to work that day... in my head,” P05 expressed confidence in her ability to do daily tasks such as washing her dishes despite it taking more effort and time than before, and P10 explained that a large part of her recovery has been learning to get

back up and put forth effort after accepting that she is feeling down. Five participants asserted that putting forth effort to engage in life is a critical aspect of taking responsibility for their own recovery. For example, P07 said, “It’s up to you and no one’s going to make you do it. Um—no one’s going to tell you to do your homework, your repetitions, even with your depression—it’s really up to you.” One participant expressed frustration that despite her efforts across 11 years, having aphasia is still challenging for her.

**Code D: Improvement.** Many participants recognized improvements that they were making but also expressed discontent with current abilities and a desire to continue improving. Twenty described improvements they had made in their communication. Nine of these participants also delineated the actions, people, and beliefs that contributed to their perceived improvement including going to speech therapy (“Through speech therapy, I got to where I can talk” [P10]), setting goals, faith in God (“With God, I have improved” [P14]), creating structure (“My structure... forces me to communicate... and I feel like it’s helped me to learn how to communicate” [P05]), friends, “going outside” (P13), and “working on aphasia all the time” (P17). Beyond recognition of past improvement, 14 participants expressed a desire to continue improving. Twelve described feeling discontent about their progress in the present; for example, P03 said, “it’s not where I want to be... I hope I keeps trying to see something else I can do um—better.” Similarly, P17 said, “I keep thinking about it all the time: my brain. I want to get better and better.” Five participants shared past experiences in which discontentment with their speech and language skills motivated them to improve. For example, P08 recalled feeling discontent with her abilities during the first two years of her recovery. She reported thinking, “I am not going to be one of those people with aphasia. I am—I am going to just work harder and I’m going to be able to read and go back to work.”

### ***Category 2: Engagement***

The second category under the “Recovery is a Journey” theme was “engagement.” Participants described engaging in communication activities, activities outside of their living environment, and activities within their living environment. Some participants also described withdrawing from engagement in such activities.

**Code A: Communication Activities.** Twenty-one participants mentioned ways in which they proactively sought out and engaged in activities that involved communicating with others. Seven participants shared how they enjoy meeting and engaging in conversation with people. Other participants sought out communication activities through conversations with loved ones such as family members (e.g., “I call my sister five times a week and I call my father once a week” [P13]) and friends, support groups and Zoom classes, working or volunteering, public speaking, and participating in reading and/or writing activities.

**Code B: Getting Out.** Twenty-two participants specifically discussed engaging in activities outside of their living environment. These included activities such as walking regularly, outdoor sports (e.g., adaptive skiing, pickleball, golf, biking), “shopping” and other errands, aphasia groups, driving (e.g., “I love to just go outside and drive—I love going out” [P07]), “go[ing] a lot of places with friends,” exercising at gyms, work activities, interacting with family (e.g., visiting family or going on a date with a spouse), spiritual activities (e.g., going to “church” or going into nature to say “thank you” to a higher power), going “to the beach,” playing “pool competitively,” and taking care of animals.

**Code C: Engagement in Other Activities.** Fourteen participants reported engaging in activities which did not involve communication, and which took place within their homes. These included participation in hobbies (e.g., crafts, painting, coloring, pin looming, woodworking),



cooking, computer activities, and watching television. Two participants commented generally on the importance of responding to emotional challenges through engagement in activities. For example, in response to her symptoms of depression, P10 said, “you just have to get up and do something.” Likewise, P18 explained that while living with aphasia can be challenging, he chooses to “keep pretty busy and... do what [he] can do.”

**Code D: Withdrawal.** Although most participants chose to participate in activities that involved communication and took place outside their household, reports of withdrawing from such participation were also common. Specifically, nine participants described withdrawing from communication activities for reasons such as a challenging communication environment or because communicating in general was difficult for them. Withdrawing due to challenging communication environments was reported by six participants. Three chose to withdraw because their communication partner was talking too quickly and two explained that talking in a large group of people has led them to withdraw. Heightened emotions, which increased the difficulty of conversation and led to withdrawal were also described by two participants: P03 related that, “[when] I’ve tried to tell my husband something important, sometimes I lose energy even in the beginning of the conversation...it’s easier just to not say what I want to say” and P18 said he must walk away from conversations when he feels angry. Additionally, P15 described that when speaking in an environment with too much background noise she will say, “This is too much, I gotta go.” Four participants described withdrawing because “it’s really hard to talk” (P21). For example, P09 explained that she knows what she wants to say but explained, “I can’t do it and it is just easier to move on.” Likewise, P03 said, “[On] a bad day I will—I’ve tried not to talk as much.”

## **Theme 2: Having Aphasia is Challenging, but I've Grown**

The “Having Aphasia is Challenging, but I've Grown” theme illustrates that while the onset of aphasia brought many new challenges into the lives of all participants (Category 1: Challenges and Reactions), many also reported experiencing growth in how they viewed themselves (Category 2: Perception of Self), their life (Category 3: General Philosophy of Life), and their relationships with others (Category 4: Relatedness).

### ***Category 1: Challenges and Reactions***

The first category under the “Having Aphasia is Challenging, but I've Grown” theme captures challenges and reactions that participants described. Each participant discussed challenges they had experienced due to their aphasia. Although two described “enjoy[ing] the challenge,” most expressed sentiments such as, “it’s definitely hard” (P15) and “things aren’t easy: the way it was before” (P07). In addition to inherent communication challenges resulting from their language impairments, many participants discussed (a) challenging communication environments, (b) specific reactions to living with aphasia, (c) mood and mental health challenges, and (d) the impact of their emotions on their communication.

**Code A: Challenging Communication Environments.** Nineteen participants described experiencing challenges which were specific to their communication environment. These included group conversation (e.g., “crowd[s] of people”), communication partners who “don’t understand the way the aphasia works,” “talk over me,” talk “way too fast,” “didn’t talk to me, they talked to my husband,” fail to recognize that “I need just a little bit longer to communicate,” “don’t know me,” or generally have difficult personalities. “Medical situations” were described as difficult by five participants. For example, P16 described that going to the doctor’s office by herself “makes [her] feel stupid.” Additionally, participants mentioned situations with

background noise, phone calls, complex conversations, long conversations, and evenings as challenging. Several participants added that they did not have the resources or support that they needed to make progress or engage in communication with others.

Eight participants mentioned that they did not have the resources or support that they needed to make progress or engage in communication with others. Four described their frustrations with insurance and its direct impact on their being discharged earlier than they wanted. For example, P07 was discharged from speech therapy when she felt that her “aphasia was really bad” and was “begging for therapy.” Similarly, P22 shared, “[the] insurance quit, and I had to get therapy on my own.” Two participants explained that they received poor support while they were at the hospital. For example, P03 explained, “I didn’t have any support for communication... even speech told me that they would give me a communication board, but it never came.” P09 expressed difficulty with finding speech and language resources in her area (“I want to go, um... speech but there’s no one here”) and P08 started a nonprofit because she felt that there were less resources for people with aphasia than for people with other disabilities.

**Code B: “Frustrated,” “Tired,” “Mad,” Discouraged, Embarrassed, “Overwhelmed,” “Upset,” “Irritate[d],” and Lonely.** Participants described a number of reactions to living with aphasia, including frustration, fatigue, anger, discouragement, embarrassment, stress, distress, irritation, and loneliness. Fifteen participants expressed reactions similar to P22 who said, “sometimes I get frustrated!” This frustration was mostly related to their language deficits and the unsupportive communication behaviors of others. Some participants discussed frustration with how their emotions impacted their communication. Others described frustration resulting from losing their jobs or experiencing a lack of progress. Nine participants indicated that “it takes a lot of energy to communicate,” which results in “mak[ing] me tired

sometimes just saying words.” P08 explained, “it’s like running a marathon just to read a paragraph, and I’m exhausted.” This fatigue was described by five participants as negatively impacting their ability to communicate well (e.g., “I don’t know how to make it make sense and then--then it’s more when I’m tired”). Eight participants explained feelings of anger that were associated with their aphasia.

In addition to frustration, anger, and fatigue, participants described feelings of discouragement and embarrassment. Eight participants expressed feeling discouraged in their language abilities. Four indicated that they were generally discouraged by their language impairments whereas two explained their perception that even though they try to communicate, “it doesn’t matter because I can’t do it.” This led one of them to wonder, “why bother doing anything?” (P07). Two participants expressed feeling embarrassed when talking in a group of people or with doctors or when saying something “that I shouldn’t have said out loud to somebody.”

Other negative emotions were also shared by nine participants. Four described feeling “stress[ed]” (P20) or “overwhelmed” (P22). Two shared that they felt “upset,” such as when P05 had a difficult phone call and explained, “I was upset that day.” Another two described feeling “irritate[d]” or “bother[ed]” by their aphasia. Finally, one participant expressed feeling lonely because her neighbors don’t know or talk to her.

**Code C: Mood and Mental Health.** Seventeen participants discussed their mood and mental health challenges. Many described feelings of happiness associated with their growth, while others shared feelings of sadness as a result of their aphasia. Some participants also described their experiences with mental health challenges that they have experienced since the onset of their aphasia.

Thirteen participants shared about their mood. Ten expressed feelings of happiness, which several attributed to their personality or being around friends and family. Other participants described feeling happy despite the challenges associated with aphasia or because they recognized benefits or progress related to the aphasia. For example, P08 said, “as the recovery process changes... you start to enjoy life” and P20 said, “you don’t want it to happen to anyone... but I’m—I’m happy.” Conversely, six participants shared feelings of sadness. Five commented on the sadness they have felt since the onset of their aphasia. For example, P09 expressed that she regularly cries because she has aphasia and P04 said that right after his stroke, “[for] two weeks I was crying ‘cause I’m so sad.” One participant described feeling sad for a few days after she had a negative communication experience.

Nine participants discussed mental health challenges they have experienced since the onset of their aphasia. Four talked specifically about their experience with anxiety and depression. For example, P10 said, “I was depressed— well, I’m still depressed, which I have a medication for. So, I don’t know. Um— you just have to get up and do something.” One participant shared her experience with suicidal ideation. She said, “my family [and] my friends... that was a tough two years for them. The depression kicked in, suicidal thoughts. Um—yeah, it’d be better if I wasn’t here. They could collect my life expense, things like that.” Another participant shared her story of surviving a suicide attempt. One participant expressed concern for others with aphasia who are experiencing mental health challenges. She said, “if I’m feeling like this and I’m not talking about it, how are these individuals that don’t have a voice? How are they dealing with the depression?” (P08).

**Code D: Emotion Impacts Communication.** Eleven participants discussed how their emotions impacted their communication. Ten shared that emotions have a negative impact on

their ability to communicate. This sentiment was captured by P07 who explained, “I have my emotions [then] I—I break down or I can’t express.” Participants named four specific emotions which negatively affected their communication: “stress” or “pressure,” “excite[ment],” agitation (e.g., “I can be really good at talking, but then there’s something that I get... upset about... my speech will go... downhill quick,” P05), and anger (e.g., “when I get mad... I can’t speak,” P18). Conversely, one participant explained that anger facilitates her communication. She said, “when I get angry, my- m- my boys say I get the words out when I’m angry” (P16).

### ***Category 2: Perception of Self***

The second category under the “Having Aphasia is Challenging, but I’ve Grown” theme captures the views of participants about (a) personal attitudes that contribute to their growth, (b) experiences renegotiating their post-aphasia identity, and (c) perceptions about how they had grown since the onset of aphasia.

**Code A: Attitudes of Growth.** All 23 participants expressed personal attitudes which they felt contributed to their growth. Rather than emerging immediately after the onset of aphasia, these were attitudes that the participants fostered throughout their journey with aphasia. Attitudes include determination, positivity, and self-efficacy.

**Subcode 1: “I was Determined.”** Eighteen participants described the determination they had since the onset of aphasia. General descriptions of this determination included comments about not giving up, fighting against challenges, conquering their disabilities, advocating for themselves, and holding on despite setbacks. This was modeled by P15 when she said, “I have a disability but... I have to conquer that,” and by P16 when she stated, “I have to overcome it.” Several participants also made comments similar to P03 who said, “I’m not ready to give up.”

***Subcode 2: Positive Outlook.*** Twenty-two participants spoke of or exemplified a positive outlook on their life. Most expressed a positive attitude about current or past events while some exhibited a hopeful outlook specifically about the future. Positive attitudes about current or past circumstances were mentioned by 21 participants. Nineteen indicated that “most days are good days.” For example, P20 said, “Every day is a good day. There are some things that they suck, but it’s never—it’s never something that ruins my day.” Similarly, 14 participants exhibited positivity and a resolve to move forward despite challenges they faced in their daily lives. For example, P18 said, “what I can’t change I accept it... I will move on.” Four participants showed positive attitudes by recognizing their growth since the onset of aphasia. For example, P18 said, “I couldn’t speak at all, and uh, uh, my right side is uh, uh, paralyzed. But uh, I think I’m doing great.” P22 also demonstrated this positivity when he said, “It’s a roller coaster but it’s getting better in time.” Three participants noted that having a positive attitude contributed to their feelings of success. For example, P01 said that happiness and a good attitude helped him feel more successful and P08 remarked, “I think right now I’m more successful than I ever thought I would be.”

A hopeful outlook about the future was mentioned by 11 participants. This included a general hope for the future as well as anticipating benefits of hard work. For example, P06 said, “If I keep understanding and work on saying everything, uh, it’ll get better” and P03 stated, “maybe I can’t do that right now, but I can do it if I try real hard. There’s a way, you know, there’s always another way to try.” For two participants, hope was rooted in their spirituality and faith. P04 described holding onto hope despite uncertainty. He said, “whether I’m doing it or not doing it, I don’t know, whether now or before in the future, but I’m still going to.” Another participant explained that help from others gives him hope.

**Subcode 3: Self-Efficacy: “I’m Capable of Doing [Things].”** Twenty-two participants indicated that they had confidence in themselves and in their abilities (i.e., self-efficacy). Generally, participants demonstrated this self-efficacy through comments such as “I’m capable of doing anything” (P02), “just getting through each day— it makes me believe that I can do things” (P15), “some things I can do great” (P17), and “I feel capable at what I do” (P19). Six participants specified that they had confidence in their ability to successfully complete daily tasks. These tasks included washing dishes, driving, cooking, doing chores, exercising, checking out books, running a business, etc. Five participants expressed confidence in their ability to do things differently. For example, P08 said, “I am capable of doing many things, I just have to learn to do it a different way.” Three participants discussed the importance of having high self-esteem. They shared, “you have to have, you know, high self-esteem” (P03), “I feel real special, all my life” (P18), and “I love me, which is most important for—for living with aphasia” (P20).

**Code B: Renegotiating Identity.** Nineteen participants indicated that they had reflected on their identity pre- and post-stroke. Some shared that they feel their identity has remained the same regardless of changes in abilities, while others felt that who they are had fundamentally changed. Six participants spoke generally about how they view their identity. Four emphasized that their identity has remained (“I’m still me” [P08] and “I am who I am” [P04]), while two participants spoke of how their identity has changed (“I wasn’t like I used to be” [P05]). Many other participants demonstrated reflection on their identity by sharing comments about how their roles, activities, and overall autonomy have changed since the onset of their aphasia.

**Subcode 1: Changing Roles.** Fifteen participants discussed changes that they have experienced in various occupational and familial roles. Eleven related that they had lost their job since the onset of aphasia. They reflected on their previous roles and identities such as an “ESL



teacher” (P03), “an art therapist” (P07), “an accountant” (P17), “a supervisor” (P18), “a salesman manager” (P19), etc. Two participants described that they did not lose their job, but that their role within their job changed. Three participants shared that they have found new part-time work since the onset of their aphasia. Four participants discussed changes in family roles that they have experienced. Three explained that they used to play the primary role in taking care of various financial tasks, such as bills and taxes, but that now their spouse has assumed this responsibility. Two participants described that their role in household chores has changed. For example, P16 said, “I used to do all the stuff... I’m trying to teach [my husband] what to do.”

***Subcode 2: Changing Activity Participation.*** Fourteen participants mentioned their changed involvement in activities including comments about activities that they can no longer engage in, new activities, and activities that they have adjusted to match their new abilities and interests. Activities in which participants mentioned no longer engaging included various forms of exercise (e.g., going to the gym, doing Zumba, aerobics, running, biking), cooking, homeschooling children, going to church, going to lunch with friends, cleaning, working a saw independently, driving to a university, and playing the flute. Descriptions of new activity engagement included new forms of exercise (e.g., “triking,” lifting weights, pickleball), art projects (e.g., coloring with crayons, painting with acrylics), attending workshops or trainings, and taking care of horses and donkeys. Adjustments to activities were also mentioned. Three discussed reading and writing, such as P03 who has learned to write for herself and not for a job. Other changed activities included playing pool one-handed, learning to golf one-handed, and painting rocks that say “aphasia” instead of painting “pictures of frogs or happy faces” (P08).

***Subcode 3: Working Toward Autonomy.*** Twenty-two participants described that they feel a sense of congruence between their desires and their actions. Essentially, they noted that

they were able to do what they wanted to do and make choices that aligned with their preferences. All 22 indicated that they experience freedom of choice. For example, P02 said, “I can do whatever I want” and P22 shared, “I’m so thankful because my decisions are perfectly in uh—inclined to what I feel.” Eight participants noted that they experience autonomy in some areas but not in others. For example, P08 related, “if it is a difficult task, I do as much as I can on my own” and P03 shared, “some limitations have been on me, but I feel that I’ve been able to make my own decisions.” Signs of independence that participants shared included going to appointments or therapy alone, freedom to go anywhere that they would like, and taking responsibility for their own recovery. In relation to taking responsibility for your own recovery, P07 said, “it’s up to you” and P15 explained, “I rely on myself to get more answers... I’m learning that obviously I have to do more for myself because of the aphasia. Okay, you just can’t let people, you know, answer for you.”

**Code C: “I Think That I’m Stronger.”** Fourteen participants expressed that, since having aphasia, they have discovered that they are stronger than they previously thought. Most commented on their personal strength generally, such as P03 who remarked, “you have experience that taught you to be strong and that you can be successful.” Four participants specified that they have discovered that they are strong enough to speak with and interact with others. For example, P21 said, “I didn’t think I could do it, but I can” and P06 said, “Sometimes I would think that I wasn’t gonna be—how could it be uh—strong to say a word, but... I think that I’m stronger.” Four participants reflected on how they’ve grown stronger throughout their recovery process. For example, P07 explained, “There’s always up and downs—ups and downs but thank goodness I always bounce back and um—I just keep on going.”

### ***Category 3: General Philosophy of Life***

The third category under “Having Aphasia is Challenging, but I’ve Grown” captures reported changes in the participants’ view on life and their priorities, including appreciation for their life, increased humility, and views about spirituality.

**Code A: “I Slowed Down.”** Six participants indicated that aphasia had positively impacted their lifestyle and perspective by causing them to slow down. Four explicitly shared that slowing down had improved their lives. For example, P08 said that aphasia “narrowed things down... I don’t have the time and the effort for some of this other stuff in my life so I kind of got rid of some, what I call baggage” and P06 related, “I was always on the go, and I wasn’t home... my life was a little—a lot different now. I’m just uh—grateful uh—with my life a little bit more now.” Three participants described that slowing down has changed the focus of their lives. For example, P05 shared, “then my aphasia came when my stroke happened, and it stopped. Everything stopped. And that stopping I feel was a good thing for me, because I help—I help—tell others... about aphasia.”

**Code B: New Perspective.** Eighteen participants described experiencing a changed sense of what is important, or a new view of life. Six indicated that communication had become more important to them. For example, P16 said, “I can’t speak, and I can’t get out my words... it makes me be aware of that and I value my life with that.” Another six participants shared that connecting with loved ones had become more of a focus for them. P20 captured this sentiment when he said, “I care so much for those people, and they care for me. And that’s all that matters.” Two of these participants specified that spending time with loved ones had become more of a priority for them because they realized that “life is uncertain” (P15). Two participants explained that they had “let go” of previous priorities because “the things that are [most]

important are still there.” Other participants listed various new priorities such as writing a memoir and advocating for and helping others.

Comments about having a new view or attitude toward life were expressed by 10 participants. Generally, they expressed that their experiences with aphasia had made them “think differently” (P03) and decide to “get more out of life” (P22). For example, P22 said, “I got passion now, you know. I had passion before, but [now]... I have the purpose in life.”

Participants related this new perspective to better valuing what they had, being ok with the “way things work out,” and acknowledging and sharing feelings. One participant expressed that aphasia has led him to think less about himself and more about the people around him. He related, “pre-stroke I wanted to be huge because I thought, ‘maybe—maybe people will like me’... ‘Like, so now, I’m like, ‘I helped you’” (P20).

**Code C: “I’m... Grateful.”** Sixteen participants expressed gratitude during their interview. Participants expressed appreciation for loved ones, survival of their stroke, improvements, remaining abilities, their situation in comparison to others, God, and their “new life.” For example, P11 expressed gratitude for “my husband, and my mom, and my kids, and—and friends” and explained, “I am really lucky... a lot of survivors are lone—uh—alone.” P02 explained, “I have uh—half a brain, but I’ve been very fortunate because I’ve been able to do basically everything I want to do.” Four participants also shared how they have experienced more feelings of gratitude since the onset of their aphasia. For example, P10 said, “I notice that I have a great a—a—appreciation for life because, just the birds, or the animals, or—yeah” and P03 said, “I um—take more time to appreciate things.”

**Code D: “I Think Aphasia Makes You Humble.”** Two participants made comments about how they have developed more humility since having aphasia. P03 shared, “I think aphasia

makes you humble.” She described that, “aphasia has made me have to go back to learning English,” which she said was humbling for someone who had previously taught English as a second language to students. Additionally, P17 said, “when you have—if you have aphasia I usually be—usually a humble, but you are that aphasia be humble each other.”

**Code E: Spiritual Beliefs, Practices, and Growth.** Twelve participants made comments about their spirituality. Five expressed specific religious beliefs, such as “Buddhism uh—is a lot of what I deal with spiritually” (P10) or “I’m a Catholic... faith is everything” (P22). Participants also discussed their engagement in spiritual activities and described the spiritual growth they have experienced. Four shared comments about attending religious services. For example, P23 said, “when I go with uh—to church, that’s part of my—that part of my freedom.” Two participants discussed reading scripture or religious literature. For example, P05 said, “I read my Bible every day” and P06 explained that he reads a “meditation book... it’s not a Bible, but it’s kind of... different parts of the Bible each day.” P03 shared that she is participating in “spiritual um—um—trainings” and P08 described her spiritual engagement this way: “I always go outside and um—I just do a thank you. Some people call it a prayer or whatever, but I get up every morning... and I just go out there and say thank you for another day.”

Ten participants indicated that they had grown spiritually since the onset of their aphasia. Five expressed this generally through statements such as, “I have always had faith in my life, but it got stronger” (P22) and “I was spiritual before, but now I’m more spiritual, because now I—I—I’m thankful to God” (P05). Four participants specifically indicated that surviving the near-death experience that caused their aphasia has led them to grow spiritually. For example, P08 shared, “When I got home from the hospital... I started knowing there’s gotta be—there’s gotta be an upper being. There’s gotta be a reason why I’m here.” Additionally, P05 said, “because if

He didn't intervene, then I would not be here. The doctors helped too, but I think God has a lot to do with it." Three participants described poignant spiritual experiences that had occurred since the onset of their aphasia. For example, P14 shared that her sister passed away three months prior to the interview and that she had felt her sister's presence with her. Additionally, P20 described that after his stroke, he heard his recently deceased grandfather speaking to him, saying, "It's not your time. I wish it was. But you can't—you can't because you have—you have—you need to help others."

Additional ways in which participants described spiritual growth in relation to aphasia were by making connections between their spiritual growth and improved communication and allowing them "time to think about what [God has] done... [and] grow spiritually." For example, P13 said, "God is—is more important to me because he's gotten me to grow better" and P06 shared that he has grown spiritually as he has been required, because of the aphasia, to put forth effort to understand a religious text. Two participants also described that their beliefs and view of spirituality have expanded since the onset of their aphasia. P08 said, "I think I'm more appreciative [of] all different types of religion... I call it more of a spiritual thing." Additionally, P20 shared, "I was raised Roman Catholic, but that's not me... What I've come to realize is, maybe it's one God? Maybe it's 40 Gods?"

#### ***Category 4: Relatedness***

The fourth category under the "Having Aphasia is Challenging, but I've Grown" theme captured changes that allowed participants to better connect with others. These included internal changes related to (a) greater empathy and (b) accepting help from others, (c) changes in their connection to others including friends and family, and (d) new or changed desires to make an impact on the larger community.

**Code A: Greater Empathy.** Nine participants felt that they currently had more empathy for others than they did before the onset of aphasia. Four described that this was because they could relate better to people in general. For example, P14 said that she now has more compassion for others. She noted that having aphasia is “hard,” and this helps her appreciate the challenges that others go through. Additionally, P19 said, “[Now] I can relate to others. Um—it may be for different reasons, but I can still relate.” Three participants explained that they have more empathy for other people with aphasia. For example, P16 said, “I see these people with aphasia, and I realize how lucky I am—and I feel for them. They have such a tough time getting the words out... and it just makes me feel for them.” Two participants shared that having aphasia has taught them how to be a better listener and more supportive communication partner. For example, P17 has learned to remind conversation partners to “Take your time! I don’t care, 30 seconds, I don’t care... Don’t worry about it.” Two participants specified that their empathy for people with disabilities has grown. For example, P15 stated:

Because I have aphasia, so—a—a—disability – not that I was a rude person ya’ know, but you kind of look at it going, ‘Oh’. Ya’ know?... a lot of people are having some type of a disability, so I’ve gotten—learned to be a little bit more patient because of that.

**Code B: Accepting Help From Others.** Seventeen participants indicated that they accept help from others or that they have learned to accept help from others since the onset of aphasia. Sixteen made comments which demonstrated that they recognized their limits and accepted help from others. For example, P23 shared, “It’s hard for me to be on the phone. And a guy helped or uh—stopped and helped me call... if you um—ask them, most [people] will help.” Four participants described that learning to accept help from others was difficult for them. They shared comments such as, “I didn’t want any help from anybody, but I learned I have to” (P03),

“it’s hard to accept that I need help” (P06), and “now I have to lean onto other people, and I really don’t like to do that” (P07). Four participants expressed that they are both giving and receiving help, such as P17 who related that he and his wife “help each other.” Two participants shared their confidence that they can do everything they would like to do, with help. For example, P20 shared, “I feel confident because if I can’t do ‘X’, you know? That’s okay because I have so many others that could um—can help.” Finally, two participants said that they have learned that “accepting help is a strength” (P03). For example, P08 explained, “I know that if I need help or I need an accommodation, [it] doesn’t make me a loser. It just makes me smarter... it’s okay to want help every now and then.”

**Code C: Connection to Others.** Seventeen participants made comments about changes in their connection to others since the onset of their aphasia. These included comments indicating positive and negative changes as well as a desire to feel more connected with others. Positive changes were mentioned by 14 participants and included comments about new and strengthened relationships. For example, P08 explained, “I’ve been able to um—meet so many different people that I wouldn’t have that opportunity.” Many participants commented on new friendships with other people who have aphasia, such as P07 who said, “[now] I have friends that are going through the same things and I feel a lot [more] comfortable” and P22 who shared, “aphasia uh—uh—friends are important... I had friends, but man. Aphasia friends are by m—your side... through thick and thin.” In connection to strengthened relationships, P13 remarked that her friends and family “were very important to me earlier, but now they are *extremely* important to me.” Participant comments indicated that these strengthened relationships were the result of learning to ask for help, changed perspectives on life, and putting more effort and energy into their relationships.



Negative changes in connection to others were mentioned by seven participants and included comments about lost friendships and strained relationships. In relation to lost friendships, two participants described relationships that “slowly went away” (e.g., “I had a lot of friends. And then I had—had a stroke. And they slowly, slowly went down because you know, ‘Oh man I-it might be catching!’... I don’t know what they thought, but... they slowly went away”) while three described intentionally choosing to not associate with certain friends because of their aphasia (e.g., “I only associate p—with people who are positive. I don’t—I can’t deal with people... who feel bad for me. I don’t like that.”). In relation to strained relationships, participants described feeling ignored (e.g., PG03 said that even after requesting time with family and friends, “nobody was coming”) and having difficulty in relationships because of their language impairments.

A subset of six participants expressed a desire to feel more connected with others. Sometimes this desire was driven by not having enough connection, and other times this was driven by the increased connection they felt. Five shared that they wanted to be more connected with current loved ones. For example, P01 explained that while he wishes to connect more with his family members, travel constraints and communication challenges made it difficult. Three participants expressed a desire to find more connection within new relationships. For example, P21 shared that she wants to become connected with her neighbors and P06 expressed that he wants to become connected with more people with aphasia.

**Code D: “I Can Help Others.”** Fourteen participants expressed new or changed desires to make an impact on the larger community. Participants described actions they were taking to serve others and advocate for people with aphasia.

***Subcode 1: Altruism.*** Thirteen participants described their desires and/or efforts to care for others. Eight participants discussed the ways in which they can “help others.” For example, P05 said, “I can help others with aphasia by—by talking to them, encouraging them” and P17 said that he wants to participate in more research studies that will help others with aphasia. Six participants spoke of mentorship programs or volunteer work that they are, or will be, involved in. For example, P04 takes time to visit stroke patients in the hospital and P17 is looking into a mentor program at a hospital for people with aphasia. Three participants spoke of altruism as their “passion.” For example, P08 expressed, “that’s always been my ultimate thing: always helping other people.” Two other participants spoke of altruism as a new goal or passion. For example, P20 said, “I wanna’ do more helping people, it’s my passion. It’s my way to live now.”

***Subcode 2: Advocacy.*** Nine participants discussed their efforts to advocate for others with aphasia and/or educate the public about aphasia. Six participants shared ways that they are educating “people who don’t know about aphasia.” For example, P07 said, “I’ve been talking to people and telling about the aphasia because a lot of people don’t know about aphasia.” P15 said, “I think we just need to make it more open, that people need to know more about aphasia and [be] aware of it.” Five participants described how they are helping other PWA find their voice. Of these five participants, four made general statements such as, “I’ve been able to help other people with aphasia [who] don’t have the voice” (P08) and three of these participants mentioned helping PWA find their voice specifically through groups or organizations. For example, P22 started his own support group with no caregivers allowed. Three participants used public speaking as an avenue to educate medical professionals, students, the public, and other PWA about aphasia. For example, P05 expressed, “I’ve helped other people learn about aphasia

because of what happened to me.” One participant described how she has advocated for herself throughout her recovery, such as when she had negative communication experiences with medical professionals. She said, “Even in the beginning I was um—advocating, even though I couldn’t talk.”

### **Discussion**

The purpose of this study was to explore PTG in participants with post-stroke aphasia as well as to explore possible contributors to PTG in a diverse sample of participants with aphasia. Qualitative findings suggest that PWA experience PTG across all three primary domains: (a) changed perception of self, (b) changed relationship with others, and (c) changed general philosophy of life. The challenging circumstances associated with aphasia appeared to be integral to the development of PTG within these domains across participants. Findings also highlight that PTG does not necessarily develop in a linear trajectory for PWA and that processes such as acceptance and slowing down may potentially contribute to the development of PTG in PWA.

#### **The Challenging Circumstances Associated With Aphasia are Integral to the Experience of Posttraumatic Growth**

PTG results from one’s struggle with traumatic or highly challenging life circumstances (Calhoun & Tedeschi, 2001). In this study, comments from participants with aphasia suggest that chronic challenges associated with aphasia were a critical element in the development of their positive psychological growth. Results indicate that it was the wrestle with challenges related to aphasia that led to growth in the way participants viewed themselves, their relationships with others, and their life generally.

As mentioned previously, the presence of posttraumatic growth does not denote the absence of chronic psychosocial stress and pain (Calhoun & Tedeschi, 2001). It is widely known that PWA report significantly worse quality of life than neurologically healthy adults (Hilari, 2011; Ross & Wertz, 2003). Additionally, up to 60% of PWA have been found to experience depression and other psychopathologies (Baker et al., 2018; Code & Herrmann, 2003; Kauhanen et al., 2000; Parr et al., 1997; Zanella et al., 2023). Findings from the present study in no way minimize these realities. Rather, they suggest that positive psychological growth is possible for PWA because of their struggle to face the challenges associated with living with aphasia.

### ***Changed Perception of Self***

Coping with the challenges that accompany life with aphasia led to positive changes in the self-perceptions of many PWA. For example, participants commented on how daily hardships led to growth in their self-perceptions such as developing greater self-efficacy (e.g., “just getting through each day – it makes me believe that I can do things” [P15])) and in seeing themselves as stronger (e.g., “I think that I’m stronger” [P06]). Additionally, these challenges led many participants to renegotiate their identity and reframe their participation in life. Some participants defined growth as discovering and accepting accommodations. These participants recognized growth in the way that they viewed themselves as they gained access to activities they were involved in prior to their stroke (e.g., “I am capable of doing many things, I just have to learn to do it a different way... it just makes me smarter.” [P08]). Other participants felt that they experienced growth through engagement in new activities (e.g., “And so I uh—now I’m trying to uh—to do new things” [P06]). The role that renegotiating identity and reframing participation played in psychological growth for participants in the present study is consistent with previous research, which showed that participation in meaningful activities (whether

resumed, adapted, or newly developed) was an important aspect of living successfully with aphasia (Brown et al., 2012; Cruice et al., 2010). Specifically, Shiggins et al. (2020) noted that while PWA experience “fragmentation after [their] stroke,” they can rebuild their sense of self and their well-being through engagement in new or regained interests. Clinicians can play a vital role in supporting PWA as they wrestle to renegotiate their identity by helping them engage in meaningful activities. One way that clinicians can help fill this need is by assessing their clients’ interest in various life activities through the use of materials such as Life Interests and Values (LIV) cards (Haley et al., 2013). Clinicians can then discuss priorities with PWA and help them to set goals regarding their engagement. Inviting PWA to engage in group therapy and aphasia support groups may also help PWA as they reframe their participation and renegotiate their identity.

Another finding that revealed growth in the self-perceptions of PWA was that almost all participants in this study discussed the importance of fostering a positive attitude amidst their challenging circumstances (e.g., “Maybe I can’t do that right now, but... there’s always another way to try” [P03]). This finding is consistent with previous research, in which both PWA and their family members state that having a positive attitude and focusing on strengths is necessary for living successfully with aphasia (Brown et al., 2010, 2012; Grohn et al., 2014; Shiggins et al., 2020). There is certainly value in clinicians supporting PWA in developing a positive attitude about aphasia and their recovery by helping them recognize successes, identify how they are improving, set goals, etc. These practices can help PWA build confidence and hope in the future. However, qualitative results in this study also emphasize the critical role that difficult circumstances play in the psychological growth of PWA. While helping PWA to think positively can be beneficial, we may miss opportunities to help them experience true growth if we do not

also acknowledge the serious challenges of living with aphasia. Indeed, from the perspective of a posttraumatic growth framework, these challenges are the impetus for much of the growth (Tedeschi & Calhoun, 2004). People with aphasia have commented in previous research on how it is beneficial to focus on more than just positive thinking. For example, feedback from PWA and family members on the “Staying Positive” module of The Aphasia Action, Success, and Knowledge program indicated that participants needed a better opportunity to “express emotions such as the frustration, sadness, and grief associated with living with aphasia” (Ryan et al., 2017, p. 293). The authors reported that one family member explained, “You can’t be positive all the time... staying positive of course is important...but... You need to be allowed to say, ‘this is pretty rough’ sometimes.” (Ryan et al., 2017, p. 293). Acknowledging challenging emotions and experiences instead of only focusing on positivity may help PWA grow and even recognize the good that can come from their adversity.

### ***Changed Relationships With Others***

The difficult circumstances that PWA live with led many participants to develop positive changes in their relationships. For example, participants reported developing a greater amount of empathy for others (e.g., “it just makes me feel for them” [P16]), an increased willingness to accept help from loved ones, new and strengthened relationships, and an interest in serving the larger community (“I’ve helped other people... because of what happened to me” [P05]). Research about PTG broadly suggests that as people who struggle with adversity develop an increased sense of compassion for others, there is a greater probability that they will engage in altruistic activities (Calhoun & Tedeschi, 2001). Previous studies about PWA align with these findings (Manning et al., 2019; Shiggins et al., 2020). For example, a systematic review which analyzed research regarding personal recovery and living successfully with aphasia found that all

31 articles discussed how PWA want to make a positive contribution to society (Manning et al., 2019). PWA may benefit from the support of clinicians in their altruistic efforts, such as in being connected to support groups and service opportunities (Shadden & Agan, 2004).

While almost two-thirds of participants discussed positive changes in their connection to others, it is important to note that almost one-third of participants also discussed negative changes in their relationships. Participants discussed new and strengthened relationships, but also relationships which were strained or lost. This dichotomy reflects the complex reality of adjusting to life with aphasia and is a reminder that while at least some PWA likely experience PTG, their wrestle with chronic challenges resulting from aphasia may continue to cause pain and distress for them even as they experience positive changes (Calhoun & Tedeschi, 2001). Qualitative research in aphasia emphasizes that living successfully with aphasia happens in the context of meaningful relationships (Brown et al., 2012; Cruice et al., 2010; Ross & Wertz, 2003), and that a person with aphasia's satisfaction with their social network is more important for their psychological wellbeing than the number of social connections within that network (Hilari et al., 2010). Clinicians can play a role in helping PWA strengthen their relationships through practices such as inviting family members and friends to participate in communication partner training during therapy (Simmons-Mackie et al., 2016). Clinicians can also support the development of new relationships by providing PWA with resources such as information about virtual and in-person aphasia support groups.

### ***Changed General Philosophy of Life***

Coping with the challenges that accompany life with aphasia seemed to lead to positive changes in the perspectives PWA had on their lives generally. For example, it was the challenges brought on by aphasia that led many participants to “slow down” and experience a new

perspective (e.g., “I had passion before, but [now]... I have the purpose in life” [P22]).

Participants also expressed positive changes in their philosophy on life such as spiritual growth, increased gratitude, and increased humility. Previous literature has discussed the benefits of developing a new perspective on life. For example, Brown et al. (2012) found that SLPs, PWA, and family members all reflected on the benefits of reassessing life priorities post-onset of aphasia. This process led to positive outcomes such as improved family relationships, a more hopeful outlook on life, more engagement in life, and a mindset of moving forward (Brown et al., 2012). Although previous research has not explicitly investigated whether PWA experience increased spirituality, some PWA have expressed that their spirituality helped them better cope with life changes and improve their communication abilities (Laures-Gore et al., 2018).

While discussions about gratitude and humility are largely absent in the aphasia literature, at least one study has discussed how participants felt they had become more “modest” and a “better person” since the onset of aphasia (Shiggins et al., 2020). Studies within both PTG and the broader psychology literature suggest that gratitude is a key aspect of engendering PTG and positive functioning (Bono & Sander, 2018; ; Kim & Bae, 2019; Peterson et al., 2008; Ruini & Vescovelli, 2013; Vernon et al., 2009; Wood et al., 2007). Gratitude is positively associated with positive emotional functioning and positive social relationships (Emmons & Shelton, 2002; McCullough et al., 2002) and negatively associated with conditions such as anxiety, depression, and hostility (Wood et al., 2008). Gratitude interventions such as daily gratitude journals (Watkins et al., 2015) and combining meditation or mindfulness with gratitude (Duthely et al., 2017; Flook et al., 2015) have been shown to be efficacious, although experts suggest that participants must be intrinsically motivated and willing to exert effort in order for gratitude interventions to work (Lyubomirsky et al., 2011). Beyond previous recommendations within



aphasia literature to support PWA by focusing on their improvements and strengths (Brown et al., 2012; Grohn et al., 2014), PWA may experience positive psychological benefits as clinicians encourage them to engage in gratitude practices such as those listed above. Future research is needed to evaluate the efficacy of these approaches in PWA and their impact on PTG.

### **PTG Does Not Necessarily Follow a Linear Trajectory**

Results from this study suggest that the development of PTG in PWA is not a clear-cut, linear process. Participants noted variability in their growth and ability to cope with aphasia throughout their recovery. For example, they described their growth and recovery as a “roller coaster” with “ups and downs” that gradually gets “better in time” (P22). Additionally, participants described some moments where they recognized growth and others that were discouraging. For example, P06 hoped early in his recovery that, with the help of speech therapy, he would “be better.” However, later he shared that life “was really, really hard” after he realized that some of his challenges would be more chronic than he had initially thought. The same participant expressed that later on in his recovery he began feeling more “grateful uh—with my life now” and described experiencing PTG in various areas. Patterns among participants in this study, therefore, suggest that the development of PTG occurs over time and may be difficult to predict.

Due to variability across people and their individual circumstances, we cannot expect PTG to have just one trajectory for PWA. The challenges that accompany life with aphasia do not occur in a vacuum – PWA have unique responses and circumstances which may impact the trajectory of their growth. These individual differences such as family or other social support, extent of life changes (job loss, etc.), mental health challenges, additional hardships, and other circumstances likely play a role in the timing and extent of the development of PTG in PWA. For

example, while the present study did not ask participants about hardships outside of their experience with aphasia, some participants organically brought up these challenges in the context of PTG. Six participants described the difficulty of having a close family member pass away, four discussed physical injuries unrelated to stroke, one described a recent and difficult breakup, and all participants were living through a worldwide pandemic at the time of their interview. Participants described these hardships as part of their journey that led to PTG. For example, of the three participants who shared poignant spiritual experiences which reportedly impacted their spiritual growth in a drastic manner, two described that the recent death of a family member prompted these experiences for them.

Previous research on PTG in PWA suggests another potential area of variability in the trajectory of PTG development: variability of growth across individual PTG domains (relationships to others, new possibilities, etc.). Sherratt and Worrall (2020) examined the PTGI scores of 13 participants across three-month intervals (3, 6, 9, and 12 months post-onset). While the authors did not find significant differences in the mean total PTGI scores at each stage, they reported that visual inspection revealed a general trend toward higher growth over time. A visual inspection of the average trajectory of individual PTG domains across time reveals that there was variety in the “ups and downs” of the development of growth in specific domains. In other words, the average trajectories of specific PTG domains (new possibilities, appreciation of life, etc.) differed among participants, suggesting that overall growth is impacted by variability in specific areas of growth.

Variability in the development of PTG across participants as well as the “ups and downs” within individual participants is a pattern that was noted across the data in this present study. However, additional evidence is needed to support this claim. Analyzing differences among

participants and identifying individual growth trajectories was outside the scope of this study and provokes many questions. For example, what factors cause PWA to respond in a way that leads to more or less growth? What situations impact growth in PWA? Future research investigating individual variability quantitatively and qualitatively is necessary to understand these questions and the overall trajectory of PTG in PWA. The quantitative arm of this current project was aimed at validating the PTGI-Aphasia so that questions such as these can be investigated systematically in the future.

### **Potential Contributors to PTG**

Qualitative evidence from this study suggests that processes such as slowing down and acceptance may contribute to the development of PTG in PWA. While it was not within the scope of this study to produce data that would viably “prove” or provide strong evidence toward the existence and/or nature of potential contributors to PTG, this study does seek to *explore* potential contributors that may be further assessed in future studies.

Results from the present study suggest that the natural process of “slowing down” after stroke led to positive psychological growth for participants, such as the development of new perspectives, increased gratitude, increased altruism, etc. (e.g., “So it slowed me down, but it helped me grow... I needed to be slowed down” [P05]). The process of “slowing down” may relate to proposed psychological processes within the theoretical model for the development of PTG (Calhoun & Tedeschi, 2001; Tedeschi & Calhoun, 2004). Following the traumatic onset of aphasia, PWA theoretically experience a shattering of previous beliefs, goals, purposes, etc. “Slowing down” after the onset of aphasia may make room for cognitive operations such as automatic cognitive processing of trauma which are necessary so that PWA can develop new schemas and manage their initial distress. Tedeschi and Calhoun (2004) emphasize that a period

of time where survivors struggle with distress is necessary because those who come to a quick resolution, experience less enduring change and may not accommodate new perspectives of the world. While both participants in this study and theoretical accounts of PTG consider the process of “slowing down” as positive, it may be easy for clinicians to be so eager to help their clients engage in life that they view a slowed lifestyle as negative. It seems necessary for PWA to have time to slow down and process their experiences, while it is also important for them to engage in meaningful activities. How do therapists find the appropriate balance between pushing people to engage in life and giving them the necessary time to process their new experiences? Future research should clarify how to balance the messy middle ground between supporting PWA in these two important areas.

Another process which appeared to contribute to positive psychological growth in our participants was the development of acceptance. The process of acceptance in the present study included a gradual process of participants coming to understand their abilities and limitations, recognize what was within and outside of their control, and come to terms with and/or reframe the consequences of aphasia (e.g., P08 described aphasia as “a new life, or my new beginning”). The development of acceptance also harkens back to proposed psychological processes within Tedeschi and Calhoun’s theoretical model (Calhoun & Tedeschi, 2001; Tedeschi & Calhoun, 2004). They propose that it is ruminative processes that lead to outcomes such as gradual acceptance and positive accommodation of new experiences. In our study, both acceptance and positive accommodation of experiences were captured under the code “acceptance.” As survivors engage in these ruminative behaviors, becoming self-aware of their growth and learning to positively reinterpret difficult experiences has been shown to significantly relate to greater development of PTG (Cruess et al., 2000; Park et al., 1996; Tedeschi & Calhoun, 2004). While

there is no “recipe” for acceptance, clinicians can help clients become self-aware of their growth and positively reinterpret their experiences. One way that this can be done is through co-construction of personal narratives, which can then be shared with others (Calhoun & Tedeschi, 2001; Tedeschi & Calhoun, 2004). Strong et al.’s (2018) “My Story” project is an approach that provides guidelines for how SLPs can support clients in co-constructing narratives about life with aphasia. Another way that clinicians can support clients in their journey of acceptance is by listening to them and helping them find their own solutions. Solution focused brief therapy is a concrete method that clinicians can draw upon to help clients notice instances of success, identify what is already working, and use these as a foundation to move forward (Northcott et al., 2021). Identifying the appropriate time to target certain processes of PTG is an endeavor that should be explored in future research.

### **Limitations and Future Directions**

Exploratory findings from the present study should be interpreted with the consideration of its limitations. One limitation was the unrepresentative demographic makeup of the sample as well as their high level of engagement. Although the larger research team attempted to recruit a variety of participants through various sources such as aphasia support groups (e.g., National Aphasia Association, Aphasia Access, etc.), social media, hospitals and clinics, and word of mouth, it is known that minority racial and ethnic groups tend to be underrepresented in aphasia research (Nguy et al., 2022) and suspected that those who participate in research may also tend to be more engaged in social activities more broadly. In the present study, 21 participants reported their race as white (91%), one as Black or African American (4%), and one as white and Pacific Islander (4%; see Table 1). These demographics are far from representative of the national population. Additionally, 17 out of 23 participants in our study reported involvement in an

aphasia support group (74%), 10 reported involvement in a friend group (43%), nine were involved with an aphasia center (39%), eight participated in social media groups for stroke and/or aphasia (35%), six reported involvement in a stroke support group (26%), and three participated in a family group (13%). Only three participants reported that they were not connected to any groups (13%). Because both the demographic characteristics and engagement levels of our research participants were not representative of all persons with aphasia, we cannot generalize these findings to PWA broadly.

A second limitation to consider is that qualitative data for this study was collected during a worldwide pandemic where social gatherings were discouraged. For the purposes of this study, responses from participants that indicated psychological or behavioral changes directly resulting from COVID-19 (e.g., P01 felt less connected to his family because he could not visit them) were excluded from analysis (e.g., Connection to Others). However, it is likely that the COVID-19 pandemic influenced the behaviors, connectedness, attitudes, and feelings of participants in undetected ways that affected their responses in the questionnaires and semi-structured interviews.

Although findings from the present study should only be interpreted with these limitations in mind, the purpose of the study was not to make broad generalizations about an entire population or to experimentally determine the trajectory of PTG for PWA. Instead, we explored PTG within the lived experiences of PWA in order to pave the way for future research. Future research is needed to empirically determine longitudinal trajectories of PTG post-aphasia and investigate how PTG contributes to recovery of both language and psychosocial functioning. Additionally, this study set the stage for future quantitative work focused on determining whether the potential contributors mentioned by participants (slowing down and acceptance) do,

indeed, facilitate PTG for PWA. Similarly, comments from PWA in the present study indicate that certain interventions may be particularly helpful for facilitating PTG (e.g., supporting engagement, acknowledging challenging emotions and experiences, helping PWA recognize successes, encouraging gratitude, co-constructing personal narratives, etc.), which should be investigated in future work. The recently validated Posttraumatic Growth Inventory for Aphasia (PTG-Aphasia) will likely be instrumental in answering these questions quantitatively (Brancamp et al., 2022).

### **Conclusion**

People with aphasia experience traumatic experiences that cause their aphasia (e.g., stroke) as well as chronic challenges that accompany life with aphasia. Findings from the present study indicate that these lead many PWA to develop posttraumatic growth (PTG), or positive psychological changes. Specifically, PWA described experiencing psychological growth in the three PTG domains of (a) changed perception of self, (b) changed relationship with others, and (c) changed general philosophy of life. The significance of challenging circumstances associated with aphasia in leading to the development of PTG within these domains was reported by participants with aphasia. Findings also highlight that PTG may not necessarily develop in a linear trajectory for PWA but that processes such as acceptance and slowing down may contribute to the overall development of PTG in PWA. Future research should quantitatively assess the trajectory of PTG in PWA, the efficacy of interventions that may facilitate PTG, and how PTG contributes to recovery.

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## Tables

**Table 1**

*Participant Demographic Information*

Ppt ID	Age (years)	Months post-stroke	Gender	Race	Ethnicity	Education	Occupational Status	Marital Status	PTGI-A	QAB
P01	47	69	M	W	Not Hisp.	Bachelor	Full Time	Married	68	6.72
P02	77	52	M	W	Not Hisp.	Master's	Retired, NR	Married	45	4.15
P03	60	21	F	W	Not Hisp.	Master's	Retired, related	Married	27	7.87
P04	46	163	M	W	Other	Bachelor	Retired, related	Single	16	7.24
P05	50	26	F	W	Other	Associate	Retired, related	Married	71	8.87
P06	60	38	M	W; PI	Not Hisp.	Bachelor	Retired, related	Married	64	7.93
P07	49	247	F	W	Other	Master's	Retired, related	Married	53	6.64
P08	54	65	F	W	Unreported	Master's	Retired, related	Married	73	7.96
P09	51	20	F	W	Other	Bachelor	Retired, related	Single	58	4.11
P10	59	103	F	W	Not Hisp.	Some Coll.	Retired, related	Married	73	8.19
P11	64	129	F	W	Not Hisp.	Doctorate	Volunteer	Married	46	7.71
P12	53	115	M	W	Not Hisp.	Master's	Part time	Single	35	4.77
P13	57	49	F	W	Not Hisp.	Master's	Retired, related	Married	72	9.13
P14	53	193	F	AA	Other	Master's	Retired, related	Single	66	2.55
P15	50	31	F	W	Not Hisp.	High School	Retired, related	Single	60	9.47
P16	74	16	F	W	Not Hisp.	Some Coll.	Retired, not related	Married	61	9.6
P17	69	57	M	W	Not Hisp.	Bachelor	Retired, not related	Married	50	6.1
P18	78	31	M	W	Not Hisp.	Bachelor	Part time	Married	31	7.87
P19	48	33	M	W	Not Hisp.	Master's	Retired, related	Married	54	8.46
P20	27	61	M	W	Not Hisp.	Bachelor	Volunteer	Single	88	8.75
P21	76	87	F	W	Not Hisp.	Bachelor	Retired, related	Single	66	5.91
P22	60	251	M	W	Not Hisp.	High School	Retired, related	Married	92	7.74
P23	73	61	M	W	Other	Some Coll.	Retired, related	Married	81	7.62

*Note.* Ppt = participant; W = White; PI = Pacific Islander; AA = Black or African American; Not Hisp. = Not Hispanic or Latino/Latina; Education column indicates the highest degree completed; Some Coll. = Some college; Full Time = Working full time for pay; Retired, not related = Retired, not related to current medical status; Retired, related = Not working/retired early, because of

medical condition; Volunteer = Working as a volunteer; Part time = Working part time for pay; Married= Married/Committed relationship; Single = Single/Divorced/Widowed; PTGI-A = Posttraumatic Growth Inventory – Aphasia total growth score; and QAB = Quick Aphasia Battery overall score.

**Table 2***Posttraumatic Growth Inventory Scores*

Ppt ID	Personal Strength (Out of 20)	New Possibilities (Out of 25)	Relating to Others (Out of 35)	Appreciation of Life (Out of 15)	Spiritual Change (Out of 10)	Total Growth (Out of 105)
P01	15	19	23	8	3	68
P02	17	4	19	5	0	45
P03	4	11	8	4	0	27
P04	0	6	0	10	0	16
P05	8	15	28	10	10	71
P06	6	18	25	11	4	64
P07	8	11	21	13	0	53
P08	11	21	25	13	3	73
P09	13	13	21	8	3	58
P10	13	16	23	13	8	73
P11	0	14	25	7	0	46
P12	11	7	10	7	0	35
P13	10	13	28	11	10	72
P14	17	15	12	14	8	66
P15	7	11	22	14	6	60
P16	8	6	25	13	9	61
P17	11	8	18	9	4	50
P18	7	0	14	10	0	31
P19	2	17	25	8	2	54
P20	14	20	30	15	9	88
P21	11	16	23	9	7	66
P22	16	23	33	10	10	92
P23	12	20	28	14	7	81

*Note.* Ppt = participant.

**Table 3***Quick Aphasia Battery Scores*

Ppt ID	Word Comp.	Sent. Comp.	Word Find.	Gramm.	MS	Repetition	Reading	Overall
P01	9.58	5.00	7.42	6.75	5.00	5.83	3.75	6.72
P02	5.00	0.00	5.25	7.38	2.50	1.67	4.58	4.15
P03	10.00	5.83	8.75	9.75	7.50	9.58	9.58	7.87
P04	10.00	6.25	6.25	5.50	7.50	7.50	6.67	7.24
P05	10.00	8.33	9.00	10.00	5.00	9.58	10.00	8.87
P06	10.00	2.50	9.00	8.75	10.00	7.92	9.58	7.93
P07	10.00	0.42	5.5	7.75	7.50	8.33	8.75	6.64
P08	10.00	6.67	4.00	9.25	7.50	9.17	7.08	7.96
P09	9.58	4.17	2.25	0.75	5.00	3.75	1.25	4.11
P10	10.00	8.33	8.00	7.25	7.50	8.33	7.50	8.19
P11	8.33	9.58	7.00	4.75	7.50	9.17	9.58	7.71
P12	10.00	3.33	2.00	6.13	5.00	4.58	0.00	4.77
P13	10.00	9.58	8.75	8.00	10.00	10.00	8.33	9.13
P14	8.33	2.92	1.50	0.13	0.00	3.75	0.00	2.55
P15	10.00	7.92	10.00	9.63	10.00	8.75	10.00	9.47
P16	8.75	10.00	8.75	10.00	10.00	10.00	10.00	9.60
P17	9.58	0.00	7.58	4.75	10.00	6.25	7.08	6.10
P18	9.58	9.58	5.25	8.25	10.00	5.83	6.67	7.87
P19	10.00	9.58	7.00	7.50	7.50	8.33	10.00	8.46
P20	9.58	9.17	6.00	9.63	10.00	8.75	10.00	8.75
P21	7.92	2.92	5.08	7.00	10.00	2.08	5.83	5.91
P22	9.58	6.25	6.50	8.75	7.50	8.75	7.08	7.74
P23	9.58	8.33	6.00	9.00	5.00	6.25	6.25	7.62

*Note.* Ppt = participant; Word Comp. = Word Comprehension; Sent. Comp. = Sentence

Comprehension; Word Find. = Word Finding; Gramm. = Grammatical Construction; and MS = Speech Motor Programming. The QAB overall score and all sub scores range from 0 to 10.

**Table 4***Categorization of Results*

Theme	Category	Code/Subcode
I. Recovery is a Journey	1. Moving Toward Growth	A. Grappling with New Reality B. Acceptance C. Goals and Effort D. Improvement
	2. Engagement	A. Communication Activities B. Getting Out C. Engagement in Other Activities D. Withdrawal
II. Having Aphasia is Challenging, but I've Grown	1. Challenges and Reactions	A. Challenging Communication Environments B. "Frustrated," "Tired," "Mad," Discouraged, Embarrassed, "Overwhelmed," "Upset," "Irritate[d]," and Lonely C. Mood and Mental Health D. Emotion Impacts Communication
	2. Perception of Self	A. Attitudes of Growth <ul style="list-style-type: none"> <li>i. "I was Determined"</li> <li>ii. Positive Outlook</li> <li>iii. Self-Efficacy: "I'm Capable of Doing [Things]"</li> </ul> B. Renegotiating Identity <ul style="list-style-type: none"> <li>i. Changing Roles</li> <li>ii. Changing Activity Participation</li> <li>iii. Working Toward Autonomy</li> </ul> C. "I Think That I'm Stronger"
	3. General Philosophy of Life	A. "I Slowed Down" B. New Perspective C. "I'm...Grateful" D. "I Think Aphasia Makes You Humble" E. Spiritual Beliefs, Practices, and Growth
	4. Relatedness	A. Greater Empathy B. Accepting Help from Others C. Connection to Others D. "I Can Help Others" <ul style="list-style-type: none"> <li>i. Altruism</li> <li>ii. Advocacy</li> </ul>

## APPENDIX A

**Annotated Bibliography**

Brown, K., Worrall, L. E., Davidson, B., & Howe, T. (2012). Living successfully with aphasia:

A qualitative meta-analysis of the perspectives of individuals with aphasia, family members, and speech-language pathologists. *International Journal of Speech-Language Pathology*, 14(2), 141–155. <https://doi.org/10.3109/17549507.2011.632026>

*Objective:* The purpose of this study was to learn about the perspectives of people with aphasia, speech-language pathologists, and family members regarding living successfully with aphasia.

*Method:* The authors performed a meta-analysis of three qualitative studies. The concepts from each individual study were re-interpreted into the other studies through an iterative process, which included comparing and contrasting themes and subthemes. The authors created overarching themes to describe the similarities, differences, and relationships between the three studies.

*Results/conclusions:* Seven overarching themes were identified to describe the data across the three studies: (a) participation, (b) meaningful relationships, (c) support, (d) communication, (e) positivity, (f) independence, and (g) living successfully with aphasia as a journey over time. The authors concluded that treatment approaches for people with aphasia should be client-centered and focus on participation. Additionally, they noted that family members should be more involved in the rehabilitation process and that positivity and hope are greatly needed in therapy services.

*Relevance:* This article is relevant to my project because it identifies factors that help people with aphasia have positive experiences. Additionally, the presentation of



qualitative research using themes and subthemes helps me think about how I might want to present the data for my project.

Calhoun, L. G., & Tedeschi, R. G. (2001). Posttraumatic growth: The positive lessons of loss. In *Meaning reconstruction & the experience of loss* (pp. 157–172). American Psychological Association. <https://doi.org/10.1037/10397-008>

This book chapter defines posttraumatic growth, gives a broad picture of the domains of posttraumatic growth, briefly describes the process by which posttraumatic growth occurs, discusses questions that need to be answered through research, and provides implications for psychological clinicians. The authors describe posttraumatic growth as falling within three domains: (a) changed sense of self (e.g., viewing themselves as stronger or more capable and developing an increased sense that life is fragile and precious); (b) changed relationships (e.g., increased connection with others and a deepened sense of empathy); and (c) existential and spiritual growth (e.g., enhanced sense of the meaning of life). Posttraumatic growth is described as positive change resulting from the struggle with major loss or trauma. It is the struggle with loss and not the traumatic event itself that provides a catalyst for growth. Individuals who experience such growth may not experience it in all areas and will likely experience pain and distress as well. Individual differences such as personality and gender affect the likelihood of growth. Cognitive processing, occurring automatically at first and then deliberately, may lead to greater posttraumatic growth.

This chapter is highly relevant to my study. Its overview of posttraumatic growth and the factors which influence it provide necessary background for the research design and analysis of the present study.

Gangstad, B., Norman, P., & Barton, J. (2009). Cognitive processing and posttraumatic growth after stroke. *Rehabilitation Psychology, 54*(1), 69–75. <https://doi.org/10.1037/a0014639>

*Objective:* The purpose of this study was to understand the relationships between posttraumatic growth after stroke, cognitive processing, and psychological distress. The authors also assessed whether the amount of time post-stroke impacted the relationships between these variables.

*Method:* 60 stroke survivors completed the Posttraumatic Growth Inventory (PTGI), the Cognitive Processing of Trauma Scale (CPOTS), and the Hospital Anxiety and Depression Scale (HADS). Individuals who were unable to complete questionnaires due to cognitive impairments were not included in the study.

*Results/conclusions:* Posttraumatic growth had a positive correlation with four indicators of cognitive processing: positive cognitive restructuring, downward comparison, resolution, and denial. PTG correlated negatively with depression. The amount of time post-stroke impacted the significance of these relationships. As the length of time post-stroke increased, the correlation between PTG and downward comparisons and resolution became more positive. The correlation between PTG and anxiety and depression became more negative as time post-onset increased as well. These findings suggest that PTG is possible after stroke and demonstrate that cognitive processing may help stroke survivors experience growth.

*Relevance:* This study uses the original form of the Posttraumatic Growth Inventory (PTGI), whereas the participants in my study will have completed a modified form of the PTGI prior to their interview. The modified form (PTGI-Aphasia) has been

altered to support communication for people with aphasia. Additionally, this article is relevant because it assesses PTG in stroke survivors.

Gillen, G. (2005). Positive consequences of surviving a stroke. *American Journal of Occupational Therapy*, 59(3), 346–350. <https://doi.org/10.5014/ajot.59.3.346>

*Objective:* The purpose of this study was to learn about the psychosocial experience of stroke survivors who are participating in inpatient rehabilitation. The investigators sought to discover whether stroke survivors who were participating in inpatient rehabilitation experienced positive consequences due to their stroke.

*Method:* Sixteen stroke survivors were interviewed about the positive consequences related to their stroke. Individuals with aphasia were excluded from this study. The authors calculated frequency distributions of a response set (e.g., “yes,” “no,” “I am not sure,” etc.). “Yes” answers were recorded verbatim and analyzed for themes. Comments from a licensed clinical psychologist who reviewed the codes and themes were included in the final analysis.

*Results/Conclusions:* Sixty-three percent of participants were able to identify positive consequences of their stroke. Five themes emerged from the qualitative analysis of the open-ended interviews: increased social relationships, increased health awareness, change in religious life, personal growth, and altruism. The authors concluded that there is preliminary evidence of some stroke survivors experiencing positive consequences by reframing their experience with an optimistic outlook.

*Relevance:* Although the authors do not directly refer to posttraumatic growth, the concept of identifying positive consequences following a traumatic event is relevant. Additionally, all the participants in this study and in my study have experienced a stroke.

Grohn, B., Worrall, L., Simmons-Mackie, N., & Hudson, K. (2014). Living successfully with aphasia during the first year post-stroke: A longitudinal qualitative study. *Aphasiology*, 28(12), 1405–1425. <https://doi.org/10.1080/02687038.2014.935118>

*Objective:* The purpose of this study was to explore the perspectives of people with aphasia about what is important to living successfully with aphasia. The authors also examined changes that develop throughout their first year of recovery.

*Method:* A prospective longitudinal design was used for this study. Fifteen individuals with aphasia participated in semi structured interviews at 3-, 6-, 9-, and 12-months post-stroke. The Successfully Living with Aphasia Rating Scale (SLARS) was used as a support tool during interviews and was used to orient participants to the topic of living successfully with aphasia. Codes and themes were created using thematic analysis.

*Results/Conclusions:* Results from qualitative analysis of the data revealed one overarching theme: actively moving forward. A number of factors were found to be important in creating a successful life with aphasia across time. These included perceived communication improvement, engagement in activities, social support, and maintaining positivity. The authors conclude that a holistic approach to aphasia should be paired with direct intervention efforts to help people with aphasia and their families succeed.

*Relevance:* This study is relevant to my own due to its focus on the possibilities of a successful life with aphasia as opposed to a deficits point of view. Additionally, the thematic analysis described uses the same general qualitative procedures as my own study.

Haley, K. L., Womack, J. L., Harmon, T. G., McCulloch, K. L., & Faldowski, R. A. (2019). Life activity choices by people with aphasia: Repeated interviews and proxy agreement.

*Aphasiology*, 33(6), 710–730. <https://doi.org/10.1080/02687038.2018.1506087>

*Objective:* The aims of this study were to distinguish life activities that people with aphasia want to do, estimate consistency in preferred activities over time, and replicate previous findings about how well family members and friends are able to predict the activity preferences of their loved ones.

*Method:* The Life Interests and Values (LIV) cards were administered to 26 people with aphasia. The participants were asked which of the 95 life activities they wanted to do more in their lives. One to ten weeks later, half of the activity cards were presented to the participants again. Twenty family members or friends were administered a questionnaire with the same items and asked to respond as proxies for their loved ones.

*Results/Conclusions:* The participants with aphasia demonstrated diverse activity interests. Overall, significantly more activities from the “social” activity category were selected than from the “home and community,” “creative and relaxing,” or “physical” categories. Participants selected identical activities across time on an average of 78%. Agreement between participants with aphasia and their family members or friends was significantly lower at 69%. The authors concluded that people with aphasia are interested in many different activities and are reliable in informing others about their activity preferences. Family members and friends, however, have limited ability to predict the activity choices of their loved ones.

*Relevance:* This article is relevant to the category of “new possibilities” within the posttraumatic growth framework. This category considers new purpose, interests, and

activities following a traumatic event. The findings in this article help me understand the diversity of interests of people with aphasia and confirm the capacity of people with aphasia to understand their interests and preferences.

Hilari, K., & Northcott, S. (2006). Social support in people with chronic aphasia. *Aphasiology*, 20(1), 17–36. <https://doi.org/10.1080/02687030500279982>

*Objective:* The aim of this study was to explore the patterns of social support in people with chronic aphasia. The authors looked at the relationship between social support and quality of life to see which aspects of social support were most associated with health-related quality of life (HRQL).

*Method:* Ninety-five people with aphasia were administered the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39), the MOS Social Support Survey (SSS), and a social network questionnaire. The data from this cross-sectional interview-based survey study were analyzed using descriptive statistics, correlation, t-tests, and ANOVAs.

*Results/Conclusions:* Eighty-three of out ninety-five participants were able to self-report. The mode of the size of social networks was 4, with the size of network being associated with health-related quality of life for women only. Most participants (71%) maintained the same amount of contact with their children following their stroke. Those who maintained the same level of contact with their family as before the stroke had the highest health-related quality of life. Many participants (64%) reported seeing their friends less since their stroke. The SSS scores had a mean of 3.69, which suggests that participants felt well-supported overall. Social companionship and informational support were both significantly correlated with health-related quality of life. The authors concluded that complementing and supporting existing social networks as well as

facilitating access to information and social participation could improve quality of life for people with aphasia.

*Relevance:* This study is relevant because the factors of social support in people with aphasia are related to their relationships, which is one of the five domains of posttraumatic growth.

Hinckley, J. J. (2006). Finding messages in bottles: Living successfully with stroke and aphasia.

*Topics in Stroke Rehabilitation*, 13(1), 25–36. <https://doi.org/10.1310/FLJ3-04DQ-MG8W-89EU>

*Objective:* The aim of this study was to explore what it takes to live successfully with aphasia using published accounts written by people with aphasia.

*Method:* The author searched for published personal narratives (books or journal articles) authored or co-authored by a person with chronic aphasia following a stroke. 20 published articles and books were reviewed and analyzed qualitatively.

*Results/Conclusions:* Four themes emerged from the question, “What does it take to live successfully with stroke and aphasia?”: social support, renegotiating self-identity, setting new future goals, and taking responsibility for one’s own continued improvement. 70% of the accounts fit within the definition of a quest narrative, one article was consistent with the definition of a chaos narrative, and 25% were classified as restitution narratives. The author concludes that clinicians must listen to the stories of people with aphasia to know how to best support them.

*Relevance:* This article is relevant due to its positive approach in learning how people with aphasia are successful following a stroke. Their use of thematic analysis is relevant to this study as well.

Holland, A. L. (2006). Living successfully with aphasia: Three variations on the theme. *Topics in Stroke Rehabilitation*, 13(1), 44–51. <https://doi.org/10.1310/13D7-R31R-8A0D-Y74G>

*Objective:* The purpose of this study was to explore the experiences of three individuals with aphasia who live meaningful lives.

*Method:* Three people with aphasia were selected from a larger set of 28 participants. The three selected were chosen because of the diversity in their aphasia and lifestyles. One-to-two-hour long interviews were conducted with each participant to understand their success in living with aphasia.

*Results/Conclusions:* Themes from analysis of the interviews include “who you were before you had a stroke,” autonomy and independence, severity of aphasia, overall good physical and emotional health, and time post onset. The author concludes that good health, aphasia severity, financial security, and personal qualities such as resilience and optimism all contribute to living well with aphasia. Results from this study support the notion that it takes 2-3 years post-stroke for people with aphasia to begin to live life again.

*Relevance:* This article is relevant due to its positive focus regarding the lives of people with aphasia following the traumatic incident of a stroke. The author points out aspects of her participants’ lives that are better since the onset of their aphasia, which directly relates to the concept of posttraumatic growth.

Joseph, S., & Linley, P. A. (2005). Positive adjustment to threatening events: An organismic valuing theory of growth through adversity. *Review of General Psychology*, 9(3), 262–280. <https://doi.org/10.1037/1089-2680.9.3.262>



*Objective:* The authors in this article propose an explanatory positive psychological theory of growth. The organismic valuing theory of growth is intended to explain the processing that leads to both growth and distress following a traumatic event.

*Method:* Four criteria for a comprehensive theory of growth through adversity were established and the strengths and weaknesses of existing theories were examined. A new theory was introduced that meets all four theoretical criteria.

*Results/Conclusions:* The organismic valuing theory of growth was described. The authors proposed three potential outcomes of cognitive-emotional processing after trauma: assimilation, negative accommodation, and positive accommodation. They conclude that while assimilation is likely most common, those who positively accommodate their experiences will experience positive changes in their psychological well-being.

*Relevance:* This study provides a relevant discussion of Tedeschi and Calhoun's PTG theory along with descriptions of other growth theories. Additionally, the organismic valuing theory of growth through adversity demonstrates why some individuals may experience growth while others experience symptoms of psychopathology. Seeing how growth is achieved using this model can guide my understanding during the analysis of data in my study.

Kelly, G., Morris, R., & Shetty, H. (2018). Predictors of post-traumatic growth in stroke survivors. *Disability and Rehabilitation*, *40*(24), 2916–2924.

<https://doi.org/10.1080/09638288.2017.1363300>

*Objective:* The purposes of this study were to (a) use a longitudinal design to test the hypothesis that posttraumatic growth would develop after a stroke, (b) demonstrate that

levels of PTG in this study were comparable to stroke survivors in similar samples, and (c) test the predicted variables associated with posttraumatic growth from two models.

*Method:* Forty-three stroke survivors were evaluated using the Posttraumatic Growth Inventory and a series of other questionnaires at two time points which were six months apart. Individuals who experienced significant cognitive difficulties were excluded from this study.

*Results/Conclusions:* Posttraumatic growth appeared between four- and five-months post-stroke and significantly increased over time. Deliberate rumination, active coping, and denial coping were associated with posttraumatic growth. These results demonstrate the complexity of positive growth following a stroke.

*Relevance:* Kelly and Shetty's work is relevant to my study due to its focus on posttraumatic growth, the exploration of PTG in stroke survivors, use of the PTGI, and the interest demonstrated in factors that contribute to PTG.

Kuenemund, A., Zwick, S., Rief, W., & Exner, C. (2016). (Re-)defining the self – Enhanced posttraumatic growth and event centrality in stroke survivors: A mixed-method approach and control comparison study. *Journal of Health Psychology, 21*(5), 679–689.

<https://doi.org/10.1177/1359105314535457>

*Objective:* The main aim of this study was to explore both negative and positive changes associated with a stroke. Other purposes include comparing positive and negative changes of stroke survivors to matched control participants and exploring relationships between posttraumatic growth and measures of mental health.

*Method:* Forty-two stroke survivors at 21 months post-stroke and 42 controls participated in filling out standardized questionnaires to assess identity changes.

Individuals were excluded from this study if they were unable to complete self-report questionnaires due to receptive and expressive language deficits. Twenty-six stroke survivors then participated in a semi-structured interview via telephone. The authors created codes and themes that represented the qualitative data.

*Results/Conclusions:* Stroke survivors demonstrated significantly higher posttraumatic growth when compared to the control group. Stroke survivors also reported integrating the traumatic event into their identity. Qualitative analysis resulted in two main positive changes: increased appreciation of life and more intense/selective relationships.

*Relevance:* This article is relevant to my study due to its focus on posttraumatic growth in stroke survivors, its use of the PTGI, its study design which incorporates both quantitative and qualitative analysis, and the inclusion of a similar number of participants engaging in a semi-structured interview.

Laures-Gore, J. S., Lambert, P. L., Kruger, A. C., Love, J., & Davis, D. E. (2018). Spirituality and post-stroke aphasia recovery. *Journal of Religion and Health, 57*(5), 1876–1888.  
<https://doi.org/10.1007/s10943-018-0592-4>

*Objective:* The purpose of this study is to explore the spiritual experiences of adults with aphasia to better understand the potential contribution of spirituality in the aphasia recovery process.

*Method:* Thirteen people with aphasia were administered a modified spirituality questionnaire and subsequently participated in a semi-structured interview. Interviews were analyzed using thematic analysis.

*Results/Conclusions:* All thirteen participants reported that they consider themselves to be spiritual in the questionnaire. All participants reported improvements in communication following their stroke during the semi-structured interview, and eleven believed that spirituality and religion had contributed to these improvements in their recovery. Two themes were identified: (a) belief in a greater power being in control of events and (b) belief in a greater power as a helper. Spirituality offers a form of coping that may be a helpful resource for people with aphasia when coping with major life changes such as a stroke.

*Relevance:* The spirituality of people with aphasia and its impact on their recovery is relevant to the final domain of posttraumatic growth: spiritual change. This article is one of few which explore spirituality in people with aphasia. It is also relevant because its qualitative analysis of the semi-structured interviews is similar to the method I will be using.

Linley, P. A., & Joseph, S. (2004). Positive change following trauma and adversity: A review.

*Journal of Traumatic Stress, 17*(1), 11–21.

<https://doi.org/10.1023/b:jots.0000014671.27856.7e>

*Objective:* The purpose of this study was to review research that has investigated the variables accompanying positive growth in response to adversity.

*Method:* The authors looked at findings from 39 studies that investigated positive change associated with trauma and adversity. Included literature were found by searching three major databases (PsychINFO, PILOTS, and Ingenta) using specific search terms (thriving, perceived benefit, perception of benefit, positive adjustment, and positive adaptations). Other sources were found by checking for references within publications

containing search terms and through references known by the authors with relevance to the review.

*Results/Conclusions:* There were three main findings from the results of the review. First, the authors conclude that those who experience perceptions of life threat, uncontrollability, and helplessness resulting from traumatic experiences are more likely to experience growth. Second, individuals who are optimistic and who deal with events through positive reinterpretation, acceptance coping, and effortful rumination are more likely to report greater growth. Third, a range of negative and positive associations between growth and distress are possible.

*Relevance:* This article provides a comprehensive review of empirical studies that document positive changes following a myriad of traumatic and adverse circumstances. This is relevant to my study due to its focus on posttraumatic growth and the factors that are likely to precipitate growth in individuals.

Manning, M., MacFarlane, A., Hickey, A., & Franklin, S. (2019). Perspectives of people with aphasia post-stroke towards personal recovery and living successfully: A systematic review and thematic synthesis. *PloS ONE*, *14*(3), Article e0214200.

<https://doi.org/10.1371/journal.pone.0214200>

*Objective:* The purpose of this study was to synthesize research exploring the perspectives of people with aphasia on living successfully. The authors aimed to advance understanding about how to best promote recovery and living well with aphasia

*Method:* A systematic review was conducted using 7 electronic databases. Thirty-one articles were selected. Thematic synthesis was used to develop initial descriptive

codes, identify similarities and differences among codes, and develop analytical themes which represented the data.

*Results/Conclusions:* The results of the thematic synthesis of the 31 articles are described by the following five themes: (a) Aphasia occurs in the context of a wider social network that provides valued support and social companionship and has its own need for formal support; (b) PWA want to make a positive contribution to society; (c) The participation of PWA is facilitated by opportunities and supportive, enabling environments; (d) PWA benefit from access to a flexible, responsive, life-relevant range of services in the long-term post-stroke; and (e) Accessible information and collaborative interactions with aphasia-aware healthcare professionals empower PWA to navigate the health system and direct their own recovery. The authors conclude that these themes represent the perspectives of people with aphasia concerning factors that have to do with living well.

*Relevance:* This study is relevant because it integrates findings from many different studies regarding positive factors in the recovery of people with aphasia. The qualitative thematic analysis used and the asset-based focus which was present are both also relevant to the present study.

Ross, K., & Wertz, R. (2003). Quality of life with and without aphasia. *Aphasiology*, 17(4), 355–364. <https://doi.org/10.1080/02687030244000716>

*Objective:* The purpose of this study was to identify which of the 24 facets of quality of life proposed by the World Health Organization (WHO) differentiate quality of life between people with aphasia and people without aphasia.

*Method:* The authors implemented a prospective, observational, non-randomized group design using two measures. The short form of the WHO quality of life instrument (WHOQOL-BRIEF) and the Psychosocial Well-Being Index (PWI) were administered to 18 people with chronic aphasia and 18 neurotypical adults. The authors used indices of determination (ID) and degrees of overlap (DO) to identify which of the 24 facets of quality of life proposed by the WHO were best at differentiating between the two groups.

*Results/Conclusions:* Level of independence, social relationships, and environment were the three domains which were best at differentiating the quality of life of people with aphasia from people without aphasia. The authors concluded that therapy goals which focus on participation in society and situation-specific communication will be most helpful in improving the quality of life of people with chronic aphasia.

*Relevance:* This article is relevant to my study because it identifies some of the barriers to quality of life that people with aphasia face. These are important factors to consider when investigating the growth that some individuals may experience while struggling with these factors in their recovery.

Sherratt, S., & Worrall, L. (2019). *Changing and growing: An exploration of posttraumatic growth narratives in aphasia*. Research Gate.

<https://doi.org/10.13140/RG.2.2.24767.97446>

*Objective:* The aim of this pre-print study was to discover whether people with aphasia documented unsolicited posttraumatic growth in their academic and self-written reports.

*Method:* The authors conducted a systematic search of the literature using research databases, writings from pioneering authors involved in qualitative research on

people with aphasia, and writings by individuals with aphasia. Qualitative analysis was used to identify themes.

*Results/Conclusions:* Ninety-one documents were found and analyzed. Analysis demonstrated that some people with wrote about non-specific PTG statements as well as comments specifically relating to PTG domains. Findings show that some people with aphasia experience posttraumatic growth

*Relevance:* The study is relevant due to its focus on PTG in people with aphasia. The study provides helpful background for PTG and its relationship to stroke and aphasia.

Sherratt, S., & Worrall, L. (2020). Posttraumatic growth following aphasia: A prospective cohort study of the first year post-stroke. *Aphasiology*, 35(3), 291–313.

<https://doi.org/10.1080/02687038.2020.1787945>

*Objective:* The aim of this study was to discover if people with aphasia experience posttraumatic growth during their first year of recovery.

*Method:* A prospective longitudinal cohort study design was used to assess thirteen people with aphasia during their first-year post-stroke. The Posttraumatic Growth Inventory (PTGI) was administered to participants prior to a semi-structured interview conducted in the participant's homes.

*Results/Conclusions:* Quantitative results demonstrated no significant differences in the mean total score or the five individual domains of the PTGI. There was, however, a trend of greater growth over time since the stroke. Comments from participants illustrated growth in relationships, positive traits, appreciation of life, and a sense of what is



important. The authors conclude that some participants can experience posttraumatic growth.

*Relevance:* There are many similarities between this study and my own. The authors explored posttraumatic growth in people with aphasia, both quantitative and qualitative measures were used, and, specifically, the PTGI and semi structured interviews were conducted. This is a preliminary study that recommends research investigating a larger pool of participants and greater range in time after the traumatic event which causes aphasia. The present study aims to expand the findings of this study.

Shiggins, C., Soskolne, V., Olenik, D., Pearl, G., Haaland-Johansen, L., Isaksen, J., Jagoe, C., McMenamin, R., & Horton, S. (2020). Towards an asset-based approach to promoting and sustaining well-being for people with aphasia and their families: An international exploratory study. *Aphasiology*, 34(1), 70–101.

<https://doi.org/10.1080/02687038.2018.1548690>

*Objective:* The purpose of this study was to explore the relevance of interventions focused on promoting well-being in the lives of people with aphasia and their families.

*Method:* 95 people with aphasia and 25 family members from the United Kingdom, Norway, Israel, Ireland, and Denmark were interviewed and involved in group discussions. Participants were asked about what makes them feel good/well/healthy. Thematic analysis was used to analyze the data.

*Results/Conclusions:* An asset-based approach to promoting and sustaining well-being is relevant and demonstrates great potential. Key themes of what helped participants live with aphasia are as follows: (a) personal journey; (b) helping others; (c) connecting to self; (d) connecting to others; (e) recreation; and (f) personal attributes.

These results strengthen the case for a greater focus on how people with aphasia can connect to what keeps them well, rather than focusing on deficits.

*Relevance:* This study is relevant because of its focus on encouraging wellness and other positive outcomes in people with aphasia. Additionally, the authors' use of thematic analysis for qualitative data is similar to the process I will be using in my study.

Strong, K. A., Lagerwey, M. D., & Shadden, B. B. (2018). More than a story: My life came back to life. *American Journal of Speech-Language Pathology*, 27(1S), 464–476.

[https://doi.org/10.1044/2017\\_AJSLP-16-0167](https://doi.org/10.1044/2017_AJSLP-16-0167)

*Objective:* The purpose of this study was to explore the experiences of people who participated in a personal narrative construction project to support identity renegotiation.

*Method:* Three adults with aphasia participated in qualitative interviews following a month-long personal narrative coconstruction project. The project included administration of the Communication Confidence Rating Scale for Aphasia at the beginning and end of the program. The authors analyzed results using interpretative phenomenological analysis.

*Results/Conclusions:* Analysis of data revealed three themes: (a) More than a story: It changed my life; (b) A positive experience; and (c) Hope. These themes provide evidence that the narrative coconstruction process supported a positive view of identity, empowered the participants to experience confidence in themselves and in their communication abilities, and that participants enjoyed the process.

*Relevance:* Reframing traumatic and lifechanging experiences such as stroke through personal narratives is relevant to the domain of posttraumatic growth regarding

personal growth. This study describes a method that can help empower people with aphasia in the process of positive growth.

## APPENDIX B

**Institutional Review Board (IRB) Approved Consent Form**

# Consent to be a Research Subject

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Title of the Research Study: Measuring and understanding the experience of posttraumatic growth in aphasia

Site-Specific Principal Investigator: Tyson G. Harmon, Ph.D., CCC-SLP

IRB ID#: IRB2020-408

**Introduction**

This research study is being conducted by **Drs. Tyson Harmon (Brigham Young University) and Michael Biel (California State University-Northridge)** to determine **how people with aphasia experience emotional growth**. You were invited to participate because you:

- were diagnosed with aphasia
- are at least 18 years of age
- are at least 6 months post-stroke
- have access to reliable internet and a webcam
- speak English as your primary language
- have no history of degenerative neurological disease, dementia, diffuse brain injury, or brain disease

## Procedures

This study will include **one or two sessions** on different days. Session 1 will last up to 2 hours. Two-thirds of participants will be randomly selected and invited to participate in session two. This session will last between 30 and 60 minutes. Sessions will be completed virtually over the internet via **Zoom**.

In **Session 1**, you will:

- answer **demographic questions**
- complete tasks to evaluate **language** (e.g., listening to words and sentences, naming pictures, etc.)
- answer **questions about your emotional growth** related to aphasia

- rate how aphasia has impacted areas of your life

In **Session 2** you will either:

- **retake** a posttraumatic growth assessment (30 minutes total)

**OR**

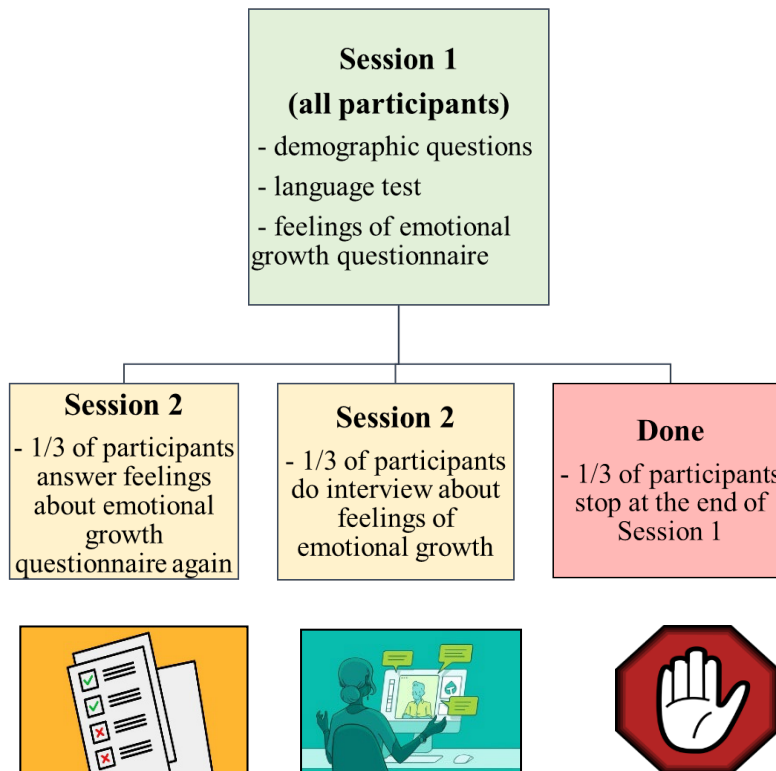
- answer questions during an **interview** with a researcher regarding your emotional growth after aphasia (30-60 minutes). The **interview** will involve questions about:
  - Some responses that you provided to questions in session 1
  - Your **day to day communication**
  - **Strategies** that help you communicate

Video Recordings

During the study, researchers will **video record** your sessions for later analysis. Your consent below allows Brigham Young University (BYU) to use these recordings for purposes associated with the Study.

### Participant Consent

I understand that researchers will take video recordings of me as part of this Study. These recordings will include both audio and visual information, which may allow me to be identifiable to viewers. I give permission for BYU to use the Media in scientific publications, scientific conferences or meetings, educational presentations, public presentations to non-scientific groups, and other uses related to the Study so long as my name is not used. I agree that all Media will become the property of BYU, and I waive my right to inspect, approve, or be compensated for BYU's use of the Media.



By signing below, **I certify that I have read** this Consent to Use Video Recording **and agree** to its terms.



Name of Participant:

\_\_\_\_\_

*(Please Print)*

By signing below, the researcher indicates that verbal consent was obtained and recorded:

Researcher Signature: \_\_\_\_\_ Date \_\_\_\_\_

#### Risks/Discomforts

There are minimal risks associated with participation but no greater than those encountered in everyday life. You may become tired or frustrated. **You can take a break or discontinue your participation at any time.** Confidentiality risks are similar to those inherent in any type of questionnaire research.

#### Benefits

Since this is not a treatment study, there is likely no direct benefit to you. However, your participation in this study will provide us with information that might generally improve the knowledge base about services and assessment of people with aphasia.

#### Confidentiality

Data collected for the purposes of this study will be **kept confidential** and will only be reported without the use of your personal information. As stated previously, if video files are shared, your name will not be used.

You will be given a number that will identify you for this study. All data obtained from you will be associated with this number instead of your personally identifiable information. Any paper forms or test protocols will be kept in locked cabinets in a locked research lab or office at BYU or California State University-Northridge. Any electronic forms or files (e.g., video files) will be kept on a secured, password protected server. Only those directly involved with the research will

have access to these data. A single password protected file linking your research ID and name will be kept on a password protected server in a separate file from the research data. Only the principal investigator and co-investigators will have access to this file.

We will keep the information we collect about you during this research study for analysis and for potential use in future research projects. Data from this study may be shared with the research community, with journals in which study results are published, and with databases and data repositories used for research so long as your name and other personal information is omitted.

### Compensation

All who complete phase 1 of the study will be **entered** into a drawing **to win one of ten \$25 Amazon gift cards**. Those who participate in phase 2 will be entered into the gift card drawing a second time. The odds of winning a gift card are 2% for those who participate in only session 1. The odds of winning are 8% for those who participate in both sessions.

### Participation

Participation in this research study is **voluntary**. You have the right to withdraw at any time or refuse to participate entirely. If you choose to drop out of the study, your data may still be used for the research unless you request otherwise.

### Questions about the Research

If you have questions regarding this study, you may contact Tyson Harmon, Ph.D., CCC-SLP (phone: 801-422-1251; email: tyson\_harmon@byu.edu) or Michael Biel, CScD, CCC-SLP, BC-ANCDS (phone: 213-503-8954; email: michael.biel@csun.edu).

### Questions about Your Rights as Research Participants

If you have questions regarding your rights as a research participant, contact the Human Research Protection Program at (801)-422-1461; [BYU.HRPP@byu.edu](mailto:BYU.HRPP@byu.edu).

**Statement of Consent**

I have read and understood the above consent and desire of my own free will to participate in this study.

By signing below, the investigator indicates that verbal consent was obtained and recorded:

Investigator Signature: \_\_\_\_\_ Date \_\_\_\_\_



## APPENDIX C

**Institutional Review Board (IRB) Approval****Memorandum**

To: Tyson Harmon

Department: BYU - EDUC - Communications Disorders

From: Sandee Aina, MPA, HRPP Associate Director

Wayne Larsen, MAcc, IRB Administrator

Bob Ridge, PhD, IRB Chair

Date: October 28, 2020

IRB#: IRB2020-408

Title: Measuring and understanding the experience of post-traumatic growth in aphasia

Brigham Young University's IRB has approved the research study referenced in the subject heading as expedited level, categories 6 and 7.

The approval period is from 10/28/2020 to 10/27/2021 . Please reference your assigned IRB identification number in any correspondence with the IRB. Continued approval is conditional upon your compliance with the following requirements:

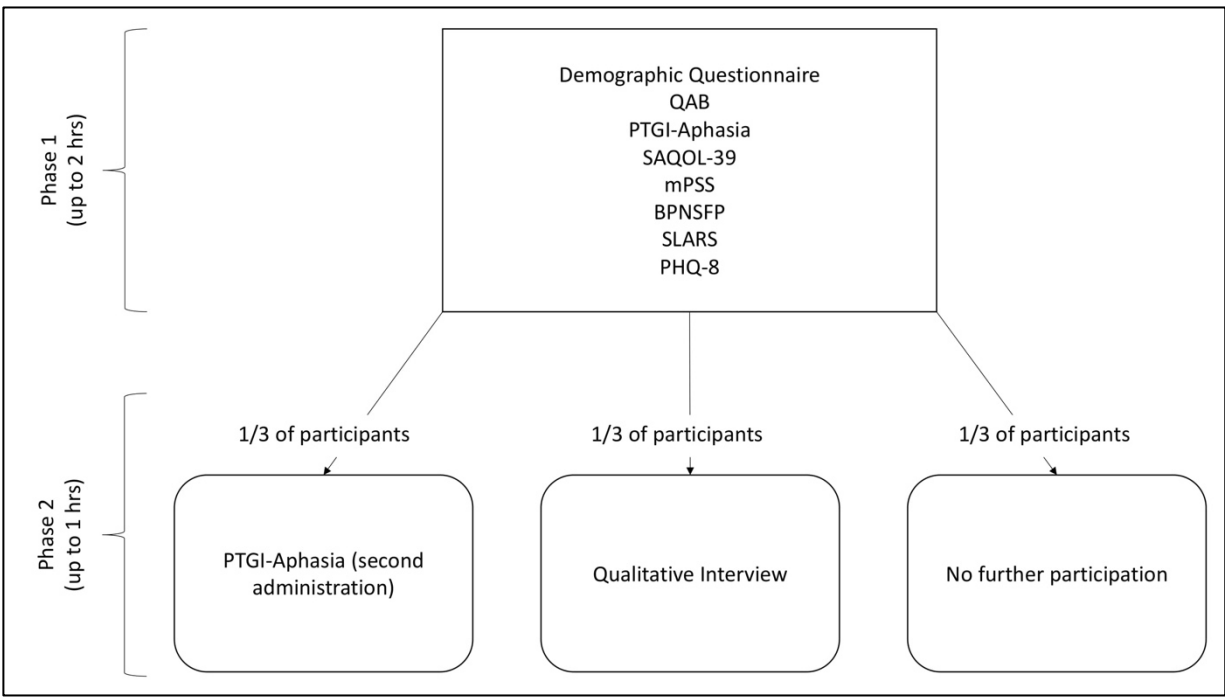
1. A copy of the approved informed consent statement and associated recruiting documents (if applicable) can be accessed in iRIS. No other consent statement should be used. Each research subject must be provided with a copy or a way to access the consent statement.
2. Any modifications to the approved protocol must be submitted, reviewed, and approved by the IRB before modifications are incorporated in the study.
3. All recruiting tools must be submitted and approved by the IRB prior to use.
4. In addition, serious adverse events must be reported to the IRB immediately, with a written report by the PI within 24 hours of the PI's becoming aware of the event. Serious adverse events are (1) death of a research participant; or (2) serious injury to a research participant.
5. All other non-serious unanticipated problems should be reported to the IRB within 2 weeks of the first awareness of the problem by the PI. Prompt reporting is important, as unanticipated problems often require some modification of study procedures, protocols, and/or informed consent processes. Such modifications require the review and approval of the IRB.
6. A few months before the expiration date, you will receive a prompt from iRIS to renew this protocol. There will be two reminders. Please complete the form in a timely manner to ensure that there is no lapse in the study approval. Please refer to the [IRB website](https://irb.byu.edu/iristraining-resources) for more information.

Instructions to access approved documents, submit modifications, report complaints and adverse events can be

found on the IRB website under iRIS guidance: <https://irb.byu.edu/iristraining-resources>.

APPENDIX D

Study Procedure Diagram



## APPENDIX E

### Semi-Structured Interview Guide

#### Introduction

*“Thank you for agreeing to participate. We are very interested to hear about your experiences living with aphasia. We want to learn what makes people with aphasia successful or helps them thrive and how they cope with communication challenges.”*

*“During the interview, we will ask some open-ended questions. There is no right or wrong answer. We want to learn from you about your experiences, thoughts, and feelings. If you don’t understand a question right away, that is ok. We will provide support throughout the interview to help you understand and respond as best as possible. This interview will last approximately 30-60 minutes.”*

#### Questions

1. “First, we will review some of your responses from phase one.”
  - a. Refer to PTGI-Aphasia and specifically address one “a” question from each of the five categories to which the participant responded “yes.” Questions with the highest ratings will be selected.
    - i. [Read the question] “When you responded to this question, you answered “yes.” What has contributed to this change? Describe a time when you noticed this change.”
  - b. Refer to BPSNF and specifically address one question from each category to which the participant responded with a rating of 4 or 5 for odd-numbered items. Questions with the highest ratings will be selected.
    - i. [Read the statement] “What caused you to answer this way? Describe a time when you experienced this recently.”
  - c. Refer to SLARS
    - i. “When you answered this question [refer to SLARS question], you indicated that you think you are [very successful, successful, somewhat successful, not successful, not at all successful]. Please describe why you responded this way. What do you think contributes to your success/lack of success?”
  
2. “Describe what a good day looks like for you (What do you do? Who are you with? What situations are you in? What is it like to communicate?). How often do you have a good day?”

3. "It is normal for people with aphasia to feel like they communicate better in some situations and worse in others. What is a situation in which you find it hard to communicate? How do you react when faced with this situation? What strategies do you find helpful?" [Continue to ask for another example until the participant cannot think of others]

### Conclusion

*"That concludes our interview. Thank you so much for sharing your thoughts and perspective. If you have additional comments or questions, please feel free to contact Dr. Tyson Harmon."*