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CO-CONSTRUCTION OF PERSONAL NARRATIVES IN SUPPORTING IDENTITY
AND COMMUNICATION IN ADULTS WITH APHASIA:
THE 'MY STORY' PROJECT

by

Katie A. Strong

A dissertation submitted to the Graduate College
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CO-CONSTRUCTION OF PERSONAL NARRATIVES IN SUPPORTING IDENTITY
AND COMMUNICATION IN ADULTS WITH APHASIA:
THE 'MY STORY' PROJECT

Katie A. Strong, Ph.D.

Western Michigan University, 2015

Stroke and subsequent aphasia can impact a person's identity negatively, interfering with quality of life. Co-constructing personal narratives about stroke and other aspects of a person's life is a promising intervention for addressing identity issues. This series of three dissertation studies explored key aspects related to identity, personal narratives, and the perceived impact of telling one's story.

Study 1 involved a survey examining whether speech-language pathologists view themselves as having a role in supporting the reconstruction of self-identity in adults with aphasia through the use of personal narratives. Results revealed that, whereas the majority of respondents viewed themselves as having a role in supporting self-identity, less than one-half reported targeting self-identity directly in treatment of recent cases. Additionally, approximately 40% reported having had no educational activities in self-identity and in personal narratives. Results indicated a potential gap between the perceived role in supporting self-identity and existing educational activities. This could account for infrequent use of techniques used to support self-identity in treatment.

Study 2 used a collective case study design to explore a framework for clinicians working to co-construct narratives with adults who have aphasia. This involved

developing and piloting a 'My Story' protocol to co-construct personal narratives in adults with aphasia. The seven session protocol was piloted with three participants who have aphasia. Results showed that the co-construction process allowed for participants to organize and make meaning of the events of their lives, including goals and imagining the future. Participants reported co-construction to be a highly positive experience.

Study 3 used qualitative interviews with the three participants in the 'My Story' Project to learn about their perceptions of the work. Interpretative phenomenological analysis was used to explore self-reported changes resulting from participating in the project. Results revealed three super-ordinate themes: *More than a story: My life came back to life; Co-constructing 'My Story' was a positive emotional experienc*e; and *Hope*. The study provided support of the meaningfulness of co-constructing a personal narrative in contributing to positive identity changes and communication confidence.

DEDICATION

For Chris and Nikki, who showed me to the power of narrative co-construction and

provided the inspiration for this work.

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The 'My Story' Project is about co-construction. The essence of co-construction is work which is strengthened by the space created through collaboration. I have been fortunate to have many collaborators who have opened up new spaces for me through this dissertation process and who deserve mention here as this work would not have been possible without their guidance.

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CHAPTER I

INTRODUCTION

Overview of Chapter and Dissertation

"My story is myself, and I am my story" (Baldwin, 2005, p. 21). As evident in the

statement by Baldwin in her book, *Storycatcher: Making Sense Through the Power and*

Practice of Story, the stories we tell may well influence the identity of who we are as

persons. In fact, some say that we are the stories we tell (McAdams, 2008; Randall,

1995). Others say that language has power to influence who we are as a person (Ruth &

Kenyon, 1996). Romanoff (2001) referred to narrative as a vehicle for change in

individuals who suffer traumatic losses. Language and communication play an important

role in a person's ability to construct and tell a story about oneself. Such stories create

and contribute to a person's identity. Consequently, what happens to identity when a

person's ability to form and tell stories is impaired after an acquired injury such as

stroke?

Aphasia is a language and communication impairment that results from acquired

brain injury after a stroke or trauma to the head. The incidence of aphasia following

stroke is estimated to be 60 per 100,000 people per year (Dickey et al., 2010). Aphasia

can have lasting and devastating impacts on the lives of people it touches, including the

possibility of a change or disruption in identity (Brumfitt, 2008; Shadden, 2005). People

with aphasia may have difficulty communicating their thoughts verbally, thinking of

words they want to say, writing their thoughts, understanding directions, or reading. They

also may have difficulty constructing and telling stories. This disruption in language

skills may impact confidence in communicating, which may lead to relying on others to

make decisions about complex issues in their life thus reducing their ability to actively participate in their own life (Babbitt & Cherney, 2010). Of specific interest to this dissertation, is the process of constructing and sharing personal narratives or stories about one's life, supported by professionals in different disciplines, and in the face of potential communication barriers posed by the aphasia.

Speech-language pathologists (SLPs) play a principle role in the rehabilitation of language and communication in people who have aphasia. One question addressed in this dissertation (Study 1) is how SLPs view their role in working with people with aphasia in the area of identity. The philosophy and training of the SLP greatly influences the direction of rehabilitation. Historically SLPs were trained within and utilized a medical model in which the goal of rehabilitation was to focus on the elimination or reduction of the language or communication impairment caused by aphasia (Chapey et al., 2008). However with cases of chronic disability such as aphasia, there is no cure, and using a medical model alone leaves compensatory and coping techniques as an afterthought. This may leave people with aphasia to cope with residual deficits in language and communication and adjustment issues related to aphasia after discharge from therapy (Kagen & Simmons-Mackie, 2007). As aphasia is a chronic and lifelong disability, focusing solely on fixing the deficits may ignore personally significant issues that have a large impact on life.

In 2001, the World Health Organization (WHO, 2002) adopted a universal classification of disability and health, the International Classification of Functioning, Disability, and Health (ICF) which provided a framework for the description of health and health-related status. The ICF embraces two models of disability, characterized as the

medical model and the *social model*. The medical model views disability as a feature of the person, directly caused by the disease or trauma. This model relies on interventions aimed at correcting the problem of disability. Contrastively, the social model views disability as a socially created problem generated by the attitudes and features of an environment and not an attribute of the individual. Individually, neither model is adequate. Together, they form a biopsychosocial model, on which the ICF is based, which provides a more integrated view of health.

In recent years, treatment approaches to aphasia have emphasized a model called the Life Participation Approach to Aphasia (LPAA). This approach supports the concept of *living successfully* with aphasia (Chapey, et al., 2008; Holland, 2006). What it means to live successfully lies in the eyes of each person with aphasia, and the clinician's role is to support them in this pursuit (Brown, et al, 2011). Adopting the LPAA involves emphasizing the positive aspects of life with aphasia from the perspective of the person with aphasia, rather than focusing on the impairment, in order to support living a full life despite the challenges caused by aphasia (Brown, et al, 2011; Brown, Worrall, Davidson, & Howe, 2010; Cruice, Worrall, Flickson, 2006).

This dissertation is based on the premise that targeting communication and language through personal narratives about the stroke and living with aphasia may impact identity in persons with aphasia, which in turn may contribute positively to their adjustment to living with aphasia. Armstrong and Ulatowska (2007) reported that engaging in constructing stories about a person's stroke provides a promising way for clinicians and the person with aphasia to approach identity issues. They also indicated

that supporting the construction of stories about a person's stroke and aphasia may be a well suited intervention for group, family, and individual settings.

The series of three dissertation studies provides a platform to explore topics related to identity, personal narratives, and aphasia. Study 1 examines questions about whether SLPs view themselves as providing a role in supporting people with aphasia to renegotiate their identity through the use of personal narratives. Study 2 offers a framework for clinicians working with adults who have aphasia through the development and piloting of a protocol to systematically co-construct personal narratives in persons with aphasia. Additionally Study 2 provides a preliminary analysis of the products that result and entails a qualitative exploration of the parallel and interactive experiences of the clinician and the person with aphasia when utilizing the developed protocol for co-construction of personal narratives. Study 3 focuses on the impact that co-constructing and sharing a 'My Story' personal narrative may have on identity and communication confidence from the perspective of persons with aphasia.

<div align="center">

Key Constructs

</div>

Identity and Narratives

Identity, as defined by Taylor (1994), is "who we are, and where we are coming from" (p. 33). Narratives may have an important role in identity. Personal narratives of life stories are a way for "people …[to begin] to put their lives together…by reconstructing the past and imagining the future as an ongoing narrative that depicts who they were, are, and will be" (McAdams, 2008, p. 21). McAdams (1996) argued that people learn to think of their own identity through a narrative process and that as a

narrative is told and retold, it changes as a reflection of the narrator of the story and the listener in the environment.

Whereas McAdams' (1996, 2008) work in the field of psychology applies to all individuals, with or without disability, Ellis-Hill, Payne and Ward (2008) have applied the concept of narratives in reformulating identity through the *Life Thread Model* to individuals with chronic disability such as stroke. The Life Thread Model focuses on supporting a positive sense of self through the creation of narratives between a clinician and a client with a chronic disability, with the goal of learning how to live a life that is not dominated by the disability. This model is based on principles drawn from the disciplines of psychology and sociology, but it has been presented primarily as a clinical commentary and thus far does not have strong evidentiary support validating its claims. Additionally, no specific structure for how to develop the life narrative is provided in the model.

Many disciplines, such as psychology, sociology, narrative gerontology and psychiatry, have focused on the importance of narratives in the formation of identity. Hyden and Brockmeier (2008) compare constructing narratives to providing an opportunity to make sense of an altered life that must now accommodate for illness or disability (e.g., aphasia), as one might have to accommodate for an uninvited guest. From the field of psychology, Hampl (1999) identified the importance of humans not merely telling their stories but listening to what their stories tell them. From a relationist approach in the field of psychology, therapeutic opportunities to co-construct narratives are described as "two subjectivities (e.g., clinician and person with aphasia) meeting a

unique situation and creating a third space in which new experiences become possible"
(Shafer, 2004, p. 251).

From the perspective of narrative gerontology, Freeman (2011) introduced the
concept of *narrative foreclosure* in which a person's inner stories are at a dead end and
no hope is seen in how things could be any different. Freeman further remarked that, in
this state of narrative foreclosure, the weight of one's personal past is so burdensome that
it results in immobility to view a reviving of one's story. This also may apply to a story
that doesn't end at the point of chronic disability. Although Freeman refers to disorders
such as dementia in his examples on the concept of narrative foreclosure, having aphasia
may put a person at risk for narrative foreclosure as well. Freeman suggested that,
through narrative, comes opportunity to move beyond the present and 'reopen the story'
to gather a broader perspective on life.

Aphasia, Identity and the Role of Language and Communication in Narratives

Evidence suggests that identity is altered following stroke among individuals who
have no significant cognitive, communicative, or perceptual residual difficulties (Ellis-
Hill & Horn 2000). If identity is impacted following stroke in people who do not have
residual deficits in language and communication, and if functional language and
communication play a role in creating the stories to support the construction of identity, it
makes sense that people who have had a stroke and have impairments in language and
communication due to aphasia may be at risk for even more significant changes to their
identity. Shadden (2005) went so far as to assert that aphasia is 'identity theft.' In a
survey of 66,193 residents living in long-term care facilities, Lam and Wodchis (2010)

found aphasia to have the largest negative relationship to health-status index scores, followed by cancer and Alzheimer's disease.

Within the LPAA literature, interest in changes in identity after onset of aphasia is emerging (Brumfitt, 2008; Moss, Parr, Byng, & Petheram, 2004; Shadden, 2005; Shadden & Agan, 2004). Recent literature has shown increased attention to the impact and importance of identity in working with persons with aphasia (Brumfitt, 2008; Ellis-Hill & Horn, 2000; Hersh, 2009; Shadden, 2005, Simmons-Mackie & Elman, 2011; Worrall et al. 2010). Fraas and Calvert (2009) noted redefinition of identity as a major theme in successful recovery and living a productive life in brain injury survivors.

An assessment for aphasia, the Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagen et al., 2008) includes a subsection aimed at assessing personal identity, feelings and attitudes. The *personal identity* component of the A-FROM assesses concepts such as *the future*, *your view of yourself*, *aphasia and who you are*, and *feelings.* These are provided as components of meaningful life change. The A-FROM is intended for SLPs to use as a tool in assessing aphasia. Hence, SLPs have an assessment that targets personal identity. It is unclear, however, whether the majority of SLPs view supporting identity as a part of their professional role. And further, if SLPs do view this as their professional role what techniques and tools are they using to support identity in speech and language therapy? These were questions addressed in Study 1.

Communication Confidence as One Measure of Identity

Identity is a complex construct and measuring change in identity is difficult. One proposed approach to measuring at least one aspect of identity is through communication confidence. Babbitt and Cherney (2010) hypothesized there is an interaction between

communication confidence, autonomy and self-determination, and participation in life activities. Babbitt and Cherney defined confidence as "a feeling or consciousness of one's powers" (p. 215). Communication confidence is referred to as a potential barometer for measuring the 'health' of identity because when confidence in communication skills increases, a person may be more open to participating in activities that require communicating. An increased confidence in communication may in turn allow for increased opportunities for social communication interactions. The Communication Confidence Rating Scale for Aphasia (CCRSA) was developed as a self-assessment outcome tool to target the domains of personal identity, attitudes and feelings (Babbitt & Cherney, 2010). It is as a measurement tool in Study 3 of this dissertation.

Aphasia Services and Speech-Language Pathologists

SLPs are the primary service provider for the rehabilitation of language and communication for people with aphasia. The underlying philosophy of the individual SLP has an influence on the approach taken in rehabilitation. Armstrong and Ulatowska (2007) remarked that most research to date has focused on people with aphasia describing pictures, re-telling stories, or using procedural discourse which typically conveys relatively concrete, factual information. As such, SLPs may rely on these tasks, which focus on improving language and communication as the target of therapy, instead of using emotive and abstract concepts, which may be more characteristic of personal narratives. Although this is not necessarily negative, it may be that by solely utilizing tasks to target concrete, non-emotive language, SLPs may be missing an opportunity to support identity by targeting language that is personalized and has emotive content specific to that individual client. Simmons-Mackie and Elman (2011) remarked that

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"traditionally SLPs have either ignored the role of 'self' [identity] in therapy, assumed that improved language or communication (by virtue of aphasia therapy) would bolster the developing sense of self [identity], or assumed that 'being 'supportive and helpful' contributed to a healthy identity" (p. 314). They declare that aphasia therapy must focus on both improved communication and enhanced identity in order to maximize treatment outcomes. Brumfitt (2008) stated that development of a positive identity should take just as high precedence as therapy targeting language and communication. She further postulated that a person with aphasia may find the motivation to use language is increased if he or she is given sufficient emotional support to try to talk about the predicament – having aphasia.

Life Participation Approach to Aphasia and Speech-Language Pathologist View of Rehabilitation

The LPAA, which is based on of the WHO IFC model of disability, supports a social view of disability (Chapey, et al., 2008). According to this model, therapy should be structured to support the concept of living successfully with aphasia. Thus therapy focuses on what a person with aphasia can do, which is in contrast to a medical model which focuses on fixing impairments caused by the aphasia.

Qualitative interviews with people with aphasia have identified the importance of the SLP role in supporting people with aphasia in understanding and expressing their views in order to participate in discussions about their lives with individuals important to them (Cruice, Worrall, & Flickson, 2006). Brown and colleagues (2011) noted that most of the research conducted on living successfully with aphasia was from the perspective of persons with aphasia or their significant others. They theorized that the SLP's underlying attitudes, values, or beliefs about living successfully with aphasia would likely influence

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the clinical decision-making and practice. Additionally, and to differentiate this from a medical model, they provided evidence that SLPs recognize that the role of communication extends beyond the function of relaying information to include establishing and maintaining social relationships.

Personal Narratives and Life Participation Approach to Aphasia

The use of personal narratives in speech-language therapy fits well within the LPAA model as the narrative itself focuses on the perspective of the person with aphasia, making it an essential component of the living successfully with aphasia philosophy. Shadden and Hagstrom (2007) stated that the narrative processes are critical to the concept of recovery in the LPAA model and can be tools for regaining active participation in one's life.

Although the literature on aphasia has acknowledged the importance of developing and telling narratives or analyzing the content for deeper meaning and trends, most of the accounts focus on qualitative interviews for research purposes (Barrow, 2008; Boyles, 2006), group activities (Simmons-Mackie & Elman, 2011) and personal accounts written by people with aphasia (Hussey, 2010; Lew, 2007; Vail, 2000). It is difficult to find actual methods described in the literature for constructing personal narratives designed for use in clinical work, particularly individual work, which is the most typical delivery method of reimbursable insurance services with persons with aphasia.

Filling this gap was a primary purpose of Study 2. Two prior studies of techniques to support identity using personal narratives were found in the existing literature. Corsten, Konradi, Schimpf, Hardering, and Kelimann (2014) used a biographic-narrative approach which combined individual life story interviews and group therapy to improve quality of

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life. Another exception was a case study highlighting a collaborative intervention between a nurse and an adult with aphasia, which lasted over eight consecutive sessions. It involved using worksheets and supported conversation techniques (Bronken, Kirkevold, Martinsen, Wylle & Kvigne, 2012).

Value of Sharing Personal Narratives

The value of sharing personal narratives has been emphasized in the aphasia literature. Cruice and colleagues (2006) identified the positive experience of sharing one's life with others as a key component to living successfully with aphasia. The protocol for Study 2 of this dissertation includes a sharing component. There is evidence of the role that sharing life stories may plays in social communication in persons with aphasia (Davidson, Worrall, & Hickson, 2006). People use narratives to share their life stories to help themselves establish an identity that is recognized and validated by communication partners (Shadden & Hagstrom, 2007). Supporting the telling of stories may help with adjusting to life with aphasia and has been recommended as a focus of intervention (Davidson, Worrall, & Hickson, 2008). However specific frameworks for the process of sharing the stories are not found in the literature on aphasia. It was a purpose of Study 2 to begin to fill this gap.

<div align="center">Significance of the Research</div>

What is Already Known on this Subject?

The construction of personal narratives may provide an opportunity for healthy adjustment to threatening life events, such as aphasia, by assisting those affected to search for meaning, make sense of what happened to their lives, and redefine their identity, including who they are from the present day forward (Shadden, Hagstrom, &

Koski, 2008). Personal narratives have garnered recent interest in the literature on aphasia. Two textbooks and an issue of *Topics in Stroke Rehabilitation* have been devoted to this topic of personal narratives (Hinckley, 2008; Hinckley, 2010; Shadden, Hagstrom, & Koski, 2008). Published in peer reviewed journals are a number of personal accounts from individuals with aphasia providing their personal stories on living with aphasia (Barrow, 2008; Boyles, 2006; Hinckley, 2006; Hinckley, 2010; Hussey, 2010; Lew, 2007; Nanko & Hinckley, 2010; Shadden & Hagstrom, 2007; Vail, 2000).

What this Series of Studies Adds

The existing aphasia literature has focused on the value of personal narratives and potential links to renegotiating a more positive identity, but little is known about whether or not SLPs view supporting identity as a part of their role in working with people with aphasia. Study 1 provided an opportunity to explore the opinions of SLPs who have expertise in aphasia as whether or not they believe supporting identity is a part of their professional role in working with adults with aphasia and what methods they are using to address this concern, including personal narratives. Study 2 developed and piloted a protocol for co-constructing personal narratives with a person with aphasia. This study provides partial validation of one method for co-constructing personal narratives with persons with aphasia through a qualitative analysis of the process of co-constructing personal narratives from the viewpoint of the person with aphasia, the researcher/clinician and those with whom the story is shared, as validated protocols to construct narratives with persons with aphasia do not yet exist in the literature. Study 3 examined the impact participation in the project had on identity and communication confidence from the perspectives of the persons with aphasia. No current studies have

documented for the experience of co-constructing and sharing personal narratives or have examined the benefits or risks for sharing such personal narratives.

Summary

Narratives and identity are intricately related with each influencing each other in an ongoing manner. Aphasia impacts the language and communication of people and may in turn disrupt their ability to develop and share narratives about their life. LPAA supports the social aspects of the WHO ICF model, which embraces moving beyond domains related only to impairment and supporting domains of participation, environment, and personal factors. The LPAA has embraced the concept of living successfully with aphasia. Successful living is in the eyes of the beholder, that being the person with aphasia. Personal factors are related to concepts of identity, such as who persons with aphasia perceive they were, are, and will be.

As SLPs engage in the rehabilitation of persons with aphasia, it is important to understand if they view themselves as having a role in supporting the reconstruction of identity in persons with aphasia. Personal narratives may be one way SLPs can support identity in people with aphasia. Personal narratives have been published in the literature, however methods for constructing and sharing personal narratives with people who have aphasia are limited.

This series of three dissertation studies explored topics related to identity, personal narratives, and aphasia. Through survey work, Study 1 examined SLPs views in providing a role in supporting people with aphasia to renegotiate their identity through the use of personal narratives. Study 2 provided a framework for clinicians working with adults who have aphasia to co-construct personal narratives. Additionally Study 2

included an analysis of the products that resulted and entailed a qualitative exploration of

the parallel and interactive experiences of the clinician, the person with aphasia, and

those with whom the story was shared. Study 3 explored the experiences of the person

with aphasia on identity and communication confidence after participating in the project.

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CHAPTER II

WHAT SPEECH-LANGUAGE PATHOLOGISTS SAY ABOUT THEIR ROLE IN
SUPPORTING SELF-IDENTITY THROUGH PERSONAL NARRATIVES

The philosophy of the individual speech-language pathologist (SLP) influences

the approach that is taken in treatment. Medical models of rehabilitation focus on the

impairment, whereas social models shift the focus to promoting health from the

viewpoint of the person with aphasia (Simmons-Mackie, 2008). One social model, the

Life Participation Approach to Aphasia (LPAA; Chapey et al., 2008; Holland, 2006)

supports the concept of *living successfully* with aphasia, which is a holistic approach to

supporting people with aphasia in living a full life despite the challenges caused by

aphasia (Chapey et al., 2008; Holland, 2006). In order to support the concept of living

successfully with aphasia, a clinician aids the person with aphasia to identify positive

aspects of life instead of focusing on deficits caused by the aphasia (Brown, Worrall,

Davidson, & Howe, 2010, 2011; Cruice, Worrall, & Flickson, 2006).

SLPs play a primary role in the rehabilitation of language and communication in

persons with aphasia. Traditionally, SLPs have focused on improving linguistic or

cognitive functioning and have focused less on their clients' personal experience with

aphasia and life adjustments to changes in communication (Simmons-Mackie, 2008).

However, their role in facilitating life adjustment and participation is evolving, as

evidenced by the increasing use of social models of aphasia (Holland, 2006; Chapey et

al., 2008; Simmons-Mackie, 2008). Part of this evolving role may be to help support the

identity of persons with aphasia (Brumfitt, 1996; Shadden & Agen, 2004; Shadden,

Hagstrom, & Koski, 2008; Simmons-Mackie & Elman, 2011). Despite recent

recommendations, it is unclear whether SLPs see their role as supporting self-identity in

persons with aphasia and if so, what methods they use to support this area. In order to explore this, a survey was designed to explore SLPs' views of relationships among self-identity, personal narratives, and aphasia, as well as the role of the SLP related to these constructs.

Stories play an important role in shaping people's identities. According to Jerome Bruner (1990), narratives simultaneously function as agents of self-discovery and self-creation. Others have commented that narratives are "a primary communicative practice through which the author's identity evolves, is enacted, and is put to use" (Harter, Japp, & Beck, 2005, p. 10). Shadden, Hagstrom, and Koski (2008) added that "in one sense, our stories become our identities" (p. xii). They also posed questions regarding what happens to people's identities when a major life event, such as a stroke, reduces access to the necessary language and communication skills for people to develop and tell their stories.

Changes in self-identity have been documented among stroke survivors who have no language or cognitive impairment (Ellis-Hill & Horn, 2000). It is not surprising then that people who have aphasia as a consequence of stroke may face even more dramatic changes in self-identity. In addition to changes in their language, and potentially their motor skills, damage to the tools (i.e., communication skills) that people use to create and revise their stories are damaged. Thus, people with aphasia may face extra challenges in renegotiating their identity after stroke.

Narratives and Self-Identity

Personal narratives may have an important role in self-identity formation as well as reflecting a person's self-identity. Bruner (1987) and Ricouer (1990) were two of the

earlier researchers to use the concept of narrative identity. Personal narratives have long

been recognized as an important part of healing from loss (Romanoff, 2001). A person

may use language to make sense of the resulting chaos and life alterations, such as those

associated with a stroke. Brumfitt (1996) identified language as a necessary tool for

defining one's identity. However when stroke damages language skills, such as in the

case of aphasia, it is uncertain as to how a person navigates through the chaos to make

sense of their life.

Aphasia and the Role of Language and Communication in Self-Identity

Aphasia is a disruption in the ability to use and understand language. It is

typically caused by stroke or other acquired neurological injury. Having aphasia has been

found to have a more negative impact on quality of life than cancer or Alzheimer's

disease (Lam & Wodchis, 2010). By definition, aphasia involves compromised language

ability. People with aphasia may benefit from the use narratives to share their life stories

as a way to re-establish an identity (Shadden & Hagstrom, 2007). However, their

language impairment may disrupt their ability to articulate their narratives. This in turn

may impact the ability of such individuals to negotiate changes in their self-identity

independently.

Recent literature in aphasia has shown increased coverage of the impact and

importance of self-identity. SLPs have been challenged to consider the impact of loss of

language on self-identity and the important role SLPs may play in supporting people with

aphasia in renegotiating a new identity (Brumfitt, 1996; Holland & Beeson, 1996;

Simmons-Mackie, 2008; Shadden, 2005; Shadden, Hagstrom, & Koski, 2008; Simmons-

Mackie & Elman, 2011). For example, three assessment methods that target concepts of

identity have been developed; the Living with Aphasia: Framework for Outcome Measurement (Kagen et al., 2008); the Communication Confidence Rating Scale for Aphasia (Babbitt & Cherney, 2010); and a qualitative interview approach (Hagstrom 2004). These tools provide SLPs with means to assess identity in people with aphasia and use identity as a component of framing a treatment approach. Despite these recent developments in assessing identity among people with aphasia, surveys indicate that most SLPs report using impairment-based assessment tools aimed at quantifying deficits in language and communication (Katz et al., 2000; Simmons-Mackie, Threats, & Kagen, 2005; Verna, Davidson, & Rose, 2009).

Treatment methods for supporting identity are beginning to emerge as well. These methods often focus on group treatment. For example, Shadden and Agen (2004) described a method for supporting identity within a stroke support group. Similarly, Simmons-Mackie and Elman (2011) argued for the importance of addressing identity as part of speech-language therapy for aphasia and described a method for analyzing identity negotiation during social interaction in group therapy. Further, Worrall and colleagues (2010) discussed the importance using a life-coaching model and having a goal of helping people with chronic aphasia to fit the aphasia into their lives rather than trying to fix or eliminate the aphasia. Through this, the role of the SLP extends beyond traditional support in language and communication and reaches out to support adjustment to life with aphasia. Although there has been increased interest in self-identity in the literature, specific tools and protocols for supporting self-identity, particularly in individual speech-language sessions, are difficult to find.

Impact of SLPs' Viewpoint and Philosophy on Aphasia Rehabilitation

SLPs provide a primary role in the rehabilitation of language and communication of people who have aphasia. In fact, people with aphasia have identified SLPs as playing an important role in supporting their participation in discussions about their lives with individuals important to them (Cruice, Worrall, & Flickson, 2006). Brumfitt (2008) surveyed 173 SLPs in the United Kingdom on the importance of psychosocial aspects in aphasia treatment. Of those surveyed, 97% reported that psychosocial aspects were important to the overall outcome of their intervention. However only 77% believed they had received adequate training to support psychosocial aspects in therapy and, on average, they devoted less than 50% of time in therapy sessions to psychosocial issues. Not all SLPs, however, viewed themselves as having roles in recovery beyond the improvement of language skills.

Holland and Beeson (1996) have drawn attention to the idea that clinicians who work with people with aphasia (i.e., SLPs), despite having expertise in communication, historically have had difficulty embracing a role in supporting the interpersonal interactions and interpersonal perceptions that are the core of communication. Brown and colleagues (2011) theorized that the SLPs' underlying attitudes, values, or beliefs about living successfully with aphasia would likely influence their clinical decision-making and practice. They interviewed 25 SLPs in Australia on their perceptions about living successfully with aphasia and reported that SLPs recognized that the role of communication extends beyond the function of relaying information to include establishing and maintaining social relationships. However Brown et al. cautioned that despite these findings, assessments tend to focus on an impairment based approach. SLPs

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vary in the degree to which they see themselves as treating language disorders or supporting life participation.

Personal Narratives and the Life Participation Approach to Aphasia

Narratives are a fundamental human way of giving meaning to experience (Garro & Mattingly, 2000). Narratives are used to make sense of being at risk of disease, accident or death (Jurecic, 2012). In his classic text, *The Wounded Storyteller*, Frank (1997) outlined three main types of narratives: the restitution narrative, the chaos narrative, and the quest narrative. An increasing number of scholars across disciplines envision narrative as a new frontier for advancing health-related theory, research and practice (Harter, Japp, & Beck, 2005). The power of telling one's story fits well with the LPAA as the possibility to create supports for therapeutic story telling where individuals share their stories as part of their journey into wellness.

Much of the literature on personal narratives following stroke has focused on physical changes that result from other health conditions, such as paralysis. Relatively little has been explored with individuals with aphasia. Armstrong and Ulatowska (2007) hypothesized that this gap might be due to the nature of communication impairments caused by aphasia. They stated that less research may have been conducted with individuals with aphasia and personal narratives because the symptoms of aphasia are more likely to interfere with the process of constructing personal narratives.

The lack of research on personal narratives in people with communication disorders is not due to lack of attention in the literature. Two textbooks (Hinckley, 2008; Shadden, Hagstrom, & Koski, 2008) and an issue of *Topics in Stroke Rehabilitation* (Hinckley, 2010) have been devoted to the topic of personal narratives. Further evidence

of interest in self-identity and personal narratives is found in personal accounts from individuals with aphasia, who have published their personal stories on living with aphasia in peer reviewed journals (Lew, 2007; Vail, 2000) and accounts of personal narratives of living with aphasia reported by researchers (Barrow, 2008; Boyles, 2006; Hinckley, 2006; Hinckley, 2010; Hussey, 2010; Nanko & Hinckley, 2010; Shadden & Hagstrom, 2007). This lack of research may be due to challenges associated with constructing personal narratives with individuals who have language impairment due to aphasia.

Using personal narratives in speech-language intervention with a person who has aphasia fits well within the social and LPAA models, as the content of the personal narrative is customized to that particular person's life experiences. Hinckley (2008) discussed how using narratives can contribute to self-identity. She credited SLPs with having an awareness of the nature and importance of narrative discourse in supporting the functional communication of clients, but also noted that SLPs may not be fully aware of the power that narratives have in reformulating one's self-identity.

Summary

Self-identity can be framed through narratives (McAdams, 2008). Language and communication are necessary tools for constructing narratives. People with aphasia have impaired language which may in turn impact their ability to construct narratives and negotiate changes in their self-identity in their life after stroke and with aphasia. The LPAA supports the concept of living successfully with aphasia by helping people with aphasia cope with an altered identity following what often is a life-altering event. Personal "life-story" narratives may serve as a tool for supporting the concept of living successfully. At present, however, there is limited information about this potential area of

intervention. In fact, although researchers (Brumfitt, 1996; Kagen et al., 2008; Simmons-Mackie & Elman, 2011) have argued the importance of addressing identity as an integral part of speech-language therapy, no studies to date have measured whether SLPs view themselves as having a role in supporting identity in working with people who have aphasia.

Research Questions

The current survey research was designed to explore how familiar SLPs are with methods for supporting the reconstruction of self-identity after the onset of aphasia and particularly for using personal narratives to do so. This may help fill important gaps in the literature in this emerging area of therapeutic intervention. Five research questions were posed: 1) What proportion of SLPs view aphasia as having an impact on self-identity? 2) What proportion of SLPs report a role for themselves in supporting the reconstruction of self-identity? 3) What proportion of SLPs report targeting self-identity as an explicit goal? 4) What proportion of SLPs report using life-story personal narratives in treatment? and 5) What factors (i.e., training, work environment, and experience) are associated with reported use or lack of use of life-story personal narratives?

Method

Study Design and Human Subjects Protections

The design of this study was a cross-sectional online survey of SLPs. Its recruitment and procedural protocol was approved by a university's Human Subjects Institutional Review Board. Participants who opted to click on the 'next page' of the survey were assumed to have provided their consent for participation. Specific wording for consent is provided in the Appendix.

Participants and Recruitment

The target population was SLPs who work with adults with aphasia. Only those who reported they were certified or licensed SLPs and had worked with 10 or more adults with aphasia in the past two years were included in the survey. The survey sample was recruited from two sources, the American Speech-Language-Hearing Association (ASHA) Special Interest Group (SIG) 2, Neurophysiology and Neurogenic Speech and Language Disorders (estimated $n = 5034$), and a Facebook group called "Adult Rehab Speech Therapy" (estimated $n = 594$). What is uncertain is how many members of these two online groups actually access their accounts on a regular basis and thus might have read the invitation to respond to the survey. Additionally it unknown whether any of the SLPs were members of both groups. As discussed subsequently, these two factors complicate estimates of survey response rates.

WebSurveyor© was used to make the survey content available via the web from February 1- 21, 2012. Initial invitations were posted on February 1, 2012 to the ASHAcommunity for SIG 2 and to the Facebook group on February 8, 2012. A week following each of the original invitations, a second invitation was posted as a reminder of the opportunity to participate in the survey.

Survey Development and Instrument

The survey instrument was developed based on a review of the literature, followed by expert review. Both of these procedures contribute to content validity (Burns & Grove, 1993). The expert reviewers were four university-level faculty with expertise and records of publication in aphasia, personal narratives, and self-identity. Reviewer feedback was integrated into the content and design of the survey. The survey then was

piloted with two certified SLPs and four graduate students. Minor revisions were made based on pilot feedback.

The survey's final version (Appendix A) consisted of 39 questions targeting the three areas, self-identity (11), life-story personal narratives (13), and demographics (14), plus one final open-ended question, allowing for qualitative comments. Questions were a combination of fill-in-the-blank, Likert-style, multiple choice, and yes/no formats. The term *life-story personal narrative* was defined for participants as "a way for people to begin to put their lives together by reconstructing the past and imagining the future as an ongoing narrative that depicts who they were, are, and will be – and how the past, present, and future are meaningfully linked" (McAdams, 2008, p. 21). Similar terms used to refer to this concept include personal narratives, life-story narratives, or life stories. For this survey, life-story personal narrative was not intended be exclusive or used as a reference to a particular approach, but instead to connote the process of using stories about a person's life in therapeutic settings. Additionally, the term *self-identity* was defined as "who we are, where we are coming from, and where we are going" (Taylor, 1994, p. 33). Other terms used to refer to this concept include identity, personal identity, self, and sense of self. Again, survey terminology was not intended to be exclusive but instead to ensure the respondent understood this concept was referring to how a person views his or her own identity.

Data Analysis

Descriptive statistics, including frequencies, means, and medians, were used as a first step in data analysis and to answer the initial four research questions. Additionally, to answer the fifth research question, chi-square and logistic regression procedures were

used to analyze factors associated with targeting self-identity explicitly in treatment with adults with aphasia and the use of life-story personal narratives. The 12 original response options for "primary work environment" were collapsed into four categories: (1) outpatient (i.e., *outpatient, aphasia specialty clinic, university clinic*); (2) inpatient/subacute rehab (i.e., *inpatient rehab, nursing home/extended care facility*); (3) acute care; and (4) other (i.e., *home health, community based, private practice, university research/teaching*). "Training" was defined as self-report of having completed one or more of the following six types of educational activities: *mentoring from a colleague, continuing education workshop, journal article(s), personal goal to learn more from multiple sources, textbook; university coursework*, or *other* (specified by participant). The number of activities selected was counted (range from 0-6) and coded for logistic regression into three groups: *0 reported educational activities*, *1 reported educational activity*, and *2 or more reported educational activities*. This process was repeated for life-story personal narratives.

For both chi square and logistic regression analyses, categories for explicit and indirect targeting of self-identity in speech-language treatment and frequency of use of life-story personal narratives as a therapeutic approach were collapsed to create binomial variables of *more use* (comprising *always* and *most of the time*) and *less use* (comprising *about half of the time*, *hardly ever*, and *never*). For logistic regression, the variables of *0 educational activities* in life-story personal narratives was used as referent. Only those participants who had no missing values on variables in the final model were included in the logistic regression. The α significance level was set at $p = .05$. SPSS 18 (IBM Inc., Armonk, New York) was used in the data analyses.

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<center>**Results**</center>

A total of 120 individuals responded to the survey. Seven responses were eliminated due to not meeting eligibility criteria or incomplete data. The responses of the remaining 113 participants were included in the results reported here. The response rate was estimated at 2% of entire listserv members. This estimate was derived by dividing the 120 participants by the potential pool of 5628 members of the on line groups where the survey was posted. This is a conservative estimate because it was impossible to know how many of the 5628 reported group members actually saw the invitation to participate.

Participant Demographics

Of the 111 participants reporting gender, 95.5% were female. Of the 113 reporting race, 90.3% were white/non-Hispanic. These demographics are representative of ASHA's 2009 healthcare survey (95% female; 95% white). Mean age was 45.24 ($n = 105$, SD = 12.19, range 26-74). The mean number of years working as an SLP was 17.45 ($n = 112$, SD = 11.12, range 1-40) and years working with adults with aphasia was 16.06 ($n = 112$, SD = 10.24, range 1-40). Again, these demographics are representative of ASHA's 2009 healthcare survey (mean age, 44; mean years working as SLP, 17). The estimated percentage of current caseload of adults with aphasia was 39.38 ($n = 112$, SD = 38.66, range of 0-100). Table 2.1 outlines the primary work setting of the respondents. Outpatient was the most frequently reported work setting. As shown in Table 1, these demographics also are representative of ASHA membership working in health care settings (ASHA, 2011).

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Table 2.1

Primary Work Settings of Respondents (n = 113)

Primary Work Setting (collapsed)	Frequency	%	% (ASHA 2011)
Outpatient	51	45.1	42.6
Inpatient/Subacute Rehab	32	28.5	35.4
Acute Care	22	19.5	17.4
Other	8	7.1	n/a

Impact of Aphasia on Self-Identity and Perceived Role of Supporting Self-Identity

When asked "to what degree do you think that having aphasia has a NEGATIVE impact on a person's self-identity?" 92% selected *moderate* or *strong degree of negative impact* (Figure 2.1). No participants selected *no degree of negative impact*. When asked the question in the converse direction "to what degree do you think that having aphasia has a POSITIVE impact on a person's self-identity?" 48.7% selected *no degree of positive impact*; however, 46.9% selected *mild degree of positive impact*.
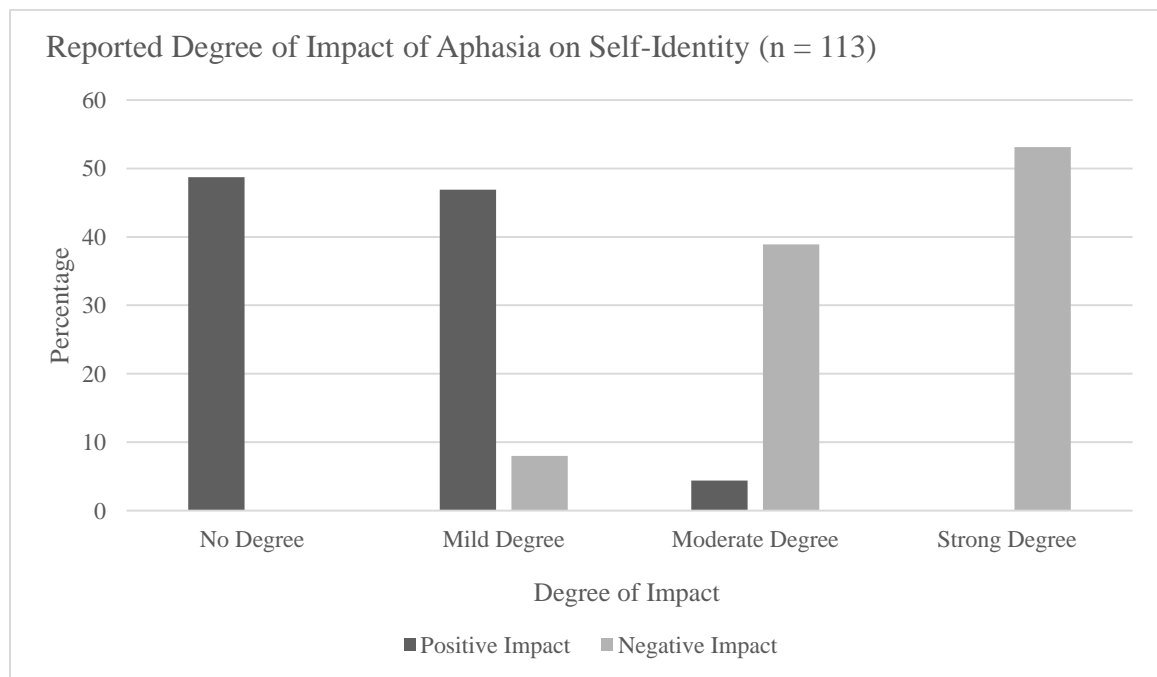
Figure 2.1. Reported degree of impact of aphasia on self-identity (n = 113).

Participants were asked to identify which of 10 identified professional groups had a role in supporting the reconstruction of self-identity. Professional role could be described as primary, secondary, limited, or no role. Results are reported in Figure 2.2. Almost all (96.4%) of participants indicated SLPs had a primary or secondary role, while none believed SLPs "do not have a role in supporting self-identity." Most frequently selected as having a primary role were SLP (80.5%), psychologist (72.6%), occupational therapist (57.5%), physical therapist (47.8%), and social worker (46.9%).
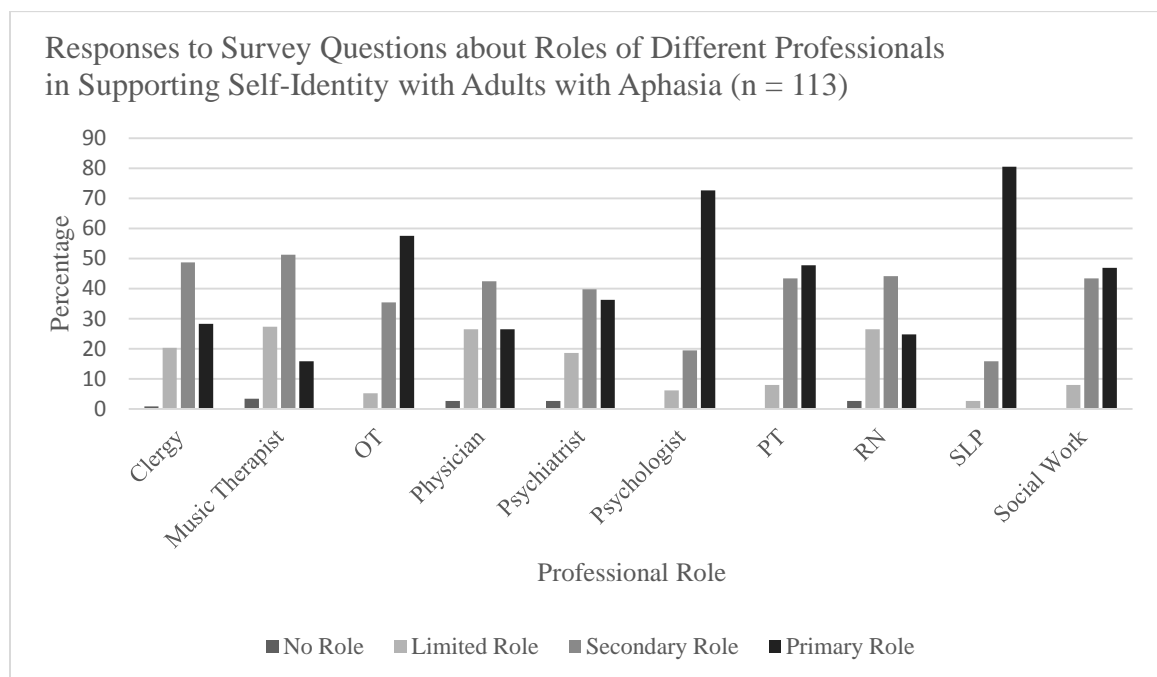
Figure 2.2. Responses to survey questions about roles of different professionals in supporting self-identity with adults with aphasia (n = 113).

Targeting Self-Identity as an Explicit Goal

When asked "considering your own work with adults with aphasia over the past two years, how frequently did you engage in activities with the EXPLICIT goal to help them reconstruct their identity?" 72.3% (*n* = 112) selected *never, hardly ever, or about half the time* while 27.7% responded *most of the time*, or *always*. When asked the same

question, but with regard to using such activities to address INDIRECT goals, 39.3% (*n* = 112) responded as *never*, *hardly ever, or about half the time* while 60.7% responded *most of the time*, or *always*.

Participants were asked their level of familiarity with activities designed to support the reconstruction of self-identity on a 7-point scale from *highly unfamiliar* to *highly familiar*. Results are shown in Figure 2.3. The most frequently selected category was *somewhat unfamiliar* (45.1%). Only 4.4% selected being *highly familiar* with activities to support clients' reconstruction of self-identity.
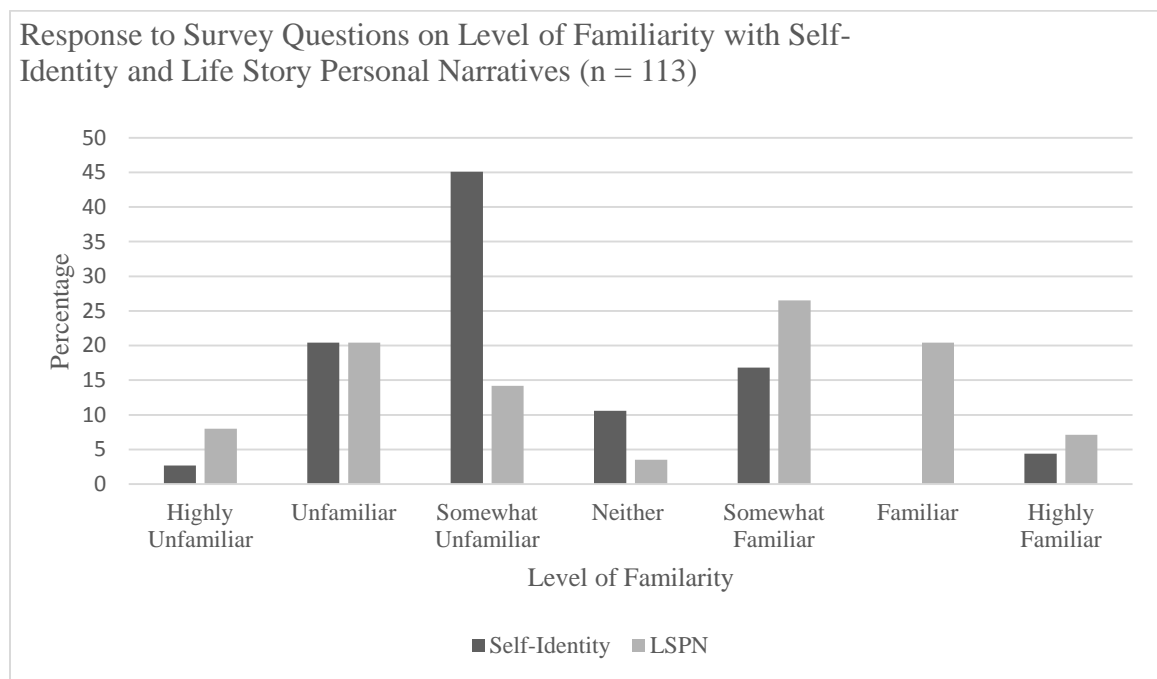
Figure 2.3. Responses to survey questions on level of familiarity with self-identity and life story personal narratives (n = 113).

Of further interest was whether participants reported having completed educational activities related to self-identity and if so, what type of activity. Of participants, 37.2% reported no activities, 26.3% reported one type of activity, and the

remaining 36.3% reported two or more types. Results for types of educational activities

are shown in Figure 2.4. Journal articles were the most frequently selected.
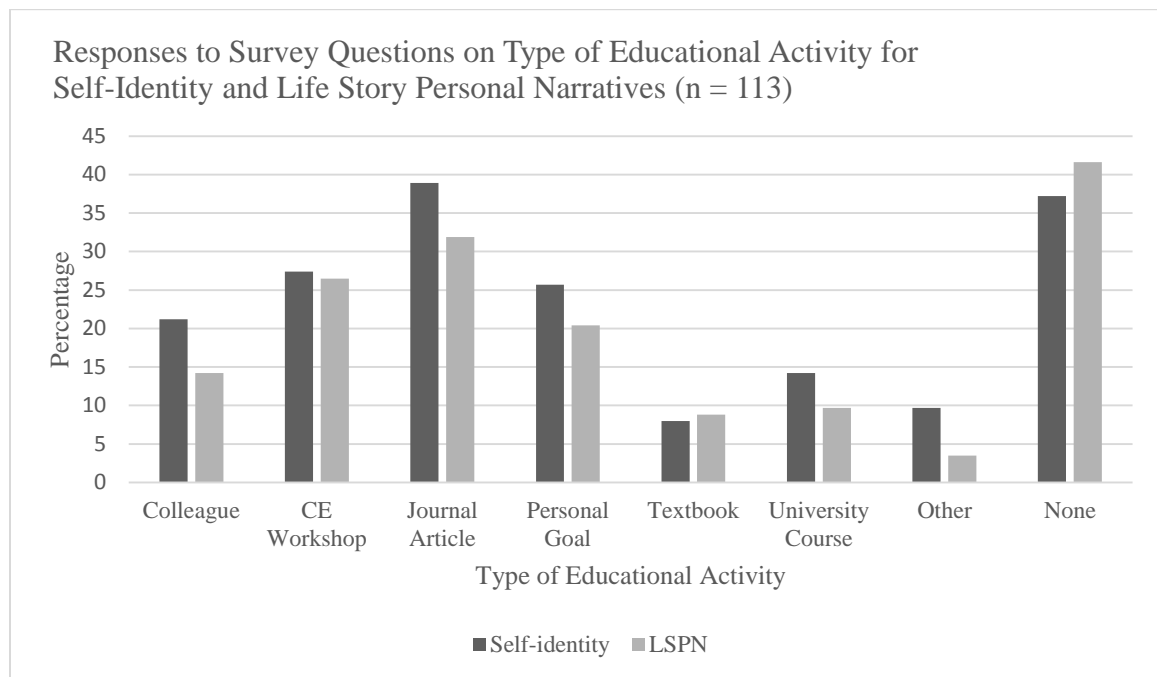
Figure 2.4. Responses to survey questions on type of educational activity for self-identity and life story personal narratives (n = 113).

Participants were asked to identify the top three reasons to engage in activities

designed to support the reconstruction of self-identity (out of 6 choices) and barriers to

engaging in such activities (out of 10 choices). Results are reported in Table 2.2. The top

three reasons for engaging in activities that support the reconstruction of self-identity

were providing person-centered care (79.6%), addressing client concerns (68.1%), and

addressing functional needs (62.8%). Addressing language needs was the least selected

reason (1.8%). The most frequently selected barriers to engaging in activities supporting

reconstruction of self-identity responses were lack of education (55.8%), time (46%), and

language problems due to aphasia (44.2%).

Table 2.2

Selected Reasons for Using Activities Designed to Support Reconstruction of Self-Identity and Life-Story Personal Narratives and Selected Barriers for Use (n = 113)

	Activities to support the reconstruction of self-identity		Life-story Personal Narratives	
	Frequency	%	Frequency	%
Reasons for Using *(selected top 3 choices)*				
Provide person-centered care	90	79.6	85	75.2
Address client concerns	77	68.1	54	47.8
Address functional needs	71	62.8	46	40.7
Address communication needs	68	60.2	73	64.6
Address significant other concerns	25	22.1	18	15.9
Address language needs	2	1.8	18	15.9
I would not engage in activities	0	0	10	8.8
Barriers for Using *(selected all that apply)*				
Lack of education in topic	63	55.8	44	38.9
Time	52	46	49	43.4
Language problems due to aphasia	50	44.2	44	38.9
Funding/reimbursement	44	38.9	29	25.7
Limited awareness of topic	44	38.9	39	34.5
Client resistance	34	30.1	36	31.9
Comfort in topic	29	25.7	27	23.9
Significant other resistance	21	18.6	23	20.4
Limited relationship of topic to language and communication	20	17.7	5	4.4
No perceived barriers	5	4.4	4	3.5
Greater effectiveness with other methods	4	3.5	13	11.5

Use of Life-Story Personal Narratives in Speech-Language Treatment

A separate section of the survey explored the use of life story personal narratives to support self-identity. Participants were asked the level of familiarity they had with constructing such narratives in working with adults with aphasia on a 7-point scale from *highly unfamiliar* to *highly familiar.* Results are shown in Figure 2.3. The two most

frequently selected categories were *somewhat familiar* (26.5%) and *familiar* (20.4%). Only 7.1% selected *highly familiar*.

As with self-identity, participants were asked whether they had completed educational activities related to life-story personal narratives and if so, to report what types of activity. Of the 113 participants, 41.6% reported no educational activities, 23.9% reported one type of activity, and 34.5% reported having two or more types. The most frequent type of educational activity was journal article (Figure 2.4).

Participants were asked to select the top three reasons to use life-story personal narratives and the barriers to using them. Results are reported in Table 2.2. The top three reasons selected were *providing person-centered care* (75.2%), *addressing communication needs* (64.6%), and *addressing client concerns* (47.8%). *Addressing language needs* (15.9%) was the least selected reason. The most frequently identified barriers were *time* (43.4%), *language problems due to aphasia* (38.9%), and *lack of education* (38.9%).

The issue of language interference in construction of life-story personal narratives was probed more directly with the question, "To what degree have you found the language problems of your clients to interfere with any attempts to construct personal narratives?" The response rates for each choice were: *no degree* (4.5%), *mild degree* (25.7%), *moderate degree* (33.6%), *strong degree* (7.1%)*,* and *I have never attempted to construct personal narratives with my clients with aphasia* (28.6%).

Factors Associated with Targeting Self-Identity and Using Life-Story Personal Narratives

Of interest was whether SLPs who reported targeting self-identity as an explicit goal were more likely to report use of life-story personal narratives. A chi square analysis

(n = 111) was completed using factors of *more* use and *less use* for explicitly targeting self-identity and *more use* and *less use* of frequency of using life-story personal narratives. Results revealed a statistically significant association between the reported targeting of self-identity and use of life-story personal narratives ($x^2(1) = 22.250$, $p <$ .001). The odds of SLPs using life-story personal narratives were 11.59 times higher if SLPs selected targeting self-identity as an explicit goal than if they did not.

Logistic regression utilizing the factors of setting (i.e., acute care, outpatient, and other), number of types of educational activities in self-identity (i.e., 0 trainings, 1 training, 2 or more trainings); and number of types of educational activities in life-story personal narratives (i.e., 0 trainings, 1 training, 2 or more trainings) was completed to determine which factors were associated with targeting self-identity explicitly in treatment. Initial analysis indicated that 2 or more types of educational activities in both self-identity and life-story personal narratives significantly predicted targeting self-identity explicitly in treatment in the crude models; therefore, these variables were used in the final model. The same process was conducted to determine significant factors for life-story personal narrative use. Initial analysis again revealed the similar predictors in the crude model as for explicit use of self-identity. The adjusted models for both variables, explicit use of self-identity and frequency of use of life-story personal narratives are shown in Table 2.3.

Results indicated that having more types of self-identity educational activities was significantly associated with increased targeting of self-identity explicitly in treatment. Likewise, having more types of personal narrative educational activities was significantly associated with increased use of personal narratives in treatment.

Table 2.3

Logistic Regression for Factors Associated With Targeting Self-Identity Explicitly in Treatment and Life-Story Personal Narrative Use (n = 112)

Predictor	Targeting Self-identity Explicitly in Treatment			Life-Story Personal Narrative Use		
	OR	95% CI	*p*	OR	95% CI	*p*
2+ trainings in self-identity	1.967	.2.415-21.173	*.001	.987	.725-9.916	.139
2+ trainings in life-story personal narratives	0.841	.793-6.789	.125	1.759	1.485-22.677	*.011

Note. OR = Odds Ratio; CI = Confidence Interval
*p < .05

Discussion

This study used an online survey to provide insight into how SLPs view self-identity and aphasia and the use of life-story personal narratives. One strength of this investigation is that supporting self-identity through personal narratives is a topic that has generated increasing interest in aphasia services but has been explored little using empirical methods. Further, as self-identity and personal narratives are newly developing areas within the profession of speech-language pathology, the sample was gathered from select SLP groups with known interest in adult neurogenic communication disorders. The purpose of this was to survey SLPs who may have more knowledge and interest in these topics than other SLPs, as well as those who would be most likely to have experience with the techniques.

In revisiting the five primary research questions posed for this study, the initial question inquired as to proportion of SLPs that view aphasia as having an impact on self-identity. All participants viewed aphasia as having a largely negative impact on self-identity. These results are not surprising as having aphasia has been documented as

negatively impacting quality of life (Lam & Wodchis, 2010). However an unexpected result was proportion of SLPs who viewed aphasia as also having a mild degree of positive impact. How can it be that aphasia can have both a negative and positive impact on self-identity? Speculating on this, perhaps there is space for what McAdams (2007) refers to as redemptive sequences. In a redemptive sequence, a demonstrably 'bad' or emotionally negative event or circumstance leads to a demonstrably 'good' or emotionally positive outcome (McAdams 1999). The plot of the story begins negatively and moves to a positive one. This question should be explored in further research.

The second and third research questions sought to determine whether SLPs report a role for themselves in supporting the reconstruction of self-identity and whether they target self-identity explicitly in treatment. All participants reported SLPs having a role in supporting self-identity in persons with aphasia, with an overwhelming majority reporting SLPs having a primary role in supporting self-identity. However, results also indicated most SLPs reporting targeting self-identity more frequently indirectly vs. explicitly in treatment. Participants reported lack of education on self-identity as the top barrier to targeting self-identity in treatment. Reported educational activities in self-identity were found to be influential in SLPs' consideration of self-identity in treatment of individuals with aphasia. Providing access to interdisciplinary training in self-identity to SLPs may be beneficial to support SLPs targeting self-identity directly in treatment and ultimately providing services that embrace a social model of aphasia services.

The fourth and fifth research questions explored the proportion of SLPs who reported using life-story personal narratives in treatment and which factors (i.e., work environment and educational activities) were associated with reported use of these

narratives. The majority of SLPs did not use life-story personal narratives in treatment. However, of those who did, having completed two or more types of educational activities related to self-identity was a predictor of targeting self-identity explicitly in treatment. Likewise, having two or more types of educational activities related to personal narratives was a positive predictor of narrative use in treatment. These findings are not unexpected as targeting a topic in treatment is expected if one knows more about that topic. Of interest however was that, although identified early in the logistic regression model as a predictor, having more training in personal narratives was not a significant predictor in the final model for predicting explicit targeting of self-identity. This was also true of having more training in self-identity not predicting life-story personal narrative use. It appears that SLPs are providing services for the areas they are trained in, but not identifying a relationship between self-identity and personal narratives when applying these concepts to treatment. Providing access to interdisciplinary training in self-identity may be beneficial to support SLPs targeting self-identity directly in treatment and ultimately providing services that embrace a social model of aphasia services.

Although not a specific research question, of additional interest was the degree to which language difficulties associated with aphasia interfered with the construction of personal narratives. The majority of SLPs reported only a mild or moderate degree of interference, suggesting that, despite some degree of interference, their patients' status as having aphasia was not a primary reason to avoid constructing personal narratives. The idea that language impairment due to aphasia may influence decisions whether to use narratives in aphasia intervention is supported in literature by Armstrong and Ulatowska (2007). They remarked that the inherent nature of the disruption in language caused by

aphasia and subsequent challenges in constructing narratives with people who have aphasia may be a reason why little research has been done in this area.

SLPs participating in this study did not select *addressing language needs* as a top reason to engage in activities to support the reconstruction of self-identity or the use of personal narratives. In the case of both self-identity and personal narratives, SLPs selected *addressing functional needs* as a more frequent reason for use. This is consistent with Hinckley's (2008) statement that SLPs may have a reduced awareness of the possible connection between narrative and identity, but rather, they see the use of narratives as a means of addressing functional needs.

Limitations

The SLPs who participated in this study were members of specialty groups associated with interest in neurogenic communication disorders. While this was purposeful, it may be that this non-random sample of those who chose to participate in the survey had greater familiarity or interest in the topic than other SLPs who work with this population. This may impact the generalizability of this study to the wider SLP population who work with adults with aphasia. Additional limitations impacting generalizability include the relatively low survey participation. However, as with most on-line survey tools, it is not possible to determine which members viewed the invitation and chose not to respond in order to track non-response rates with the on-line community; therefore, an exact response rate cannot be ascertained (Wright, 2005). Another limitation of this study is that many of the response choices were researcher-generated lists. While options were made to write in additional responses, most participants selected the responses provided in the survey. Furthermore, the term "self-identity" itself might have

been insufficiently unfamiliar to affect participation and responses. And finally, the definition of personal narratives given to respondents included wording that implied self-identity; thus, this concept could not be separated from personal narratives. This could have inflated the results of personal narrative use for the support of self-identity.

Future Research and Recommendations

Future research may involve investigations of the actual process of constructing personal narratives with people who have aphasia to determine the impact on self-identity. Qualitative methods could add insights from the perspectives of the clinician, person with aphasia, and family members. Such research could answer questions about the process of constructing narratives to support self-identity reconstruction and accommodations for the language barriers posed by aphasia. Finally, as many disciplines have interests in self-identity and narratives, this work lends itself well to interdisciplinary research possibilities. Recommendations include the need to explore the implications for inter-professional and in-service education, including interdisciplinary collaboration as the fields of psychology, narrative gerontology, and occupational therapy have more extensive research work in the area of narratives and self-identity. Additionally, interdisciplinary treatment methods, such as collaborations with psychology, nursing, and speech-language pathology to combine expertise to support changes self-identity and language through personal narratives in persons who have aphasia.

Conclusions

SLPs surveyed in this study overwhelmingly identified themselves as having a role in supporting the self-identity of persons with aphasia in speech-language therapy.

However less than half of those surveyed reported targeting self-identity explicitly in their treatment. Identified barriers to targeting self-identity were not having specific educational activities in self-identity and personal narratives. Journal articles were the most frequent type of educational activity reported for both self-identity and personal narratives. This research has identified a gap in that SLPs view themselves as having a role in supporting self-identity, however they may not have the necessary education or tools to successfully support self-identity in their work with adults with aphasia. One reason for this may be the lack of research on the process of using life story personal narratives to reconstruct identity following aphasia. Future research might include the development of specific techniques for the co-construction of personal narratives to support the reconstruction of self-identity in persons with aphasia.

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CHAPTER III

PILOTING A PROTOCL FOR CO-CONSTRUCTING PERSONAL NARRATIVES TO SUPPORT IDENTITY WITH PERSONS WITH APHASIA THE 'MY STORY' PROJECT

Introduction

"Stories reassert a kind of conventional wisdom about what can be expected, even (or especially) what can be expected to go wrong, and what might be done to restore or cope with the situation" (Bruner, 2002, p. 31). In other words stories help people to understand, accept, and perhaps even embrace events that happen in their lives. Catastrophic experiences that involve major loss, such as living through a stroke with residual chronic aphasia (loss of language), can be reframed through the telling and retelling of stories about this experience. Neimeier (2001), a psychologist, conceptualized meaning reconstruction in response to loss as a central part of the grieving process. He further remarked that experiencing major loss has implications for an individual's identity, which may require deep revisions to his or her self-definition.

Stories are one way to construct and reconstruct meaning. Language is a tool that is used to create stories (Shadden, Hagstrom, & Koski, 2008). The power of language contributes to the construction of identity as a person (Ruth & Kenyon. 1996). Bury (2001) wrote about these connections in the following statement:

> Not only do language and narrative help sustain and create the fabric of everyday life, they feature prominently in the repair and restoring of meanings when they are threatened. Under conditions of adversity, individuals often feel a pressing need to re-examine and re-fashion their personal narratives in an attempt to maintain a sense of identity. (p. 264)

The current research project was based on the hypothesis that targeting communication and language through personal narratives about one's stroke and living with aphasia may positively influence identity in persons with aphasia, which in turn may contribute positively to adjustment to living with aphasia. This project provides a platform to explore topics related to identity, personal narratives, and aphasia. It offers a framework for clinicians working with adults who have aphasia by developing and piloting a protocol, 'My Story,' to co-construct personal narratives. In this project, the term 'co-construction' indicates a collaborative act of assembling a story together. Specifically, due to impairments in language, the person with aphasia may benefit from a partner to support the development and sharing of a story about their life. Additionally this study provides a preliminary analysis of the products that result and entails a qualitative exploration of the parallel and interactive experiences of participating in the 'My Story' Project for the person with aphasia, the researcher-clinician, and those with whom the stories are shared.

Storytelling and Aphasia

Aphasia can have a lasting and devastating impact on the lives of people it touches, including the possibility of a change or disruption in identity (Brumfitt, 2008a; Shadden, 2005). The challenge caused by aphasia and loss of command of communication capacities also may impact a person's ability to create and tell stories about themselves. This in turn may negatively impact identity. Despite this challenge, the use of personal narratives may be one method to support persons with aphasia in reconstructing identity. Shadden and Hagstrom (2007) proposed integrating personal narratives with the Life Participation Approach to Aphasia (LPAA) as a method to

support persons with aphasia in regaining a sense of coherence. LPAA is a social model that supports the concept of *living successfully* with aphasia (Chapey et. al, 2008; Holland, 2006). Living successfully lies in the eyes of the person with aphasia, and it is the clinician's role to facilitate treatment approaches that support the client's view of a successful life instead of focusing treatment on what the clinician deems important.

Constructing and telling a story relies on language abilities. Language is social in its role as a medium of communication and requires two or more persons who share a common understanding of words and meanings (Baumeister & Newman, 1994). Bruner (2002) stated, "Not only are stories products of language, so remarkable for its sheer generativeness, permitting so many different versions to be told, but telling stories soon becomes critical to our social interactions" (p. 31). A traditional autobiographical narration is based on first-person accounts and individual identity is composed through this type of narration (Hyden, 2008). However when an individual is unable to use language in ordinary ways, such as in the case of aphasia, that difficulty can present major barriers to telling stories about his or her life. In such circumstances, it may be important to consider autobiographical narration, or the telling a story about his or her life, as something constructed together with others. This process may be called co-construction. Schafer (1992) discussed co-constructed stories as a relationist approach in which the clinician and client are two entities meeting a unique situation and creating a third space in which new experiences become possible. This concept of co-constructed stories is the basis for the 'My Story' Project.

People's life stories are authored only partly by themselves; stories also are influenced by the environment and other persons who listen and react to the stories (Ruth

& Kenyon, 1996). When people tell stories about their lives, they are also 'story listening' to their own stories (Ruth & Kenyon, 1996). This story listening may have an impact on how people view themselves not only when telling the story but may also influence how they choose to retell the story in the future. Davidson, Worrall, and Hickson (2006) identified the importance of storytelling in sharing issues of importance in adjusting to life with aphasia.

The 'My Story' Project provided opportunities for both storytelling and story listening embedded throughout. It began with individual sessions, which involved initial sharing of stories with the clinician by people with aphasia, and then culminated in a more formal group sharing of the stories with others who have aphasia and a few audience members invited by the three people with aphasia who have participated in this research. Kenyon and Randall (1997) used the term *restorying* to capture the purpose of enhancing one's sense of possibility through the telling and retelling of stories. They indicated that clinicians can play a powerful role as agents of restorying. The clinician's goal is to help the client change his or her life narrative from passive to active to help the individual restory his or her life (Randall, 1996). Listening and caring can assist clients profoundly as they restory experiences into stories that are healthier and more livable. Kenyon and Randall also indicated that clinicians will likely be restorying their own lives through this act of support. This suggests that co-construction is a dynamic process for both the client and clinician and that the clinician's story may also be impacted. This concept has been introduced to the field of speech-language pathology by Hinckley (2008).

Identity and Narrative

Stories play an important role in how people view the world. In his book, *The Wounded Warrior*, Frank (1995) stated,

> People tell stories not just to work out their own changing identities, but also to guide others who will follow them. They seek not to provide a map that can guide others – each must create their own – but rather to witness the experience of reconstructing one's own map. (p. 17)

Bruner (2002) wrote about the role of narrative in constructing one's identity, saying, "We constantly construct and reconstruct ourselves to meet the needs of the situations we encounter, and we do so with the guidance of our memories of the past and our hopes and fears for the future" (p. 64). Bruner further cautioned that telling others about oneself is no simple matter. He posed the chicken or egg question of identity and narrative by asking "Is our sense of selfhood the *fons et origio* of storytelling, or does the human gift of narrative endow selfhood with the shape it takes?" (p. 73). This concept of identity founded in making a comprehensible story of past experience, present situations and future goals is also supported by McAdams (1996). Past experiences, present situations and future goals have been incorporated into the 'My Story' protocol to provide the basis of the framework for building the co-constructed story.

In some situations, stories may be characterized as *illness narratives*. Chronic illness disrupts everyday life and one's sense of continuity, identity, and autobiographical coherence (Hyden & Brockmeier, 2008). In their work on exploring where illness and narrative overlap, Hyden and Brockmeier noted that "Being ill initiates a journey toward new experiences and a new identity" (p. 5). More specifically, they indicated that telling

a story is performing it, acting out a process of interpreting, constituting, and positioning one's experience--an enacting of identity. Frank (1995) identified three types of illness narratives; the restitution narrative, a temporary illness where former life will be restored; the chaos narrative, where the intensity of illness is such that life doesn't get better; and the quest narrative, where within the illness something positive is to be gained. This emphasis on illness does not embrace the spirit of the LPAA's living successfully with aphasia. Therefore efforts were made to develop the 'My Story' Project to include the story of the author's stroke, but not to focus solely on the story of illness, (i.e., stroke, aphasia). Rather the story was about the author's life, with stroke and aphasia as one aspect of their life that may or may not be predominant in their own story.

Narrative Methods for Supporting Identity in Persons with Aphasia

Armstrong and Ulatowska (2007) reported that engaging in constructing stories about a person's stroke provides a promising way for clinicians and persons with aphasia to approach identity issues. Although there is interest and advocacy for using narrative approaches to reconstruct identity of people with aphasia (Shadden, 2005; Shadden & Agan, 2004; Simmons-Mackie & Elman, 2011), less has been written about specific methods clinicians can use to support persons with aphasia in constructing personal narratives as part of reconstructing their identity. Armstrong and Ulatowska hypothesized that this disparity might be due to the nature of communication impairments caused by aphasia interfering with the process of constructing personal narratives. However in a later study, Ulatowska and colleagues (2013) provided evidence that individuals with mild to moderate aphasia can demonstrate the ability to share a coherent story despite communication impairments.

Ulatowska and colleagues (2013) identified clinical implications for personal narratives in aphasia. Specifically, they observed that telling personal narratives allows people with aphasia to be perceived as contributors in their communication environment by allowing them to engage with society, which may contribute to overall improved psychosocial well-being. This would address concerns by Babbitt and Cherney (2010) that confidence in communication may be impacted negatively by aphasia. A lack of confidence in communication, in turn, could negatively impact active participation in the person's own life and lead to a reliance on others for decision making about complex issues (Babbitt & Cherney, 2010), thus adding to his or her sense of diminished personal efficacy. On the other hand, communication confidence has been identified as one aspect of identity that could be improved if a person with aphasia experienced a sense of efficacy and control in communication. One approach to provide an opportunity to increase communication confidence is through the reframing of personal narratives following a stroke. The opportunity to reframe their personal narrative is a premise of the 'My Story' Project.

Armstrong, Ferguson, and Mortensen (2011) asserted that as we understand more about how identity is constructed through language and the impact aphasia has on this, we may also better understand the implications for the person with aphasia. Methods to support identity through narratives are emerging in the literature. They are difficult to categorize at this point, as many methods overlap, but in the review that follows, available methods are categorized as interviews, group therapy, guided self-determination, and biographic-narrative approach. Specific studies and how they informed the development of the 'My Story' protocol are cited below.

Interviews

Interviews have been used to explore personal narratives and identity in persons with aphasia. Narrative interviews can be used for research purposes in gathering information on themes related to illness instead of direct therapeutic purposes. Pluta, Ulatowska, Gawron, Sobanska, and Lojek, (2015) used narratives, which were gathered through interviews, to establish themes in persons post stroke. Participants were asked to tell about their illness and to tell how their life changed because of their illness. No additional guidance or structure was provided. Eight main themes were reported including: medical information; strategies of coping with the illness, cognitive functioning, interpersonal changes, physical functioning, social support, emotional functioning, and information irrelevant to the question.

In another study using qualitative interviews, Mitchell, Skirton and Monrouxe (2011) analyzed narratives about the stroke story to explore narrative types and metaphors used by persons with aphasia. They described four narrative types: amelioration, discordant, regeneration, and acquiescent. They also reported four metaphors participants used to describe aphasia -- aphasia as a gift, aphasia as a barrier, aphasia as a thief, and aphasia as enlightenment. The authors postulated that storytelling with other persons with aphasia might support re-negotiation of identity and make sense of their aphasia by listening to how others portray themselves in personal narratives. This concept of sharing stories with other persons with aphasia has been incorporated into the 'My Story' protocol.

Although interviews provide a rich experience for personal narratives to be shared for research purposes, they are typically a one-time experience without opportunity to

retell the story and without a clear therapeutic rationale. In developing the 'My Story' protocol, a sole focus on illness (i.e., stroke or aphasia) was avoided. Additionally, time to develop, revise, and practice the narrative was employed in contrast to a one time interaction such as an interview format.

Group Intervention

Birren and Deutchman (1991) introduced guided autobiography, which is a semi-structured life review that is conducted using written language in a group setting. They conceptualized it as a way of helping people construct a written life review by revisiting specific life stages, and by writing about their conflicts and experiences in order to receive some resolution. Their work was not specific to persons with aphasia but rather to aging populations.

Keegan (2013) adapted Birren and Deutchman's (1991) guided autobiography technique to support stroke survivors in telling a story about their life with stroke. Richman and Hartman (2013) adapted from Keegan's (2013) protocol in a writing group for persons with aphasia at an aphasia center. Although the research design of this project was limited statistically, reported results included the finding that all participants enjoyed the process of writing a guided-autobiography and 88% felt more confident in their writing ability and had a greater willingness to take on writing projects after participating in the project.

Writing life stories may be a promising option for individuals with aphasia to address identity renegotiation; however, it is not the focus of the 'My Story' Project. Aphasia centers offer a unique opportunity for individuals to receive intensive and specialized services, including group therapy, often with a different reimbursement policy

than traditional outpatient services. While group therapy for people with aphasia may have an important role in aphasia rehabilitation, it is not widely reimbursed by insurance providers in the United States. The 'My Story' Project was intended to be delivered as individual therapy sessions in a manner consistent with current reimbursement models for clients with aphasia.

Another group approach involving the sharing of stories in community-based stroke support groups by persons with aphasia was explored by Shadden and Agan (2004) using a case study design. Stories were shared at the start of each support group, and members were encouraged to share stories about recent experiences, challenges, or successes. This research provided an overview of identity renegotiation and aphasia and practical tips for clinicians to use to support identity in persons with aphasia and their family members.

Support groups are a means of validation for adjustment with stroke and aphasia. However, support groups are typically a gratis service offered within communities. Without additional evidenced-based methods for providing services within current reimbursable delivery systems for aphasia services, this may imply that the work of supporting renegotiation of identity should be provided outside of traditional, reimbursable delivery of aphasia services. The 'My Story' Project was designed to be deliverable by clinicians who provide traditional, individual sessions that are reimbursed by insurance. The 'My Story' Project does incorporate one group session at the end, as a celebratory event, which is intended to be conducted outside of the traditional therapy environment in order to share the 'My Story' personal narrative. This activity is intended

to add to the authenticity of co-constructing one's personal narrative with an audience in mind.

Guided Self-Determination

Guided self-determination has been used as a method in which storytelling was utilized as a means of supporting identity changes following stroke with the overall goal of improved psychosocial wellbeing (Kirkevold, Bronken, Martinsen, & Kvinge, 2012). Guided self-determination was used to ensure participants were active partners in their own recovery process. Kirkevold, Martinsen, Bronken, and Kvinge (2014) provided individual and group guided self-determination intervention to stroke survivors over eight sessions provided by community-based nurses during the first year post-stroke. Specific methods for each encounter included an outline with goals and topics. Topics included building a collaborative relationship to learn about the person's values, interests and goals; supporting the process of adjustment; renegotiating roles and identity; identifying goals and how to reach them; and, talking about experiences. Results indicated that the opportunity to tell stories about experiences with stroke offered time for reflection to discuss issues they had not thought of on their own. A subgroup of this study included people with moderate to severe aphasia. The importance of differentiating persons with and without language problems when determining intervention structure was emphasized. Additionally recommendations included allowing flexibility in the frequency and number of encounters.

Two further research studies drawn directly from the project of Kirkevold et al. (2012) have specific ties to narrative use in persons with aphasia to support psychosocial well-being. The first was conducted as a qualitative multiple case study with 7 persons

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with aphasia, who were all participants in the larger intervention study reported by Kirkevold et al. (2012) (Bronken, Kirkevold, Martinsen, Wylle, & Kvinge, 2012a). Guided self-determination intervention, as described by Kirkevold et al. (2012), was modified for all individual sessions. Themes identified in post-session qualitative interviews included: benefits of assistance and reserved time and opportunity to narrate about themselves and their experiences; increasing confidence in talking; psychological support; motivation to endure and continue; and exchange of knowledge and information based on individual experiences. The second study was a single case study of one of the participants with aphasia and the nurse who provided intervention within the Bronken et al. 2012(a) study was highlighted (Bronken, Kirkevold, Martinsen, & Kvigne, 2012b). Emphasis was placed on a partnership to aid the co-construction of stories between the nurse and person with aphasia to support the recovery process. Findings indicated the partnership in telling a story to reconstruct identity was beneficial. Additionally, dedicated and guided time to talk about psychosocial issues longitudinally was necessary to meet the needs of persons with aphasia. Guided self-determination provides specific and promising methods to supporting identity through narratives with persons with aphasia. Concepts utilized in the 'My Story' Project included individualized sessions and the co-construction process.

Biographic-Narrative Approaches

Another version of narrative approaches has been termed *biographic-narrative*. Corsten, Konradi, Schimpf, Hardering, and Kelimann (2014) investigated a biographic-narrative approach that involved combining individual life-story interviews with group therapy to target improved health outcomes for people with aphasia. Seventeen persons

with chronic aphasia were provided a 10-week intervention, which included five

individual biographic-narrative interviews and seven group interventions all of which

were 90-minutes in length. Initial improvements in health-related quality of life measures

were reported to remain stable three months post intervention; however, overall life

satisfaction did not change significantly according to the measures used. Corsten and

colleagues advised that conversational aids such as pictures or other graphics should be

used with caution in order to reduce the threat of altering the narration by the therapist.

They also reported that the individual interviews appeared to be more effective than

group and cited work by McKeown, Clarke, and Repper (2006) which stated that the

rethinking of one's own life and self-concept is better addressed in one-on-one dialogues

(Corsten, et al, 2013, p. 9). The biographic-narrative approach influenced the 'My Story'

Project in length of sessions and caution of ensuring that ownership of the story, while

supported by the clinician, belongs to the client.

Additional Influences on the 'My Story' Project to Support Storytelling with Aphasia

A recent longitudinal qualitative study of persons with aphasia during their first

year of living with aphasia identified *actively moving forward* as an overarching theme

(Grohn, Worrall, Simmons-Mackie, & Hudson, 2014). Holland (2007) emphasized the

importance of the use of positive psychology when supporting people with

communication disorders in her text on counseling. Specifically, she encouraged helping

clients to focus on abilities instead of deficits and cited Seligman's (2002) three routes to

happiness-- the pleasant life, the engaged life, and the meaningful life. Actively moving

forward fits well with an engaged and meaningful life. Holland also encouraged use of a

life-coaching model, a process grounded in wellness, which emphasizes normalcy, health,

and teaching of strategies for problem solving. Worrall et al. (2010) provided further evidence of the support of life-coaching for supporting persons with aphasia. Life-coaching involves the development of goals, set by the client, and supported by the coach. Both of these references to coaching are supported in narrative-based approaches by Alheit (1995), who referred to those who support the co-construction process of life narratives as *biographical coaches*. These influences fit well within the concept of supporting living successfully with aphasia and have informed the development of the guiding principles of the 'My Story' protocol.

Because of the challenges of communicating with aphasia, it is important for communication partners to provide techniques to facilitate communication during the co-construction of the 'My Story' personal narrative. Supported Conversation for Adults with Aphasia (SCA; Kagen et al., 2001) offers one system for doing so. It was designed to reveal the competence of the person with aphasia by making sure the person with aphasia not only understands the message being communicated, but is provided with opportunities to express their message and verify that the conversation is heading where the person with aphasia had intended. Concepts of SCA will be used to support the co-construction of the 'My Story' personal narrative.

Summary

Narratives and identity have been recognized as having a complex relationship in that they may influence one another. Identity is impacted by loss, such as the loss that follows stroke and the onset of aphasia. Language plays an important role in telling stories yet, by definition, language abilities are damaged with aphasia. Narratives may have a role in supporting the renegotiation of identity in persons with aphasia. However

with the language challenges aphasia presents, it may be necessary to modify existing methods in order to support or co-construct personal narratives about their life. This area of research is gaining interest. Four categories of narrative methods, interviews, group therapy, guided self-determination, and biographic-narrative approach were reviewed. Components were drawn from each to create a protocol 'My Story' to co-construct personal narratives in persons with aphasia to support identity reconstruction.

The intent of the 'My Story' Project was to develop and pilot a protocol to co-construct a personal narrative that can be communicated in a way that will be understandable to others. The audience included other story tellers who also have aphasia and who were sharing their own co-constructed stories formally, as well as friends and family that each of the three story tellers with aphasia invited to hear their stories. Although the process of co-constructing the personal narrative was a shared experience, the person with aphasia had ownership of the ideas and story constructed. Therefore the 'My Story' Project was developed to provide a tool to clinicians who provide services to adults with aphasia that may be usable in a typical outpatient setting - beyond protocols designed for a specialized clinical setting such as a university or aphasia center.

Research Aims

The aims of this investigation, which used a collective case study design, were to describe the protocol and 'My Story' products that resulted from this co-constructive process for three primary participants (i.e., story tellers who have aphasia). This description includes any changes to the 'My Story' protocol that resulted from the co-constructive process of developing a personal narrative about their life. Additionally, the process of co-constructing 'My Story' was explored from the perspective both the of the

person with aphasia and the clinician-researcher, using data collected from post-session interviews and through data collected from reflective journaling.

Method

Design

A collective case study approach was used to pilot the 'My Story' protocol for co-construction of personal narratives with persons with aphasia (Creswell, 2007). People with aphasia were recruited to be participant-researchers in piloting the 'My Story' protocol as well as reflecting on and improving the process. They were invited to take part in a total of 6 individual 90-minute sessions with the clinician-researcher, sessions which were designed to co-construct and share a personal narrative about their life. This included: "Who I was before my stroke and aphasia;" "My stroke and aphasia;" "Who I am today;" and "My future goals." A seventh and final group session including a focus group, was held where the 'My Story' personal narratives were shared with all participants and their invited guests.

Participants

Two types of participants participated in this study—people with aphasia, and people they designated to be invited to be members of an audience to hear their stories. Members of this second group were invited to participate in a focus group after the story sharing session as well, and their informed consent was sought for this purpose. In addition, due to the nature of this qualitative investigation, I gathered journal data in my role as researcher-clinician conducting the study.

People with aphasia. People with aphasia were the story tellers who also served as participant-researchers. The primary participants in this research were those who

agreed to be story tellers. Participants were informed about the nature of the research

being conducted in aphasia friendly ways and were asked for their consent to use their

stories in describing the 'My Story' approach and in sharing the approach with others.

They also were asked whether they were willing to assume the role of research partner to

help improve the 'My Story' procedure in an effort to make it even more meaningful and

aphasia friendly for other people who may use the 'My Story' approach in the future. The

terminology for the two roles, *participant-researcher* and *clinician-researcher*, was

purposeful. This terminology was used during recruitment and the actual project to

signify that both voices were equally important in examining the process and product of

co-constructing a personal narrative.

A consumer participation approach to research supports person-centeredness in

clinical research and practice through shared decision making with people with aphasia

(i.e., the consumers of aphasia treatment) in creating and conducting research on aphasia

(Hinckley, Boyle, Lombard, & Bartels-Torbin, 2014). This collaborative attitude to

aphasia research between researchers and people with aphasia supports both an

evidenced-based approach by incorporating patient values into practice and a social

approach by allowing people with aphasia to have an active voice in clinical aphasia

research. This may in turn impact others with aphasia who will receive clinical services

based on this research. Ultimately this will contribute to improved clinical processes for

supporting the pursuit of living successfully with aphasia. This study was designed to

pilot and evaluate the 'My Story' protocol with this collaborative spirit in mind.

Purposeful sampling using a maximum variation strategy (Creswell, 2007) was

used for the recruitment of three to five individuals with aphasia who were willing to co-

construct and share their stories. This strategy was used to seek to engage participant-researchers who exhibited a range of aphasia type and severity, sex, age, and life experiences in order to represent a collection of experiences related to living with aphasia.

The inclusion criteria were: adults ages 40-75; diagnosis of aphasia secondary to stroke; minimum of 2-years post stroke; English as a primary language; and willingness to participate in the study. Participants exhibited mild to moderate chronic aphasia as determined by the Western Aphasia Battery-Revised (WAB-R, Kertesz, 2007). The rationale for this was to have participants who could provide verbal feedback on the process, despite having a language impairment caused by aphasia. Exclusion criteria included global aphasia or severe auditory comprehension deficits that could preclude their understanding of directions or concepts. Additionally, any individual who has a deteriorating neurogenic disorder such as dementia or primary progressive aphasia or a behavior or psychiatric problem (with exception of depression) as determined by self-disclosure was excluded because the goal was to pilot the 'My Story' protocol with people who have chronic aphasia.

Participant-researchers were recruited from a community aphasia support group. Initially, an email invitation to participate in this study was distributed to members of the community group (Appendix B). In the email, potential participants were provided contact information of the investigator as a means of addressing questions or concerns. Informed consent procedures were implemented with participants who expressed interest. The informed consent document was created to be 'aphasia friendly' using the Stroke Association (2012) guidelines.

At the time of consent, participant-researchers were informed that the project

involved sharing their 'My Story' personal narrative with others. Appendix C outlines the

consent process for all participants. Specifically, participant-researchers were asked to

take part in a process 'My Story' to try and find out whether constructing and sharing a

story about their life was helpful. Additionally, each participant-researcher was asked to

invite 1-2 individuals of their choosing to attend a group celebration and focus group

where they shared their 'My Story' personal narrative. This group celebration and focus

group included the two other participant-researchers who also shared their stories along

with two of their friends or family for each of them.

Five participants who were representative of a collection of experiences enrolled

in the study. Table 3.1 outlines the participants. All participants had aphasia due to

stroke.

Table 3.1

Participant Demographics (n = 5)

Name	Age (years)	Marital Status	Sex	Time since stroke (years)	WAB AQ	Aphasia Type	Completed Project
Diane	59	Married	Female	2	92.2	Transcortical Motor	No*
Dave	63	Married	Male	4	44.4	Broca's	Yes
James	66	Married	Male	5	93.1	Anomic	Yes
Nancy	67	Single	Female	12	86.5	Anomic	No**
Dennis	55	Married	Male	4	66.3	Broca's	Yes

Note. Names anonymized to protect identity. *Stopped project after 1 session due to
family issues. *Stopped project after 2 sessions due to health issues.

Diane exhibited a mild transcortical motor aphasia. She exhibited word finding

difficulty during her conversational speech. However after the initial session, Diane had

to stop participating due to a family issue. This was quite upsetting to her and will be discussed later in this paper.

Dave had the most severe aphasia of the five participants. He also had a concomitant apraxia. He communicated with primarily at the word level with occasional two word phrases, and used gestures and writing to augment his verbal productions. Dave's comprehension, both auditory and written, was a strength.

James had mild anomic aphasia. He exhibited semantic and phonemic paraphasias during his conversational speech. Despite this, James was able to communicate at the conversational level verbally without many supports.

Nancy exhibited mild to moderate anomic aphasia. She also had to end her participation after two sessions due to health issues and was distraught at having to end her participation. This also will be discussed later in the paper.

Dennis exhibited a moderate aphasia. His auditory comprehension was more compromised than his reading comprehension. He communicated verbally despite his non-fluent speech which had many paraphasias.

Due to the attrition of both female participants, the participants completing the study were more homogenous in their characteristics than the original five participants. However the type and severity of aphasia was varied among the remaining three participants.

Working with people with aphasia requires careful ethical sensitivity (Lloyd, Gatherer, & Kalsy, 2006; Morse, 2007; Sundin, Nordberg, & Jansson, 2001). People with aphasia are at risk for emotional harm, disempowerment, and lack of acknowledgement because of their communication disability (Bronken et al., 2012b). Participants may have

strong or intense emotional reactions to talking about their experiences about having a stroke and aphasia. As primary student investigator, I was prepared for this to occur. I have a master's degree in speech-language pathology and am a licensed and certified speech-language pathologist with 20 years of experience working with people who have aphasia. I will be sensitive to and supportive of the participants in this experience, be an active and reflective listener, and will ask participants if they need to stop or take a break.

Audience participants. Each person with aphasia who agreed to be part of the 'My Story' Project as a participant-researcher was asked to invite up to two individuals to hear their story at a group celebration event that involved the presentation of stories by all three participant-researchers. Criteria for inclusion in the audience group was that the person was someone who is important to the 'My Story' author and whom they view as likely to be accepting of others sharing their 'My Story' personal narratives in the group celebration format. Because these audience members were asked to participate in a focus group at the close of the group celebration, their informed consent was obtained as research participants (Appendix C). An invitation to the group celebration is provided in Appendix D.

'My Story' Project Development

The 'My Story' Project was developed in an effort to provide a clinical tool to use for co-constructing a personal narrative with persons with aphasia. I developed the preliminary protocol for co-constructing 'My Story' a personal narrative based on a review of the literature in aphasia, psychology and narrative gerontology, which is summarized in the introduction of this paper. This protocol was used to implement the current study and was refined with input from both clinician-researcher and participant-

researchers as part of the study. The protocol has two parts: 1) Guiding Principles for Clinicians Co-Constructing 'My Story' a Personal Narrative with Persons with Aphasia (Appendix E); and 2) Protocol for Co-Constructing 'My Story' a Personal Narrative for Persons with Aphasia (Appendix F). The development of each protocol is explained in the section that follows.

Guiding principles for co-constructing 'My Story' a personal narrative. The first tool in the protocol is the Guiding Principles. The intent of this document (Appendix E) was to provide a framework for clinicians in supporting a client with aphasia in sharing his or her personal narrative. These principles provide a philosophical and theoretical orientation to narrative and identity (McAdams, 2008) and how narrative and identity relate to persons with aphasia (Brumfitt, 2008a; Shadden, 2005; Shadden, Hagstrom, & Koski, 2008; Worrell, et al., 2010). Additionally, the principles were provided as a general outline of the process of co-constructing a narrative with a person with aphasia. It was made clear that there should be a beginning and an end to the co-construction, a practice session, and a formal sharing of the story with someone selected by the client. The objective was to provide enough support to construct the story while maintaining enough flexibility to evoke meaningfulness for each individual.

The use of positive psychology and a coaching model (Holland, 2007) are referenced in order to emphasize that the co-construction process should be a positive experience, even if emotional at times. Further, concepts from SCA (Kagan, 1998) was used to support conversation on complex topics. Finally BACKDROP principles including: balance; authentic audience; constructivist; keep it simple; dynamic; reflective practice; ownership; and patience from The Writing Lab Approach (Nelson, Bahr, & Van

Meter, 2003) were modified and provided as a framework for co-construction support. Also emphasized was the importance of the process being a learning experience for both participants, client and clinician.

Protocol for co-constructing 'My Story' a personal narrative. The second tool in the protocol is the Protocol for Co-Constructing 'My Story' a Personal Narrative (Appendix F). The graphics and text in this tool were intended to be used as a guide for both the clinician and person with aphasia in the process of co-constructing the personal narrative. Each participant-researcher co-constructed a personal narrative, 'My Story', about his life for this project. The content varied with the participants, but the format was controlled to a degree. To start with, each person's story was organized into four parts. The exact topics were left up to the participants; however, participants were asked to consider the following organizational structure, which is based on the work of McAdams (2008): 1) *Who I was before my stroke and aphasia*; 2) *My stroke and aphasia*; 3) *Who I am today*; and 4) *My future/goals.* It was explained to participants that part of their role was to serve as a research partner to help improve the procedure to make it even more 'aphasia friendly' and meaningful for other people who may use the 'My Story' approach in the future.

'My Story' session outline. The 'My Story' Project was conducted in seven sessions, including six individual sessions and one group session. The goal was to hold all sessions within a four week time frame. Thus, an average of two sessions was scheduled per week. The session length for individual sessions was established based on recommendations by Bronken et al. (2012) and Corsten et al. (2014), who found that an

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average of 90 minutes per session was needed for narrative construction with persons with aphasia. A detailed outline of each session is provided below.

Session 1. During this session consent was obtained and the WAB-R (Kertesz, 2007) was administered to determine type of aphasia and eligibility (45-60 minutes). Additionally the Communication Confidence Rating Scale for Aphasia (CCRSA) (Cherney & Babbit, 2011) was administered as a pretest to be used later in the follow-up study (10 minutes). Finally, the Protocol for Co-Constructing 'My Story' a Personal Narrative was reviewed as an introduction to what was to come (15-20 minutes).

Sessions 2-5. During these sessions, the participant-researcher and participant-clinician worked together to co-construct each of the chapters (each session was 90 minutes). Participant-researchers were asked to bring in any artifacts such as photos or other memorabilia to aid in developing the story. These artifacts were scanned and used to illustrate the story. The initial 15 minutes of Sessions 2-5 was spent reviewing the content from the previous session. The next 45 minutes was devoted to chapter development. The final 15 minutes of each session was dedicated to reviewing the content developed during the current session. During this time, plans were made for the next session, including making note of any additional artifacts that the participant-researcher should prepare or bring to the following session.

Session 6. This session focused on practicing to tell the story constructed during the previous sessions in preparation for sharing the story in the group session (90 minute session). Final revisions or edits to the story were completed during this session.

Session 7. This group session was a celebration event where stories were shared with the other two researcher-participants and invited guests (45-60 minutes).

Additionally, immediately following the storytelling, a focus group was held to gather feedback on the 'My Story' Project from all participants (60 minutes) (total session 2.5 hours)

Aphasia friendly format. Efforts were made to devise the 'My Story' protocol using an *aphasia friendly* format using guidelines from the United Kingdom, entitled *Accessible Information Guidelines: Making Information Accessible for People with Aphasia* (Stroke Association, 2012). Specifically, short messages using clear and simple sentences were used. Vocabulary choices were selected to facilitate ease in reading. The layout was arranged to have boxes around messages and using 14-18 point sans serif font (i.e., Arial was selected). Headings were used to increase organization of the information. Images were used to increase understanding of the message. Images were placed under sentences. White background was used with black writing. Color was used in borders and headers to increase organization. To organize a set of information, the same layout was used throughout the protocol. Flesch-Kincaid Grade Level was run on Microsoft Office for the protocol and indicated a grade-level of 4.8 with 1% of sentences being passive. Guidelines recommend a 5.0 or lower grade-level and the use of active sentences. These materials met those guidelines.

Platform for 'My Story'. Efforts were made to include tangible supports to assist persons with aphasia in the retelling of their 'My Story' narrative in this project and in other settings. For this purpose, Microsoft Office PowerPoint was selected as a platform to organize and record the personal narrative. It is affordable, widely accessible and allows for a combination of text, photos, color, clip art, sounds, and video. Additionally,

PowerPoint is flexible in how it can be shared (i.e., print out, on computer screen, tablet device, or projected).

Data Sources

A number of sources of data were collected for this study. Each data source is outlined below.

Measures of aphasia. The WAB-R (Kertesz, 2007) was used to provide a standardized measure of aphasia type and severity in participants and determine eligibility for participation. Participant-researchers exhibited mild to moderate aphasia in order to participate in the 'My Story' Project. As measurable changes in communication were not an expected outcome of this study, this assessment was only administered prior to beginning co-construction of the personal narrative, 'My Story' to determine type and severity of aphasia. The WAB-R was not used as a post-test measure.

Within-session video recordings and researcher field notes. Each session was videotaped. Video recordings were reviewed for pertinent information and portions identified as of interest were transcribed. Additionally, field notes were taken during each session to document the session and make note of any changes to the protocol or process that were found beneficial.

Post-session interviews. A brief semi-structured interview (Appendix G) was conducted at the end of each session to gather participants' views on 'My Story' process at that point. This was administered a total of five times for each participant (15 times total). These interviews were video recorded. Interviews were transcribed for purpose of analysis. Initial transcription was completed by two second year master's students trained

in phonetics and who had recently completed a graduate course in aphasia. I then edited the transcript while reviewing the videotape to ensure accuracy of transcription.

Ongoing self-reflective journaling of researcher. Following each session I recorded my thoughts in a journal to reflect on the co-construction process. This was completed five times for each participant (15 times total).

'My Story' artifacts. PowerPoint was used to support the construction of the 'My Story' personal narrative. Daily session drafts of PowerPoint of each 'My Story' personal narrative were collected and reviewed (5 per participant, 15 total). The final version of PowerPoint of each 'My Story' personal narrative was collected and reviewed (3 total). Additionally, any artifacts such as photos or memorabilia brought to the sessions by participant-researchers were scanned. These artifacts were added to the PowerPoint presentations.

'My Story' presentations. Formal presentation of 'My Story' personal narratives during the group celebration activity was video recorded and transcribed in the same method as the post-session interviews.

Focus group. Immediately following the group celebration, a 60-minute focus group was held. This allowed an opportunity for the participant-researchers to share and compare experiences on the 'My Story' Project process. Their designated invited audience members were asked to comment. In general, the purpose of a focus group is to understand how people feel or think about an issue, product service or idea and relies on the interaction of the participants to stimulate ideas and comments (Krueger & Casey, 2000). In this case, the purpose of the focus group was to understand how the participants and audience members perceived the 'My Story' Project process and to obtain feedback

on ideas as to how this process can be improved. It also allowed for participants to process their experience with the project. The focus group was video recorded and transcribed.

A protocol outlining the focus group is provided in Appendix H. The focus group was designed to be aphasia friendly by having a PowerPoint slide show to use as visual support as well as providing a structure for the format (Appendix I). The focus group included a warm up to welcome participants and provide ground rules (5 minutes), time for the participant-researchers to share their thoughts on the process using sentence lead ins (e.g., When I shared my story I felt _____) (25 minutes), time for those participants who were invited by the participant-researchers to attend to share their reactions to the presentations (15 minutes), time for all participants in the focus group to share their thoughts on the 'My Story' Project (10 minutes), and a wrap up to summarize the focus group outcomes (5 minutes). I facilitated the focus group with the support of a colleague with expertise in aphasia. The focus group was video recorded and transcribed in the same method as the post-session interviews.

Analysis

The analysis was based on a qualitative methodological philosophy (Creswell, 2007) that involved examining the reflection on the process of co-constructing the personal narrative from perspectives of persons with aphasia, the researcher, and the audience members who were invited to hear the 'My Story' personal narratives. The multiple data sources described in Sources of Data section were reviewed for themes to build a cohesive picture of the success of the protocol and how it could be improved. Key issues were explored in analyzing the data regarding the experience in the process of

developing a co-constructed personal narrative. Triangulation was used to increase

trustworthiness of data (Hays & Singh, 2012).

<div align="center">**Results**</div>

The purpose of this investigation was to describe the implementation of the

protocol and subsequent 'My Story' products that resulted from this co-constructive

process. This description included any changes to the 'My Story' protocol that resulted

from co-constructive processes. Additionally the experience of the co-construction

process from the perspective of the participants using data collected from data sources

described in the Method section was explored. Finally, participant attrition was discussed.

The 'My Story' Protocol

The 'My Story' protocol was used to provide an overview of the project to both

the clinician-researcher and the participant-researcher. The protocol had two parts: 1)

Guiding Principles for Clinicians Co-Constructing 'My Story' a Personal Narrative with

Persons with Aphasia; and 2) Protocol for Co-Constructing 'My Story' a Personal

Narrative for Persons with Aphasia. I will first begin with the Guiding Principles,

followed by the Protocol for Co-constructing 'My Story using the following criteria:

What worked as expected; Surprises; and *What to do differently.*

Guiding principles. The following sections describe what worked as expected,

what to do differently, and surprises for the guiding principles.

What worked as expected. The 11 guiding principles were adhered to by the

clinician-researcher throughout the 'My Story' Project. The framework of ensuring a

shared experience that provided enough support to construct the story but enough

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flexibility to evoke meaningfulness to each participant-researcher was well received by all participants, including the clinician-researcher.

What to do differently. In reviewing the principles, it might be useful to add in a twelfth principle to include information on restorying (Kenyon & Randall 1997). The concept of restorying involves the clinician actively helping the client reframe how they view a story in order to be able to move forward and have a new perspective. Clinicians who are not familiar with narrative gerontology literature would benefit from this perspective.

Surprises. Principle 4 outlined that the story will be short in nature, approximately 10 minutes. This was not the case. Dave's story was 23 minutes, James' was 31 minutes, and Dennis' was 24 minutes. While more time could be devoted to editing to reduce the time of the actual presentation, this must be carefully balanced with providing an environment which supports the persons with aphasia and allows them to share the story they wish to share. Putting a time constraint on communication adds a layer of pressure, which may be counterproductive to the purpose of sharing the story. However, the reality of time constraints is real. While editing was done during Sessions 2-6, this could be refined to provide a more concise story which may then naturally reduce the length of the story.

Protocol for co-constructing 'My Story'. The following sections describe what worked as expected, what to do differently, and surprises for the protocol for co-constructing 'My Story'.

What worked as expected. The 10-page protocol for co-constructing 'My Story' was printed in color and spiral bound. This product was presented to each participant

during the initial session. The protocol was reviewed with the participant-researcher. The use of an aphasia friendly format allowed for ease in reviewing content. The protocol was well-received by participant-researchers and provided the intended overview to prepare them for the work ahead. This was evidenced by them each coming to Session 2 prepared to begin the story process. It was also helpful to have all individual sessions decided upon and scheduled during the first session and the protocol provided a space to write down each appointment and time for future reference.

What to do differently. In hindsight, Tip 3, which describes the story as having 4 chapters should be revised as none of the final products were organized in chapter format. This is not to say that some clients would not benefit from using chapters to organize their stories. However, the chapter label did not seem necessary. What was important were transitions, which will be discussed under the section on feedback about the process.

Surprises. Tip 5 which warned of fatigue was included as a part of the process to emphasize the importance of communicating to the participant-researcher that at any time, they can stop if a break is needed. What actually occurred was the opposite. Time passed quickly during the 90-minute sessions.

'My Story' Session Structure

The outline of sessions provided in the Method section was generally followed. However some slight differences occurred. Table 3.2 provides a summary of how the sessions differed from what was planned and what actually occurred.

Table 3.2

Outline of 'My Story' Project Sessions Including Proposed and Actual Session Length

Session	Content	Session Length	
		Proposed	Actual
1	Western Aphasia Battery-Revised (45 minutes); Communication Confidence Rating Scale for Aphasia (CCRSA) (10 minutes), Review protocol for 'My Story' project (Appendix E) (15-20 minutes) (total session 90 minutes)	90 minutes	90 minutes
2-5	Story construction sessions (75 minutes) and post-session interview (15 minutes)	90 minutes (each)	80-110 minutes (each)
6	Practice telling 'My Story' and post-session interview	90 minutes	60-90 minutes
7	Celebration Event where stories were shared (90 minutes) and Focus Group immediately to follow (60 minutes)	120 minutes	150 minutes

Most sessions went the planned length. The exception was the celebration event, which lasted 30 minutes longer than expected due to the length of the story presentations. Also, while most story construction sessions lasted the planned 90 minutes, some lasted only 80 minutes and one lasted 110 minutes.

The proposed structure of the 90-minute sessions 2-6 was by in large followed. This involved using the initial 15 minutes as a review of the content from the previous session, followed by the next 45 minutes devoted to chapter development, concluding with using the final 15 minutes of each session to review the content developed during the current session. However, I followed the lead of each participant-researcher as to where they wanted to begin and sometimes this led to them showing the artifacts they brought in or following up on something that was discussed at a previous session. I made it a priority to ask participant-researchers what content they wanted to start with to empower them with the sense that this was their time and their story. We knew the work

that was expected of us in each session, but there was benefit to having flexibility during each session to personalize this to the specific participant's needs during that particular session. We did end each session with a wrap up and an overview of what was expected from each of us before the next session. Table 3.3 provides a general overview of the content constructed during each session. All participants chose to develop their stories chronologically.

Table 3.3

Overview of Content for 'My Story' Project Sessions 2-6

Session	Overview of content
2	Constructed story slides for life before stroke and aphasia. Focused on former work life, family, hobbies and interests. Assigned homework including finding artifacts.
3	Edited slides for before stroke and aphasia, constructed story slides for the stroke event and subsequent rehabilitation. Helpful to have participant-researcher read the slide content aloud during editing to begin to practice telling the story. Artifacts brought in and reviewed to determine where to place in the story.
4	Continued to revise and edit stroke story slides. Added slides for goals and future. Artifacts continued to be brought in. Helpful to have participant-researcher read the slide content aloud during editing to begin to practice telling the story.
5	Added content as determined by participant-researcher. Reviewed and edited story. Support provided for sequencing of events to enhance story flow. Helpful to have participant-researcher read the slide content aloud during editing to begin to practice telling the story. At end of session, provided a tour of the room for practice session and ultimately where share stories.
6	Practice session held in room in which the celebration event was to be held. Projected PowerPoint slides. Final edits were made. Practiced telling story aloud. Determined who would control the computer and how to determine the level of cuing supports.

Note. This is a general overview of the structure and content of each session to share what sessions entailed. However, allowing for flexibility to follow lead of participant-researcher is recommended.

'My Story' Products

During the initial co-construction session, a PowerPoint file was created for each participant-researcher. During each subsequent session, that file was edited as more of the narrative was added and refined. At the end of each session, a full-page, color copy of the PowerPoint was printed and given to the participant-researchers to support their preparation for the next session. As story artifacts were brought in, they were converted to digital files and added to the PowerPoint file. On the day of the group celebration event after the focus group had concluded, bound color copies of the final PowerPoint, which represented the story they shared that day, were presented to each participant-researcher. Additionally, during a follow-up qualitative interview, which is the focus of Chapter IV of this dissertation, each participant-researchers were presented with a flash drive containing the final PowerPoint file and a copy of the video recording of their 'My Story' presentation for them to use as they wished. This not only provided each participant-researcher with a tangible remembrance of their work, it also provided an avenue to continue to share their story in the future. Binding the presentation, while an added expense for the clinician-researcher, allowed for a keepsake of the experience.

Participant Perspectives

A primary objective of this study was to describe the experience of participating in the 'My Story' Project from the perspective of all participants in an effort to improve the process for others with aphasia. Each participant group; participant-researchers, clinician researcher, and audience members was reviewed.

Participant-researchers. During the recruitment process, each participant agreed to assume the role of research partner to help improve the 'My Story' procedure in an

effort to make it even more meaningful and aphasia friendly for other people who may use the 'My Story' approach in the future. Data from each of the post session interviews from each participant-researcher and the focus group were reviewed and analyzed for themes. Dennis and James provided more responses in the post-session interviews than did Dave, which was expected due to the severity of Dave's aphasia. Results revealed three themes: *value in co-construction process*, *providing perspective*, and *we had fun*. Each theme will be reviewed.

Value in the co-construction process. All three participants reported that the process worked well and was worthwhile of the time and energy invested. In fact they had minimal, if any, suggestions or constructive feedback about changing the process. The following post-session interview passage summarizes Dennis' view of the process and the importance he placed on his role as a participant-researcher in exploring this process for helping others with aphasia.

Dennis: The process has been, has been ah. The whole thing nothing but a
            blessing to me. You know? Any chance to help help somebody.
            Speech. You know what anything in life. It helps, I hope it helps
            somebody. I hope it help. Find help find one person helps them. It
            worth it.

James stated during a post-session interview, "Your input was really small," meaning that he felt ownership of his story He went on to say, "You're not overdoing it or underdoing it. It's really working."

Dennis also stated the value he found in realizing that he could do this. The

process empowered him by his revelation that he could talk. This motivated him, which

he describes below as "push me up, fire up."

> Dennis: Um um to me um I what working on the story, story, my story,
>
> Katie helped me. Made me, found out that I can I can I can do it.
>
> You know. You don't think I can't do that I can't talk, can't write,
>
> can't talk to people. Now I can, I can, I can do stuff. You know?
>
> Give me a reason to get going. You know? Push me up, fire up. I
>
> hope.

During each post-session interview, participant-researchers were asked "How

much of the story represents your own words?' using the visual analog scale described in

the post-session interview protocol. Dave and Dennis each reported 100% of the story

was their own words at every session. In the first session, James' ratings were 80%, then

increased to 85-90% (his choice of range) in the second session, and the remaining

sessions were consistently 90%. All participants reported ownership of their stories and

felt comfortable with the reported percentages at each session. During a post-session

interview when asked how much of the story represented his own words, Dennis

responded to the question by stating, "All of it. 100 percent. You helped me though. I

can't [because of the] phase it [aphasia] now.

During the focus group, Dennis mentioned the value of having practiced supports

during the sessions which then allowed him increased independence and success in

sharing his story. Specifically, Dennis had difficulty with producing multisyllabic words.

A strategy was created during the session where I wrote down the target word and then

beside it wrote out a version of a phonetic transcription which was helpful for him in producing the word. He then took the list home to practice the words. He also mentioned that he appreciated what he referred to as the "cheat chart." During the celebratory event presentation of his story, his improvement in producing the many words on the from the "cheat chart" was noticeable. Figure 3.1 shows an example of his "cheat chart."
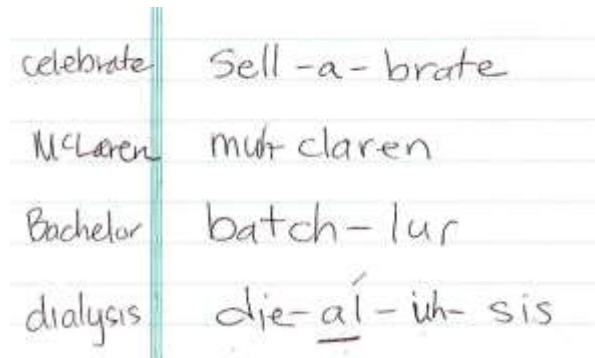
Figure 3.1. Example of strategy used with Dennis to increase his accuracy for producing multisyllabic words.

All three participant-researchers reported enjoying the partnership of them providing the verbal story content and the clinician-researcher using the computer and PowerPoint to document their stories. James and Dennis both emphasized the important role the clinician-researcher played in providing organization to the story. In the passage below from the focus group, James explained the value he found in organization.

James: One thing on me that helped me to um organize my um thoughts about what happened. And um um put things in perspective and um sequence of events and everything. It was really ni- really helpful to do to do that.

James also imparted advice to others doing this process by saying "think in advance of what you are going to say so you are organized and can get your story out."

Dennis also shared this appreciation of the roles the process provided, clinician-researcher providing the structure and using the computer while he provided the content. During a post-session interview he commented:

Dennis: It's been my words. You know? My ideas. It be help me so much. You know it. I couldn't of without you. You know? Of course. Nice for you to do the work and [for me] to tell my story. Cause my my some s- my brain goes too fast. It f-f- forgets forgets stuff you know. Well you because you can ta- you can help the words for me. You know. Still my still my still my words, but you have you have to do it. I think worked well, both of us.

Providing perspective. James stated, "We learn[ed] that um it's uh important to um um put their um life's – life in together uh b- uh before and after the uh stroke because you can uh lose track of things um in there. It helps you put your life in perspective." Dennis also shared his thoughts on the importance of thinking about his life. He commented on the value he placed on hearing the other participant-researchers' stories.

Dennis: Um the story to me is amazing, amazing thing be able to talk people same problem we have is amazing, amazing to me. Um people with good good lives, good people it's hard to b- be tell people about it you know. To me blessing to me be talk about the whole thing and so full story. Working with Katie, working with Katie is amazing. /prahy/ /prahy/ [practice] practice was cool. To me it was good chance to me to be able to think my life better you

88

know and be a better person. And the story was amazing to know

other people's other people's things that had to do with myself you

know?

During the focus group, when asked if they would tell the story again, all three agreed

that they would. James said he would practice more, but all were without hesitation

willing to share the story again. They also agreed that this was the first time since having

their stroke that they had told their story from beginning to end.

We had fun. All participants agreed that they enjoyed the co-construction

process. They demonstrated this, each in their own ways. Although Dave, whose verbal

expression was the most limited of the three participants, didn't use the word, *fun*, his

actions and gestures that were evident on the video recordings made it apparent he was

having fun. For example, Dave shared a story about sneaking water from his roommate at

the nursing home after his stroke when he wasn't allowed to eat or drink. He had never

shared this story with anyone before. He showed great pleasure in telling the story by

smiling and laughing during his mention of this story. He brought this story up frequently

during the interviews and focus group. Dave, who rarely produced more than one or two

words at a time during the final post-session interview stated, "thank you for letting me

work with you."

During the focus group, all three participant-researchers agreed that time appeared

to pass quickly during each session.

Interviewer: One of things that I noticed with all of our time together is that the

90 minutes always went really quick.

Dave: Right, right.

Interviewer: It never seemed like work or it was just we found a flow.

James: Yeah, yeah, it really went fast.

Dennis: It was fun.

Dennis was the most expressive of the three participant-researchers on the topic of having fun during the process. His statement below is representative of his feelings about the process.

Dennis: I love love it. I I have so much fun here. Do this. It's just fun I love it. You know. I know you forgot about that. [points to video camera] Doesn't matter to me. So that thing I don't care about that. They don- Forgot about it. So, I wouldn't change anything. I am what I am. You know. That's I am what I am now so.

Clinician-researcher. Data from my reflective journaling were reviewed and analyzed for themes. Results are reported in three categories; overview of experience, learning lessons, and clinical tips for implementing the process.

Overview of experience. As the clinician-researcher, I too shared the sentiment that this process was fun. Below is a passage from my first session in the story-construction process.

Journal entry for session 2 (Dave). We worked for 75 minutes and then stopped for the post-session interview. It was a really good feeling and I felt like I had generated energy vs. feeling like we had spent energy during the session. I sensed Dave felt this way too. We called in Gwen (Dave's spouse) to join us to review what we had done. Gwen told us that she was stunned that we had talked about so much…She told both of us that that was amazing as they have been married for

90

over 37 years and while reviewing the PowerPoint slides she learned at least two

new things about her husband. She even said something like "What did you guys

do in here? He never talks that much!"

The process was highly emotional for both the participant-researcher and the

clinician-researcher. When a clinician establishes a process for listening and facilitating a

story about someone's life, he or she is opening a door for learning personal details about

their client. And with that comes the responsibility to handle potentially intense content

and emotions. This occurred during the first co-construction session with participants and

continued during subsequent sessions. Below is a passage from a journal entry about

James.

> *Journal entry for session 2 (James).* What I was thinking of both during and after
>
> James's session was how quickly in his session, as well as in Dave's and Diane's
>
> first sessions, he shared deeply personal thoughts and issues with me. This is
>
> really different than other speech therapy sessions I have facilitated, where we
>
> knew there was an issue but either danced around it, or acknowledged it but didn't
>
> necessarily make it a part of the session. James was tearful a few times during the
>
> session when sharing this personal information with me.

Another journal entry from a session with Dennis about the emotional intensity is

provided below.

> *Journal entry for session 2 (Dennis).* Being respectful with other people's life and
>
> families is such a crucial part of this process. I am amazed at how open everyone
>
> has been with sharing really personal details with me during this process. Amazed
>
> and honored. I find myself becoming emotional during these sessions.

Goosebumps, teary eyes, excitement. Trying to tease out if this is directly from

the stories I am hearing, or from the space that has developed between each

author and me, or that this is my dissertation and a project that I have been

thinking of for over 5 years. Most likely a combination of all.

These entries were from the first sessions with participants; as the project progressed, the

level of comfort and sharing also increased.

Journal entry for session 4 (James). Wow. That was an intense session with

James. Productive but very emotional. I continue to be amazed at how open

people are with sharing very personal and emotional content with me. I guess it

would be good to start from the beginning of the session...He came in, pulled out

his PowerPoint slides and immediately started talking about the conversation with

his wife, since our last session. Talking about stress from his former job and

whether or not she had perceived this as impacting their marriage. From our

previous conversation, he had indicated that this had been on his mind a lot.

Probably for years but I don't know that for sure. His wife had told him that she

didn't perceive the job or him as having more stress but that she noticed his

absence during this time.

I found myself providing a dual role of researcher and clinician. A significant part of the

clinician role was that of counseling. The value of being present and listening intently to

each participant-researcher was critical as the importance was about hearing and

validating the content of the story, which often times was accompanied by an emotional

response from the participant-researcher.

Journal entry for session 3 (Dennis). I'm physically exhausted and mentally on fire. This was a lot of work. Not just for today but I think all of the stories over the past week and a half—lots of energy. Good work but definitely does take energy. As far as how could a clinician work on these stories with language goals in mind…we've done sequencing, writing, oral expression, following oral/written directions, reading, etc. I think it would be fairly easy to incorporate traditional impairment based goals into the tasks we are doing. I didn't write it before with James' session but when he was crying and talking about his first time at the aphasia group – I did feel like my role was definitely less of language expert and more of counselor to challenges and experiences caused by aphasia. Also when he was telling me he asked his wife about the stress caused by his job and if this impacted their family life…I did ask him how he felt about that. And he said relieved. I might not have been so direct to ask this before I began studying identity and other aspects of language. Or maybe I would have. But it did seem really different to me when it was happening in the moment. I'm not sure how this is different from a typical speech therapy session for a person with aphasia, but if felt different. I will say this, I have had a better return rate with 'homework' activities and expanding language tasks, than I have had previously as a clinician. Maybe I wasn't asking enough of my clients. Or maybe the interest level is so high due to the content being their own there is more internal motivation to do work between sessions – and go beyond what the clinician asks of them.

But not all sessions were emotionally intense.

Journal entry session 5 (Dave). Again, the time flew by. No warm up time needed today. Dave sat down and immediately said and wrote MRI. I knew exactly what he was talking about from our previous session where we weren't able to communicate about an abbreviation. We found the slide where the MRI was supposed be and then he told me about that experience. Once we had that straightened out, we went through the slides – back and forth – to make sure they were right, update any previous slides and add new ones. At one point, Dave was really intent on saying something and I just wasn't getting it. So he said 'Gwen' and pointed to the door. So I got up and got his wife, Gwen, to join us. She came in to clarify the information, then she left. Dave and I went back on to the story construction. I feel like we are in a routine. We both know our roles and it's fun and efficient. Collaborating. I also learned a lot about Dave today. He likes to listen to music and hunt for CDs in thrift stores.

Learning lessons. These are some of the lessons I learned throughout this project.

Co-construction process. An integral aspect of this project was the collaborative nature of the relationship between each participant-researcher and me. This was established at the start of the project and cultivated throughout. Having an authentic interest in each person and their story was of utmost importance. Also being fully present and genuinely listening to their stories established that this was a time devoted to what they deemed important. There were many techniques used to build this partnership, but one was to ask the participant-researcher what they wanted to do next or how to proceed vs. me deciding this as the clinician. The journal excerpt below provides an example of this.

Journal entry session 4 (James). I could tell that he wasn't sure where to start and that he had a lot on his mind. It seemed like he was leaning more toward the notes he had written on the slides so we started there. He had clarified some of the content with his wife, Jane, as well as added some new information as well. While he was sharing this information we were engaged in conversation. It was a lot of content. So I asked him, do you think we should keep talking or should I bring out the computer to start adding to the slides? He said he'd prefer to talk it out first then go to the slides. So we did. Asking his opinion seemed to continue the spirit of the collaborative nature to co-construction vs. me directing what should happen next seemed to be a really natural fit to this session.

After a few sessions, we each knew our role and worked together on the story instead of the clinician directing the entire process.

Journal entry session 6 (James). Today was our practice session. In comparison to previous sessions where we spent time constructing the story, today seemed more like a check in as the story was already constructed. I really felt like a coach today. He was reading off the slides – using the computer screen and then switching to the projection screen – while I helped move through the slides. He read them aloud, we found a few typos and also some areas that needed a minor tweaking. A few of the slides with the photos of boats but no text, kind of tripped him up- meaning he said more than he really needed to. He felt so too. We decided to put in numbers on the progression of the boats so the audience would be able to follow it easily and also so that he could refer to the number of the photo easily without needing to use lots of words. I really noticed that James was

getting the hang of PowerPoint and the slide transitions. At one point he said, you

know I think we need another slide here and I'll say this...then we can show the

pictures I really felt like we were a team today more than ever, but also that he

was ready to share his story.

Restorying. An example of restorying was when Dennis shared a story of an

experience with a clinician who he had worked with in the early stages of his recovery.

He verbalized that he was angry that this prior clinician didn't push him to improve and

had "lost the joy of her job." He wondered aloud if that clinician's lack of care for him

impacted his recovery. He was hesitant to include this in his formal story as he wanted to

be respectful of the clinician as a person and also because he didn't want to share

something he was angry about. I suggested that we could reframe the story to be a

message to clinicians about the importance of being present in their job and the impact

they have on their clients. Dennis was highly receptive to this and together we

constructed a message to add to his story. This allowed him to begin to move forward

from this version of the story to a new one in which he could help others, by telling

clinicians the important role they have in their client's lives.

Providing organization. One of the most important roles I provided was helping

to organize the sequence of events in the story. As the participant-researchers began to

tell their stories, initially I just listened and took notes. Then we transferred that content

to the PowerPoint slides. Often the first draft of the story was out of sequence or needed

more details. During the editing process, which occurred during each session, I was able

to ask questions for clarification of order and sequencing of the story events. This was

helpful not only for the actual story, but also for the participant-researcher to clarify these

events within their internal story. Sometimes they didn't know the answer or detail. In these cases, a note was made for them to clarify with their spouse or other family member after the session and then report back the details at our next session. As stated previously, the stories didn't end up being organized by chapter. Rather they were a chronological representation of their story beginning with life before the stroke and ending with goals for the future. One additional organization support I provided was during the editing process, helping the participant researcher to title their slides and have transitions to help the story flow.

Another organizational role I held was to be a time keeper. As stated previously, session time went by very quickly. Keeping an eye on the clock and sharing statements such as, "Okay, we are really moving along here now, we only have 20 minutes left today and we wanted to finish this part of the story and still need to plan for what we need to do for the next session. What if we took 10 more minutes to finish up what we are working on and then we can use the last 10 minutes to plan for our next session." This strategy allowed for us to keep on a schedule, but also allow control for the participant-researcher to plan how to use the remaining time in the session.

Providing clinical supports during the story presentations. Each of the participant-researchers took a lead in telling their story during the celebration event. However, our collaborative partnership continued during the presentations. During the practice session we discussed and decided upon what supports were needed for the formal presentation. Decisions were made such as: Who would run the computer? Would they use notes, the computer screen, or the projection screen for cues? What types of cueing and how much cueing did the participant-researcher want from me during the

formal presentation? Below is a passage from a journal entry about Dave's practice

session when we discovered a highly successful technique for increasing his

independence and intelligibility for the presentation.

> *Journal entry session 6 (Dave).* We met in the conference room today. From a
>
> logistical point of view, this is good for a few reasons. First and foremost, to
>
> allow each author to know the set-up of the room and what to expect. But also for
>
> the clinician-researcher – maybe coach… to make sure all of the room sets up
>
> well. Where to sit, power cords, etc. Since this was my second session in this
>
> room and doing the practice work, I approached it a little differently than I did
>
> with James. I had figured out some of the logistics a bit more about the
>
> celebration event and also shared with Dave some of the decisions James had
>
> made. Like sitting down. And the order of the presentations. Dave decided he too
>
> wanted to sit down, have me next to him. However, instead of having me run the
>
> computer, he wanted to run it. We went through a short PowerPoint presentation
>
> tutorial and then he was off and running. He also used the mouse to help cue
>
> himself with the words and also for a visual cue for the audience. Dave was off
>
> and running. He used the mouse to move through the slides – learning quickly
>
> how to use a double screen with the presentation, etc. It was then that I saw he
>
> was using the mouse to emphasize words, keep pace, etc. which increased his
>
> intelligibility significantly and provided visual cues for the audience to increase
>
> the success of his communication.

The supports provided to each participant-researcher differed depending on the type of

aphasia, and their communication needs. The continuation of the collaborative

partnership both in preparation for and during the actual presentations.

> ***Clinical tips for implementing the process:***
>
> 1. *Start with listening and taking notes with paper and pencil, bring in the computer and PowerPoint after rapport and process is established.* While the goal was to transfer the story told by the participant-researcher onto a PowerPoint document, this seemed cold and impersonal to do immediately during the first session. I found it beneficial to take notes during the first session while they were telling me their initial thoughts on the story. When it intuitively felt like a good stopping point, we then reviewed the notes I had taken to verify the content. It was at that time, still during the first co-construction session, when I introduced the computer and PowerPoint. This worked well for all participants. In subsequent sessions, this wasn't as necessary and the computer could be used from the start of the session.
>
> 2. *Have a plan but make sure it includes flexibility:* The session should have a general plan of what to accomplish; however, allow flexibility to follow the lead of the client. For example, if they brought in artifacts and want to start talking about them, start there. However, if they want to follow up on a topic from a previous session, or tell you a story that is meaningful to them, start there. Allow the client to have a sense of control over the process.

3. *Always have paper and pencils on hand:* Paper and pencil were used during each session to clarify information and to use as a support in communication for the aphasia. Having these tools available and in the same place during each session allowed participant-researchers to became familiar with the routine and they used this frequently to support their communication.

4. *Use technology but keep it simple:* PowerPoint worked well as a platform for the stories. Originally, I had envisioned slide transitions and flashy backgrounds, but when it boiled down to it, these weren't necessary and the participant-researchers weren't interested in them. We used the default settings for PowerPoint which included a plain white background and Calibri light font. Additionally the following technology was essential for the project.

   a. *Color printer:* Access to a color printer was vital for each session to print out a draft of the slides in full page size for the participant-researcher to take home for preparing for the next session.

   b. *Scanner:* Access to a color scanner was vital to make copies of the artifacts that were brought in. As I didn't have access to a scanner in my office, after each session ended, as part of my homework (see next tip), I scanned each of the photos and added them to the next version before the participant returned. This worked well for us and allowed the focus of the session to be about the story construction and artifacts, not the scanning.

c. *Use of red font for homework tasks:* During the first co-construction session with Dave, we decided he needed to do some follow up for homework before the next session. Instead of writing this down on a separate paper, I embedded the homework tasks for each of us directly into the PowerPoint slides using red font since we both received a print out of this at each session. From there on out, I used this technique with each story draft for all participants. This made it easy to see what needed to be addressed before the next session. Participants remarked on the helpfulness this technique during the post-session interviews.

d. *Number the slides, staple the printouts, and hand write a date or version number on the cover slide:* I learned the hard way that using the numbering feature on the PowerPoint slides during the initial set up and stapling the printouts instead of using a paper clip was a big help in efficiency. Some participant-researchers wrote notes on their slides and brought them back, as we would go through the notes. This helped significantly with organization particularly if they had previous drafts of the story that also were mixed in with the current draft as after a few sessions, the number of slides for each final story was between 25-39. Another simple tip was after printing out the slides, hand write in the session number or date for easy reference of the draft version.

5. *Save the file, and then save it again, and then make a backup:* I learned the hard way with Dave's first session that I hadn't saved the file for his initial PowerPoint. Luckily, I had made paper copies of the PowerPoint, so the file was fairly easy to recreate, but this did take time away from moving forward with the project. From that point on, I made sure not only to save the file as we were working but also to keep a backup. I also recommend creating the template and saving it before the first session begins with the client. And then saving as a new file before each session begins so a progression of the story development is documented. A lesson I learned is to roll with the punches – don't get stressed or show the stress to the clients – because in the end – it didn't matter that I had lost that work. We recreated it and everything was fine. The process is what is important – the product is important too but it's really about the journey.

6. *Homework isn't always tangible (Don't be disappointed if the artifacts don't come in the first session):* I was expecting lots of artifacts to be brought in during Session 2 after the initial instructions. None of three participants who completed the project brought in artifacts to the first co-construction session. At first, I took this to mean that they hadn't competed homework for the project. But in reality they were prepared to talk about the story. The artifacts, came later in sessions beginning in session 3. Some participants, like James, were apprehensive about bringing in photos or other items; however as this process was explained he became more enthusiastic about this aspect. Participants also benefitted

from a demonstration of how photos were inserted into PowerPoint and also how to search for images on line which could be inserted into the presentation. Of interesting note, both female participants, who did not complete the project, brought handwritten notes outlining what they wanted to discuss to the first session.

a. *Another note on artifacts:* The artifacts came in all shapes and sizes. Some participant-researchers had selected photos and brought in only the ones they wanted to use. Others brought in photo albums with an overwhelming amount of options to choose from. In this case, we reviewed the albums together and then, rather than taking time to choose the exact photos, we went back to the PowerPoint slides and decided which slides needed photos, and how many photos were needed. We added this in using the red font technique. Then I gave the participant-researcher a pad of post-it notes and asked him to take the albums home along with the draft of the slides and mark which photos they wanted to use. At the next session we then together reviewed which photos were selected and where they were to be placed once scanned. Others brought in trophies and plaques which we took digital photos of and then embedded into the PowerPoint slides.

7. *Include the Communication Confidence Rating Scale for Aphasia (CCRSA) before and after the process*: The CCRSA (Cherney & Babbit, 2011) is a 10-item self report of confidence in communication which uses

a 100-point rating scale. Babbitt and Cherney (2010) suggested that, by increasing confidence in communication, a speaker with aphasia may be willing to take greater risks to communicate in more complex communication situations, which may in turn increase autonomy, self-determination and support personal identity. The CCRSA was administered pre- and post-participation in the 'My Story' project. For this project, the CCRSA was included for research purposes. However, I found clinical value for the participant-researchers. During final qualitative interviews, we reviewed their CCRSA self-ratings and compared the pre- and post-scores. I asked them why they thought their scores were different. This experience is examined more closely in Chapter 4 of this dissertation, but it is worth noting the surprise and pride that all participant-researchers exhibited in seeing that they had rated themselves more as having improved confidence in communication on many of the items was very empowering. The CCRSA is a simple tool that takes less than 10 minutes to administer and is well worth the time and effort.

8. *Include the 'How much of this story represents my own words?' after each session:* Like the CCRSA, this question was intended for research purposes. However it served as a good check for me as a clinician to ensure that I was not too overpowering in the co-construction process. I also believe it had value in emphasizing the client's ownership of the story as their own which supports Guiding Principle 2.

Audience members. Data from the focus group were reviewed. Overall audience members enjoyed the 'My Story' presentations. During the actual presentations, the audience reacted by laughing at funny parts of stories and some even cried during emotional parts. Audience members also commented that it was helpful to hear the experiences of other people who had stroke and aphasia and also what the other caregivers did to support recovery in their family member. Highlighted excerpts were selected to provide some reactions and suggestions for improving the process shared by the audience members.

Dave's spouse, Gwen, admitted the difficulty she had in allowing Dave to construct and tell his own story. She explains below.

> Gwen: I think one of the hardest parts was not to interject. You know? To leave it totally his story, not to bring up things for him to mention. I just I I stayed you know stayed away from that for that you know because this was this was his story and that that was kinda hard at times. Because I was thinking why don't you mention this? But I I then in a way it's been nice to have it stretched out a little more [meaning longer than the 4 weeks of the 'My Story' Project], but then I think no because then you probably wouldn't have done it, you couldn't have kept your mouth shut.

She later stated that she would be interested in co-constructing her own story as a caregiver.

> Gwen: Katie this is just a suggestion. But maybe part of it could be the caretakers and what we've had to go through and what has worked

for us. Um it I think that would be helpful for people who are in speech. You know? To know what it's like for us too.

Jill, James's spouse, stated that she was surprised at some of the content of the story that James chose to focus on and what he had left out. In the excerpt below, she explained this further.

Jill: I'm surprised with what James left out. He does and he did before the stroke, all the cooking. And further he likes to go to Meijer and do the food shopping. And he's lucky that he's able to do those things. After he came home from the hospital I did the cooking for a couple of weeks and I think that really inspired him to really, no truly it did, to get back in the kitchen. And he does…But I'm surprised that he didn't mention the fact that he still he does all the cooking and I think it's wonderful.

Later in the focus group when it was brought up again that James didn't talk about his role in cooking, she stated, "I thought it was a big part of his life."

Kathy, Dennis' spouse stated, "Dennis would come home and he would be so excited. I mean he just really, really was excited about it. And that made me so happy to see him like that."

Participant Attrition

Both female participants, Diane and Nancy, did not complete the project. The circumstances behind each is worth exploring. Excerpts from the clinician-researcher journal are provided below.

Diane. Diane was the first individual to respond to the recruitment efforts. During our initial phone conversation she stated, "I hope you pick me." I asked her why and she told me she really wanted to write her story for the *Stroke Connection* magazine and she thought that this would help her do so. Diane called me on the day of our first co-construction session and said she needed to talk. Below is an excerpt from my reflective journal outlining that session.

> *Diane (entry 1).* When we got into my office, I could tell something was upsetting her. She told me that something had come up, a family emergency, and that she needed to go and be with her son who was in college. It was apparent that she wanted to continue with the project but knew that she couldn't. Her son had called this morning, with a situation that she felt she needed to go and 'be a mom.' I was disappointed but also felt honored that she would drive to campus to tell me this in person. She went on to say that she was so disappointed that she couldn't participate as she had already written four pages of her story, she had them in her hand, and was really excited to share them with me. She told me she had a conversation with her husband about some of the aspects of her story that she couldn't remember and that during this conversation, he told her that she had changed since the stroke. He told her that she was more assertive and really voiced her opinion more now than before her stroke. Also that she was more outgoing and talkative than before. Diane didn't know this and really appreciated learning this from her husband. I was really amazed by this --- I hadn't thought about the conversations with family members as we were preparing these stories and how those might in and of themselves be very powerful and moving – but

instead had thought primarily about the author's views during the construction and that family would not be impacted greatly until perhaps the celebration/story telling event…When we ended the session, we decided she would follow up when ready and that perhaps we could still work on her goal for the article.

Nancy. Nancy was the participant I knew best before beginning the project. She has been a member of the aphasia support group for over 10 years and she was highly interested in participating in the 'My Story' Project and working with me.

Nancy (entry 1). After finishing Nancy's first session, I was concerned…Hazel, Nancy's mom drove her to the session and waited for us until we were finished with our work today. Nancy was engaged, wanting to learn about the project. But also I am a bit concerned that because we know each other so well, she may try to please me. However I do know Nancy well enough that she will hold her own and decide what she wants to put into her story. But my concern came most after Hazel came back into the room to schedule the next five sessions. They live out of town and Nancy has some other home based therapies which don't always schedule appointments until the day they are coming. I did re-explain that if this was too much time to commit that now would be a better time to say this project isn't for them at the moment. But they agreed to participate and we scheduled five visits with the caveat that they could call to change them if necessary. Also concerning to me is that Nancy has been having heart issue. Significant heart issues. And she is scheduled with a surgeon next Tuesday. I am not so worried about this from the aspect of the project, although this is certain a small worry. I'm more worried about Nancy's health and well-being.

Nancy (entry 2). Hazel called last night to tell me that they had seen the heart surgeon today and that Nancy was scheduled for a pacemaker/defibrillator procedure two days after the group celebration event. She told me that Nancy really wanted to be in the My Story project and asked would this still work… I am overwhelmed and amazed with how devoted and genuinely interested everyone is in this project…During our session today, as we were wrapping up the session – I had turned off the camera. Nancy grabbed her 'My Story' workbook and said (these are my own words) that sharing about her life before the stroke and aphasia was a lot easier than what we were going to talk about next time, meaning the stroke and aphasia. That she didn't remember who her family was right after the stroke. She had more to say but it was difficult for her to say between the emotion and aphasia. We left it as this, for her to think about what she knows, what she wants to say and we can always change and edit in future sessions.

Nancy (entry 3 – phone call). I got a voicemail from Nancy today. She told me it was important to call her back. I wondered if she was going to drop out of the project. Her health concerns me so much…So I just got off the phone with her. Indeed that was the issue. She was crying and really upset. She fell yesterday. Her sugars were low. She is still scheduled for the pace maker/ defibrillator. She and her mom decided that it was too much for her to do the project during this time. I told her I agreed. She told me, "I'm not strong enough to do that work right now." We talked for about 10 minutes and although both sad, knew it was the right decision for her.

Both Diane and Nancy's experiences for entering and leaving the project point to the high level of emotional energy and investment the process of co-constructing a story of this type requires. And that each recognized that the timing of their participation was such that the life events that were currently happening in their life didn't allow them to fully participate so they opted to stop participating. This was a difficult and emotional decision for both of them.

Reviewing these scenarios further, despite not being able to continue with the project, Diane's one session opened an opportunity for her to have a conversation with her husband and learn important information about how she has changed since the stroke that she hadn't known in the two years since having her stroke. Diane still held her goal of authoring her story for publication, but decided this needed to take a second place to her role as a mother. Nancy verbalized that she wasn't strong enough to do this work now. While it was apparent her physical strength was of concern, she also alluded that this work was emotionally powerful and that despite her desires to participate in the project, she was not strong enough to participate, both physically and emotionally. These issues will be further explored in the discussion.

<div align="center">**Discussion**</div>

This study provided a platform to explore topics related to identity, personal narratives, and aphasia by offering a framework for clinicians working with adults who have aphasia by developing and piloting a protocol, 'My Story,' to co-construct personal narratives. It was based on the premise that targeting communication and language through personal narratives about the stroke and living with aphasia may influence

identity in persons with aphasia. This in turn may contribute positively to adjustment to living with aphasia.

Dollaghan (2007) stated that evidence-based practice has three types of evidence, "1) best available external evidence from systematic reviews, 2) best available evidence internal to clinical practice, and 3) best available evidence concerning the preferences of a fully informed client." (p. 2). Despite the rising area of interest in the personal narratives for persons with aphasia, substantial evidence in the literature necessary to generate a systematic review is not yet available. However, this study provides exploratory evidence that co-construction of personal narratives is a meaningful activity to persons with aphasia. The project used evidence-based approach by implementing a consumer participation approach to research (Hinckley et al., 2014) by engaging participants with aphasia as participant-researchers who provided input in affirming and providing feedback to improve the process. It also provided the viewpoint from the clinician-researcher to contribute to evidence internal to clinical practice. The project also follows the LPAA philosophy as this is a highly client-centered activity in both the process of co-construction and the content of the story.

Story construction can be an opportunity for making meaning of loss and reconstruction of identity (Neimeyer, 2001). The 'My Story' Project provided an opportunity for participant-researches to reflect on their lives and to think about the future. The story co-construction process also allowed for participant-researchers to organize the events of their lives, including the events surrounding the stroke, and to make meaning of these events. Participants reported the experience to be highly positive. The project supported the concept of *living successfully* with aphasia (Chapey et al.,

2008; Holland, 2006) in that it provided participants an opportunity to examine their lives and share them with persons that were important to them. An intentional aspect of the project was to focus on their lives, not on the stroke or aphasia. While stroke and aphasia were a component of the story, this was not the defining point of their story identity, but rather one part of their story.

The 'My Story' Project had deliberate components. First, the collaborative nature of the relationship between the participant-researcher and the clinician-researcher was purposeful. It was established from the start of the project that this was a partnership and that we would learn together from one another about this project. This also allowed for a reliance on one another to contribute to the co-constructed story. Next, the individual co-construction sessions were intentional in order to provide a practical tool for clinicians working with persons who have aphasia in typical outpatient clients to easily implement into sessions. Although group therapy for persons with aphasia has substantial evidence for support, it is not currently typically reimbursed by insurance providers. The individual sessions also allowed for the clinician-researcher to serve as an authentic audience as the story was initially told. I was genuinely interested in what each participant had to say, which led to a legitimacy which was well received by the participant-researchers. Additionally intentional was the planned practice session where the participant-researcher could prepare for the formal sharing of the story. Finally, the project ended with a celebratory event where the stories were shared with those who were important to the participant-researchers. Having a second authentic audience, that of those who were invited to the formal sharing, was validating to the participant-researchers. Receiving feedback from the audience members was affirming for participants. Also included was

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an opportunity for each participant-researcher to hear others' stories from people who have aphasia. The formal sharing of the story and that the process had a clear beginning and end allowed for participant-researchers to know what was expected of them and also to gain a sense of accomplish at the conclusion of the project.

Questions arose during the process that should be explored more fully. One such question was "Do participants think about coming to a session where they will be asked about their life and themselves in a completely different way than they think about coming to a speech-language pathology therapy session?" Preliminary evidence for this suggests that this experience was highly different from previous therapy experiences from the perspectives of the participant-researchers, the spouses of the participant-researchers, and the clinician-researcher. "The best moments in our lives are not the passive, receptive, relaxing times…The best moments usually occur if a person's body or mind is stretched to its limits in a voluntary effort to accomplish something difficult and worthwhile." (Csikszentmihalyi, 1990, p. 3).

Csikszentmihalyi's (1990) concept of flow is one of finding genuine satisfaction during a state of consciousness. In other words, flow occurs when people are completely absorbed in an activity which involves their creative abilities. Csikszentmihalyi stated that during this optimal experience people feel strong, alert, in effortless control, unselfconscious, and at the peak of their abilities. This occurred during the 'My Story' Project; 90-minute sessions flew by, emotional stories were shared; perspectives were reshaped into a more positive experience. This all may contribute to a more positive identity. The project was a planned conduit to this flow experience. Csikszentmihalyi maintained that this state does not simply happen. It must be prepared for and cultivated

by each person, by setting challenges that are neither too demanding nor too simple for one's abilities. The 'My Story' Project provided such an opportunity for preparation. The supports provided by the clinician-researcher allowed for activities which facilitated this state of flow, which resulted in a highly positive experience for all participants. While this was not an intended outcome of the project, it was a significant one.

Other questions which warrant further exploration are; What is the impact or consequence to the individuals who started the process but didn't complete? What happens to stories that are started but not finished? Are there risks to starting the process without completing it? Can time lapse between start to finish? Can persons with aphasia continue their story once it is started with co-constructor? Can the story be told in a different format? Can the story process be started, then stopped? And then picked up again? While these can't be answered with the current study, they are important question which should be further explored.

One aspect of the process was that of restorying (Kendall & Randall, 1997). An example of how Dennis was able to restory his negative experience with a former clinician into a positive message for therapists provided him with an opportunity for post-traumatic growth. Kenyon and Randall (1997) also cautioned that through the generation of co-construction of stories, clinicians will likely be restorying their own lives through themselves through this act of support. This experience was life changing for the participant-researchers but also impacted mine. Through this work, I was moved by the content that each person entrusted me with. It is important to reiterate that the narrative co-construction process was not intended as psychotherapy or other types of psychosocial counseling methods nor as a replacement of such services but it is intended to have a

therapeutic effect on a person's communication confidence and identity as a competent communicator.

The 'My Story' protocol was intended to support a person with aphasia to co-construct a personal narrative that can be shared with others. Interest in sharing a personal narrative by the person with aphasia was determined before proceeding with the 'My Story' Project, was part of the informed consent process. When discussing guided autobiography techniques, Ruth and Kenyon (1996) cautioned that guided narrative approaches are not necessarily for everyone, nor should storytelling be viewed as the sole technique for processing a life event. Likewise this advice should be heeded when determining who with aphasia might be a candidate for co-constructing a personal skills and training in communicating with people who have aphasia.

Additionally, some narrative approaches are intended as forms of psychological therapy and require additional training, whereas others are educationally based and do not constitute therapy (Ruth & Kenyon, 1996). Alheit (1992) stated that it is important to maintain a distinction between learning and therapy when designing a program that involves constructing life story narratives. The 'My Story' protocol was designed for any care provider to use in supporting language in an effort for a person with aphasia to construct and tell a personal narrative. It was not intended as a replacement for psychotherapy or other types of psychosocial counseling methods, but it was intended to have a therapeutic effect on a person's communication confidence and identity as a competent communicator.

Limitations

The 'My Story' Project was a qualitative collective case study with a limited number of participants. Therefore, cautions must be taken when applying the outcomes here to other persons with aphasia and to clinicians who attempt to implement this process. Furthermore the participants who constructed stories were all male. Also, while the severity and type of aphasia they exhibited was varied, they had similarities in age, marital status, and time of onset post-stroke. Additionally, the co-construction process is a labor and time as well as emotionally intensive process. Both the participant-researchers and the participant-clinician devoted a significant amount of time to the process. Some people with aphasia or clinicians may not be willing or able to provide this amount of time or emotional space to construct a personal narrative. Two of the participants were receiving additional speech therapy during the time of the project. More information is warranted to determine whether this had an impact on the outcome of the story co-construction process or the speech therapy.

Because the same clinician-researcher designed and implemented the co-construction process for the 'My Story' Project, this is a potential source of bias. Participant-researchers or audience members in the focus group, may not have been able to express in a way they wanted to since they knew that the clinician-researcher who designed and implemented the project was the same person who was collecting feedback on the process.

Future Research and Recommendations

The 'My Story' Project provided groundwork to examine one method of co-constructing personal narratives for persons with aphasia. As stated previously, while the

interest is high in personal narratives, actual methodology available for how clinicians on how to implement a co-construction process is limited in published literature. This study provided early evidence for this type of intervention. Future research should involve expanding the current study to a larger number of participants, including; females, those with severe aphasia, and a wider range of onset time from stroke. Additionally, the training of clinicians to implement the 'My Story' process should be investigated. Also of interest would be to determine the impact of the co-construction process and subsequent story telling longitudinally on identity and communication confidence. Is there a difference in a one-time sharing versus retelling the story repeatedly? How does the content of the story, and perhaps then the identity of the person with aphasia change with retelling? What if any, is the impact on language skills from this experience? What impact does sharing the personal narrative have on others who have aphasia? Further exploration should also include a process for caregivers to construct their own stories.

Additionally, what was not a part of this study, but was equally important is the content of the stories. Future research should examine the story content to identify themes related to identity and also to determine what changes have been made from the early drafts to the final product. Such an analysis would be deepened through an interdisciplinary lens, such as collaboration with neuropsychology, psychology, or social work to determine additional themes that might not be apparent to someone with training in speech-language pathology. This may also result in interdisciplinary intervention. Finally, this project provided one method for co-construction of personal narratives in persons with aphasia. It is the hope that this project will spark further research for others to investigate and expand other methods for narrative construction.

Conclusions

Co-constructing personal narratives provides a promising way to support identity in persons with aphasia using a client-centered approach. The participants in this study who co-constructed personal narratives in the 'My Story' Project using the framework of 1) Who I was before my stroke and aphasia, 2) My stroke and aphasia, 3) Who I am today, and 4) My future/goals, reported having a positive experience, which provided an opportunity for making meaning out of the traumatic experience of stroke and aphasia. This may in turn contribute positively to their adjustment to living with aphasia through an improved identity and confidence as a competent communicator.

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CHAPTER IV

SELF-REPORTED CHANGES IN IDENTITY AND COMMUNICATION
CONFIDENCE IN PERSONS WITH APHASIA WHO CO-CONSTRUCT PERSONAL
NARRATIVES

Language and communication play an important role in a person's ability to

create and tell a narrative or story about themselves (Shadden & Koski, 2007). Such

stories contribute to a person's identity (McAdams, 2008), which can be jeopardized by

illness and/or traumatic loss. Having a stroke and losing language capacity due to aphasia

is an example of such traumatic loss that can impact identity. An important component of

the experience of living with stroke is this initial loss of identity and subsequent struggle

to reconcile post-stroke identity with that experienced pre-stroke (Salter, Hellings, Foley,

& Teasell, 2008).

Romanoff (2001) referred to narrative as a vehicle for change in individuals who

experience traumatic losses. Many others have written of the importance of the illness

narrative to the individual's process of coping with illness, trauma, or loss. Questions

arise about what happens to a person's identity when that person's ability to form and tell

stories is impaired due to aphasia, which is a loss of language ability following stroke.

Shadden and Koski (2007) posed the question, "If language is essential to the

construction of the self [identity], how does one participate in self-construction in the

face of its impairment?" (p. 101). The current study examined the views of persons with

aphasia through qualitative interviews using interpretative phenomenological analysis

(IPA; Larkin & Thomspon, 2012; Smith, Flowers, & Larkin, 2009; Smith & Osborn) to

explore whether having co-constructed a personal narrative in the 'My Story' Project

impacts their perception of their own identity and confidence in communicating.

The 'My Story' Project was a pilot project designed to provide a clinical tool for co-constructing a personal narrative with persons with aphasia. The term 'co-construction' indicates a collaborative act of assembling a story together. Specifically, due to impairments in language, person with aphasias may benefit from a partner to support the development and sharing a story about their life. The objective of the 'My Story' Project was to develop a story about the story teller's life that can be actively shared by the person with aphasia with more than one audience. The 'My Story' protocol for co-constructing a personal narrative was based on a review of the literature in aphasia, psychology and narrative gerontology. This chapter will begin by providing groundwork for supporting identity in persons with aphasia through a review of the literature on identity and aphasia; identity and narratives; supporting identity in persons with aphasia.

Identity and Aphasia

Asking the question, "Who am I?" is part of the human condition. "Identities are the traits and characteristics, social relations, roles and social group memberships that define who one is" (Oyserman, Elmore, & Smith, 2011, p. 69). Oyserman and colleagues further remarked that

> Identities can be focused on the past – what used to be true of one, the present – what is true of one now, or the future – the person one expects or wishes to become, the person one feel obligated to try to become, or the person one fears one may be come. (p. 69)

The term *identity* refers to perceptions of unique and persisting qualities that distinguish the self from others (Dumont, 2013). Shadden and Agan (2004) defined identity as "a

composite of roles, values, and beliefs that are acquired and maintained through social interaction" (p. 175).

Identity also can be viewed as a way of making meaning. Oyserman, and colleagues (2011) described different types of identities, including social identities involving the knowledge that one is a member of a group; role identities signifying membership in particular roles such as a spouse or professional; and personal identities reflecting traits or characteristics that may feel separate from one's social and role identities. Ownsworth (2014) remarked that collectively these identities and their personal significance contribute to a coherent life story or self-narrative, which is influenced by the past, present, and future. For purposes of this study, Taylor's (1994) definition of identity "who we are, where we are coming from, and where we are going" will be used (p. 33).

These different identities make up one's self-concept. Shavelson and Bolus (1982) broadly define self-concept as a person's perceptions of him- or herself. Self-concept has been defined more explicitly by Baumeister (1999) as "the individual's belief about himself or herself, including the person's attributes and who and what the self is" (p. 13). In other words, self-concept can be thought of as what comes to mind when one thinks of oneself (Oyserman et. al., 2011).

Having a stroke can impact a person's life in serious and chronic ways. Self-reported changes in identity following stroke were supported by a meta-ethnography review of 13 qualitative articles focusing on the patient's experience with stroke published since 2000 (Hole, Stubbs, Roskell, & Soundy, 2014). The evolution of identity, through rehabilitation and over time, was identified as a recurrent theme post stroke.

These findings are consistent with Salter and colleagues' (2008) meta-synthesis of 9 qualitative articles that found evidence of change in identity following stroke. These articles were different than those reviewed in Hole et al. (2014). Physical, cognitive, and psychosocial changes post stroke can lead to a negative self-concept due to reduced independence (Ellis-Hill, Payne, & Ward, 2000).

Identity changes post-stroke may be exacerbated when the person experiences concurrent aphasia. Having aphasia impedes communication and places an individual at higher risk for poorer quality of life than for individuals who have a stroke but do not have aphasia (Hilari, 2011). In a study of nursing home residents by Lam and Wodchis (2010) aphasia was found to have a greater negative relationship to health-status index scores than cancer or Alzheimer's disease. Physicians also have recognized that aphasia impacts identity and that the task of reconstructing identity may be an important component to post-stroke recovery (Musser, Wilkinson, Gilbert, & Bokhour, 2015). Additionally, Musser et al. identified the importance of long-term health care provider relationships, such as relationships with primary care physicians, in supporting positive psychosocial adjustment to life with aphasia.

Identity and Narratives

Personal narratives may have an important role in identity formation. Bruner (1987) and Ricouer (1990) discussed the concept of narrative identity. McAdams (2008) described personal narratives or life stories as a way for "people …[to begin] to put their lives together…by reconstructing the past and imagining the future as an ongoing narrative that depicts who they were, are, and will be" (p. 21). This concept of life stories has similarities to Oyserman, Elmore, and Smith's (2011) definition of identity.

McAdams (2008) viewed one's personal life-story as an internal and evolving narrative of the self that provides people with some degree of coherence and purpose. In other words, as people, we make sense of who we are through the stories we tell ourselves and others about our lives.

The terms *narrative* and *story* have been distinguished as separate by some researchers, but also have been used interchangeably in psychology and narrative gerontology literature. It is beyond the scope of this study to deliberate the philosophical differences of narrative and story. Rather the intent is to provide a framework for developing a therapy tool to support persons in adjusting to life with aphasia. Shadden, Hagstrom, and Koski (2008) referred to a narrative self as "the story-framing processes we use to support our sense of self and which allow us to adapt to change" (p. 7). It is this spirit of supporting who we are and allowing for adaptation to change that is the essential element of this study. Therefore, for purposes of this study the terms *narrative*, *personal narrative*, and *story* are used interchangeably.

Personal narratives have been recognized as an important mechanism for healing from loss (Romanoff, 2001). Meaning reconstruction in response to loss is central to the process of grieving (Neimeyer, 2001). Ellis-Hill, Payne and Ward (2008) have applied the concept of narratives to reformulating identity in persons with disability through the *Life Thread Model*. In this approach, through narratives individuals, connecting the past, which is known, and the future, which is unknown. The authors indicated that clinicians using the Life Thread Model should focus on supporting a positive sense of self through the co-construction and sharing of narratives between people.

A person may use language to construct stories in order to make sense of the chaos and resulting life changes associated with a stroke and aphasia. Shadden and colleagues (2008) identified language as a necessary tool for defining one's identity. However persons with aphasia often have significant challenges in accessing their language, thus the tool is damaged. Shadden went so far as to describe aphasia as identity theft (Shadden, 2005).

Supporting Identity in Persons with Aphasia

Social models of aphasia rehabilitation, such as the Life Participation Approach to Aphasia (LPAA), depict disability as a socially created problem generated by the attitudes and features in an environment rather than an attribute of the individual (Chapey et al., 2008). Within the LPAA movement, the recognition of the importance of supporting identity has become more prevalent (Simmons-Mackie, 2008; Shadden, 2005; Shadden, Hagstrom, & Koski, 2008; Simmons-Mackie & Elman, 2011). Methods for supporting identity in persons with aphasia include group therapy (Shadden & Agan, 2004; Shadden & Hagstrom, 2007; Shadden & Koski, 2007; Simmons-Mackie & Elman, 2011); guided self-determination (Bronken, Kirkevold, Martinson, Wyller, & Kvinge, 2012a); biographic-narrative intervention (Corsten, Konradi, Schimpt, Hardering, & Keilmann, 2014); and life-story narrative approaches (Sinden, 2015).

Missing from the existing literature is the viewpoint of persons with aphasia as to whether specific methods, such for the co-construction of personal narratives, have a positive impact on their identity, or how they view themselves as a person. One exception was Corsten et al.'s (2014) use of semi-structured interviews of participants from their biographic-narrative intervention study (Konradi, Schimpf, Hardering, Keilmann, &

Corsten, 2014). These interviews revealed that participants reported a changed sense of self, specifically including increased coping regarding chronic illness, improved self-efficacy and control, and a more differentiated picture of self.

Communication Confidence as a Measure of Identity in Persons with Aphasia

Measuring change in identity is difficult. Babbitt and Cherney (2010) hypothesized that there is an interaction between communication confidence, autonomy and self-determination, and participation in life activities. Communication confidence is referred to as a potential barometer for measuring the 'health' of identity because, when confidence in communication skills increases, a person may be more open to participating in activities that require communicating (Babbitt & Cherney, 2010). Communication confidence is one aspect of identity that can be measured in persons with aphasia. Babbitt and Cherney defined confidence as "a feeling or consciousness of one's powers" (p. 215). They developed the Communication Confidence Rating Scale for Aphasia (CCRSA; Babbitt, Heinemann, Semik, & Cherney, 2011) as a self-assessment outcome tool to target the domains of personal identity, attitudes and feelings. What has not yet been explored is the degree to which communication confidence, identity, and personal narratives might be related. To fill this gap, the CCRSA was used in the current research project as a pre and post measure of communication confidence.

Summary and Research Aim

Traumatic loss, such as in the case of stroke and aphasia, can negatively impact identity. Social models of rehabilitation have emphasized the importance of supporting identity renegotiation. Personal narratives are one way to bring meaning to such traumatic events. People with aphasia are disadvantaged in creating and sharing their

stories due to the impairment of language that constitutes aphasia. The language barrier also may create a barrier to providing meaning to the traumatic event of stroke and aphasia, but not necessarily.

Linguistic meaning does not necessarily equate to emotional meaning. Despite linguistic barriers, or perhaps because of them, methods for supporting identity to increase psychosocial adjustment have emerged in the literature on aphasia. The hypothesis is that the process of co-constructing a personal narrative with persons who have had stroke and aphasia may positively impact identity. One of the few ways to know about a person's inner experiences is to ask them. Yet, feedback from people with aphasia based on actual experience with narrative co-construction is limited in the literature. Because the possible connection between communication confidence, identity, and personal narratives has not yet been fully explored in the literature, the research aim of this study was to examine the self-reported changes in identity and communication confidence as a result of participating in the co-construction of a personal narrative through the 'My Story' Project.

Methods

Design

This study served as a follow-up to a prior intervention study in which participants engaged over 7 sessions in the 'My Story' Project, which involved one introductory session that included testing, four 90-minute co-construction sessions, one 90-minute practice session, and a final session which was a formal presentation of stories by the three participants to a small invited audience. An interpretative phenomenological analysis (IPA) approach (Smith, Flowers, & Larkin, 2009; Smith & Osborn, 2007) of the

data gathered using semi-structured qualitative interviews was used to explore the personal experience of persons with aphasia in co-constructing a personal narrative about their life with stroke and aphasia in the 'My Story' Project.

IPA requires "open research questions, focused experiences, and/or understandings, of particular people in a particular context" (Larkin & Smith, 2012, p. 103) which fit well with the 'My Story' Project experience. The intent of IPA is exploratory, not explanatory (Larkin & Smith, 2010). The method of interpretation within IPA is two-fold. First, participants are trying to make sense of their world. Second, the researcher attempts to interpret the participants' accounts while trying to make sense of their world (Smith & Osborn, 2007).

This approach was well suited the current project as it allows for an in-depth qualitative analysis of complex issues or processes such as concepts of identity and communication confidence related to the experience of co-constructing a personal narrative. IPA also uses a small number of participants who are purposefully sampled and to whom the research question may be meaningful (Smith & Osborn, 2007).

Participants and Sampling

The participants had recently completed participation in the 'My Story' Project in which they co-constructed and shared personal narratives about their lives with aphasia following stroke. Participants were recruited using purposeful sampling, which started with a modified maximum variation sampling approach (Creswell, 2007). This strategy was selected to include a range of aphasia types and severity, gender, age, and life experiences in order to represent a collection of experiences related to living with aphasia. The modification on the maximum variation sampling was that persons with

severe expressive aphasia and global aphasia were excluded in order to collect qualitative interview data with verbal responses.

However, due to attrition in the 'My Story' Project, the actual sample was relatively homogeneous. Although the type and severity of aphasia did show a range, other demographic variables, such as age, sex, and marital status, were more homogenous with the three participants who completed the 'My Story' Project.

Table 4.1 provides an overview of each participant. Names have been changed to protect confidentiality.

Table 4.1

Participant-Researcher Demographics (n = 3)

Name	Age (years)	Marital Status	Sex	Time since stroke (years)	WAB AQ	Aphasia Type
Dave	63	Married	Male	4	44.4	Broca's
James	66	Married	Male	5	93.1	Anomic
Dennis	55	Married	Male	4	66.3	Broca's

Note. Names were anonymized to protect identity.

Dave had the most severe aphasia of the five participants. He also had a concomitant apraxia. He communicated with primarily at the word level with occasional two word phrases, and used gestures and writing to augment his verbal productions. Dave's comprehension, both auditory and written, was a strength.

James had mild anomic aphasia. He exhibited semantic and phonemic paraphasias during his conversational speech. Despite this, James was able to communicate at the conversational level verbally without many supports

Dennis exhibited a moderate aphasia. His auditory comprehension was more compromised than his reading comprehension. He communicated verbally despite his non-fluent speech which had many paraphasias.

Data Sources

Semi-structured qualitative interviews. Semi-structured qualitative interviews were conducted with each participant on the day following completion the 'My Story' Project. The primary purpose of the interview was to explore the participants' perceptions of taking part in the 'My Story' Project, with implications for understanding the impact on their identity and communication confidence. The interview was divided into five sections (see Appendix J). Section 1 targeted the process of developing the story (e.g., *What was it like to participate in constructing a story about your life?*). Section 2 addressed the process of sharing the story (e.g., *What was it like to share your story*?). Section 3 addressed changes in identity (e.g., *Did participating in the 'My Story' Project change how you think about yourself*?). Section 4 investigated the participants' thoughts on co-constructing personal narratives with other persons with aphasia (e.g., *What would you tell other people with aphasia about the 'My Story' process?*). Finally, Section 5 targeted questions on differences in pre and post-scores on the CCRSA. In this section, participants were asked to speculate why their answers might have been different before and after participating in the 'My Story' Project. The goal was to examine their thoughts about whether communication confidence might have been impacted through participation. Interviews were videotaped, which has been determined fundamental in the transcription and interpretation of non-verbal communications [1,2]. Interviews were transcribed for purpose of analysis. Initial transcription was completed by two second

year master's students trained in phonetics and who had recently completed a graduate course in aphasia. I then edited the transcript while reviewing the videotape to ensure accuracy of transcription.

Post-session interviews following each co-construction session of the 'My Story' project. To increase the rigor of this study through triangulation of sources, data from post-session interviews held during the 'My Story' Project (5 interviews with each of the 3 participants) were included in this analysis. The post-session interviews were structured and followed the same aphasia friendly guidelines as the qualitative semi-structured interviews held one day after the formal presentations, which are described below. Each interview was videotaped and transcribed with the same methods as the qualitative post-session semi-structured interviews that were conducted at the end of each intervention session.

Considerations for interviewing individuals with aphasia. Due to the inherent disruption in language caused by aphasia, qualitative semi-structured interviews with individuals with aphasia can pose challenges. The interaction between the researcher and the participant is important in order to create a safe environment which fosters confidence in the participant in order to increase mutual understanding (Bronken & Kirkevold, 2013). In this study, the clinician-researcher and participant-researchers were familiar with one another, having worked together over seven sessions during the 'My Story' Project (the four co-construction sessions, plus two sessions for one for pre-testing and another for practicing the story presentation). This pre-existing relationship was thought to allow for enhanced trust and rapport due to the clinician-researcher having been a

conversational partner previously with the participants, thus providing an increased opportunity for improved mutual understanding.

Luck and Rose (2007) suggested that, in order to reveal the competence of people with aphasia during qualitative research, it is necessary to adapt traditional conventions of the interviewing process and allow the researcher to step in and support the conversation. This can be done though acknowledgement of communication challenges, narrowing of questions, requests for clarification of words, meanings and gestures, the use of encouragers, and active extrapolation of ideas from participant responses. More specifically Luck and Rose provided strategies to support conversation by offering words (as appropriate), probing with yes/no questions, providing extended time to respond, using repetition to enhance comprehension, and paraphrasing participant responses. In this project, interviews were conducted primarily in a verbal format; however, communication supports were provided during the interviews. Specifically, supplemental visual materials of the interview questions were designed using the Stroke Association (2012) guidelines for aphasia friendly materials to promote understanding of the question content (Appendix K). Additionally, yes/no question probes, repetition or rephrasing of questions, paraphrasing techniques, and extended time to respond were provided.

Working with people with aphasia requires careful ethical sensitivity (Lloyd, Gatherer, & Kalsy, 2006; Morse, 2007; Sundin, Nordberg, & Jansson, 2001). People with aphasia are at risk for emotional harm, disempowerment, and lack of acknowledgement because of their communication disability (Bronken, Kirkevold, Martinsen, & Kvinge, 2012b). Additionally, participants may have strong or intense emotional reactions to talking about their experiences about having a stroke and aphasia.

Measures of communication confidence. The CCRSA (Cherney & Babbitt, 2011) was used as a self-reported measure of communication confidence, which might be affected by the 'My Story' construction process. The CCRSA is a 10-item self report of communication confidence which uses a 100-point visual analog rating scale. The CCRSA is reported to be psychometrically sound for assessing self-report of communication confidence as determined by reliability of .81 (Babbitt, Heinemann, Semik, & Cherney, 2011). This assessment was administered pre- and post-participation in the 'My Story' Project. The CCRSA was not intended to serve as a quantitative measure, but rather as an enhancement to the qualitative interviews, which could be discussed with the participants.

Analysis

After initial transcription of qualitative interviews was completed, data were analyzed using a six-step IPA approach (Smith, Flowers & Larkin, 2009). These steps are outlined in Figure 4.1. Additional methodology techniques from IPA were used from Larkin and Thompson (2012) and Smith and Osborn (2007) to deepen the interpretative aspect of the analysis.

Step 1: Reading and re-reading. This first step, involved immersing myself into the original data. Following a combination of recommendations of this step from both Smith, Flowers, and Larkin (2009) and Smith and Osborn (2007), I first reviewed the first transcript while viewing the video tape of the interview for the first participant, Dave. During this time, I made edits on the transcript which differed from the original transcription. Once that was completed, I then printed out the transcript and read through the entire document.

Step 1	• Reading and re-reading
Step 2	• Initial noting
Step 3	• Developing emergent themes
Step 4	• Searching for connections across emergent themes
Step 5	• Moving to the next case
Step 6	• Looking for patterns across cases

Figure 4.1. Six-step interpretative phenomenological analysis process (Smith, Flowers, & Larkin, 2009).

Step 2: Initial noting. Continuing with Dave's transcript, I wrote comments on the left side margin noting interesting and significant remarks as well as my own interpretation of the remarks. The intent of this step is to determine the meaning of the experience to the participant (Smith, Flowers, & Larkin, 2009). I also used a highlighter to identify significant text which was worth closer investigation. Dave's wife attended the interview so some of her comments were included in the initial analysis as well. This process is completed for the entire transcript.

Step 3: Developing emergent themes. Once I completed the initial noting, I began again at the start of the transcript and using the right margin identified emergent themes. This process was continued for the entire transcript. Next, the identified emergent themes were transferred in chronological order as they appeared in the transcript to a table format. This table had three columns: emergent theme, utterance

number, and wording. Wording represented a few key words which supported the emergent theme. These were not direct quotes from the transcript. Smith and Osborn (2007) suggested this format as the researcher will have an initial listing of the emergent themes and concise phrases to capture the essence of what was found in the transcript text to support the emergent theme.

Step 4: Searching for connecting themes across emergent themes. Using Smith and Osborn's (2007) approach, a second table was created to begin looking for connections between emergent themes. Data from the previous table were reviewed and column titles were revised to include themes, utterance number and wording. I reviewed the table and cut and pasted similar emergent themes into the same area or 'cluster.' Next, each theme was cross checked with the original transcript to ensure the intended meaning of the theme was still in place. During this step, the data under the wording column which originally had key words to support the emergent theme, was replaced with exact wording from the original transcript as an effort to ensure the primary source material. This provided me with another exposure to the original transcript. Following Smith and Osborn's (2007) approach, a third table, was constructed in which a *summary table of themes* was constructed to organize the themes with a coherent order. Headings for columns in this table included themes, utterance number, and key words. I reduced the actual transcript text to key words which were used to support the theme.

Step 5: Moving to the next case. Steps 1 through 4 were repeated for each transcript. Once this was completed, committee member, BS, reviewed my process and original transcripts and tables for each participant as a credibility-checking of my process. Larkin and Thompson suggest credibility checking as a means of achieving

trustworthiness in the process. BS made notations on the original transcript with my comments and emergent themes as well as on the tables to provide feedback on if she understood the process and where she supported my analysis or where she differed.

Step 6: Looking for patterns across cases. Using the summary table of themes for each case, a table of compiled themes from all cases was created. Columns included the same data from the summary of themes table. I decided to keep the themes separate for each participant initially. Using the highlighting feature in Word, I identified themes which were shared by all three participants, two participants, and then important themes to individuals which were not shared among others.

Upon completion of this process, I felt as if I had more of a descriptive analysis versus an interpretative analysis. Therefore, I returned to the literature. Smith, Larkin and Flowers (2009) discussed the iterative process of IPA and also that the methods of IPA allow for and encourage review of the process to provide richness to the analysis. They stated that IPA is not a linear process, despite that their 6 steps appear to be linear. In a meeting with and my committee members, MN and NN, it was also decided that I should use data from the 15 post-session interviews conducted after each co-construction session and had been previously analyzed for themes as a means of triangulating the data to establish trustworthiness of the data. Therefore, quotes provided in the results section are from both the semi-structured interviews and the post-session interviews.

With this idea in mind, we determined that I should use Larkin and Thompson's (2012) method of checking or clarifying content to expand the interpretative analysis. Using the compiled themes table from all cases, I went back and added two columns, my interpretation and a column for objects of concern and experiential claims. According to

Larkin and Thompson, objects of concern are anything that matters to participants such as events, relationships, values etc. Experiential claims are linguistic and narrative clues as to the meaning of those objects of concern. Using the table of compiled themes, I created a new table for this process. I decided to begin with the themes which were related to the co-construction experience being a positive emotional experience. I transferred all of the entries for each participant into this new table with the added columns of interpretation and objects of concern/experiential claims. As I did this I went back to the original transcript sources to take the line by line excerpt from the transcript which supported the super-ordinate theme. I also began to cluster the themes within the super-ordinate theme. I found this to be quite helpful to move beyond a descriptive analysis to a more interpretative one.

During this time I also eliminated the initial emergent themes that did not warrant being categorized as a theme. Once I completed for the super-ordinate theme of co-construction experience being a positive emotional experience, I returned to the table of compiled themes for all three participants to identify the next super-ordinate theme and repeated the process of identifying objects of concern/experiential claims and my interpretation of each theme. Finally, I reviewed the themes and comments identified during the 15 post-session interviews and added these into the three existing super-ordinate themes using the same process for line by line transcript review, interpretation, and objects of concern/experiential claims to further support the super-ordinate themes.

IPA Super-Ordinate Themes

   Three super-ordinate themes were identified in the interviews. They were: *More than a story: It changed my life*; *Co-constructing 'My Story' was a positive emotional experience; and Hope*. Each super-ordinate theme will be examined in detail in this section.

   More than a story: It changed my life. The first super-ordinate theme identified was *More than a Story: It Changed my Life*. This theme validated the idea that the process of co-constructing the story was a deeply meaningful experience in providing perspective on their life and supported a positive view of their identity. This theme was found in all three participants. In the statement below, Dennis' summarizes the value he placed on this experience and that it was more than just a story.

   Dennis: I was I was I was stoked to do it. Yeah I didn't know it would be a be a choice my /tʃɚs/ [XXX] my words. It did. It really did it came out great. You know? I loved. The whole thing just blows my mind. It's an amazing story. Not the story, just the whole, not the story, my story is just a story, my life. But the whole the whole thing we did here. It changed my life. It really did. It's amazing.

In this excerpt, Dennis recognizes that the process of co-construction had a life changing impact on how he viewed himself. Two subordinate themes supported this super-ordinate theme. They included: *My life came back to life* and *post-traumatic growth*. Each subordinate theme will be explored.

My life came back to life. Participation in the 'My Story' co-construction process

provided participants with an opportunity to reflect about how their life and identity had

changed with their stroke and aphasia. The process helped to facilitate or reinforce a

positive outlook on a new life as well as a chance to imagine life in the future. Below

Dennis shares how his life 'came back to life' through the co-construction process. He

also remarks on how enjoyed reflecting on the past and reminiscing about his family.

Interviewer:	Was sharing your story helpful for you in thinking about your life?
Dennis:	Yeah, you know what, it's j- it's just my life. But it /aim/ [came] back to life.
Interviewer:	It came back to life?
Dennis:	I guess for now. You know? You know? Seeing the my sisters stu- when we were younger. They're amazing people, you know, my sister funny, funny, funny people. In-laws are funny too so I just laugh at them.

Similarly, James remarked on how the co-construction process allowed him to explore a

new identity. He stated that whether you like it or not, stroke and subsequent aphasia

create a new life. The project allowed him to think about the future and his goals. He

stated that the process was beneficial as it helped him to put his life in perspective. This

reinforces findings in a recent longitudinal qualitative study which identified *actively*

moving forward as an overarching theme of importance to persons with aphasia (Grohn,

Worrall, Simmons-Mackie, & Hudson, 2014).

Interviewer:	Some people think that sharing stories is a way to help people think about who we are, where we're coming from where we are

going, and how the past, present, and future are meaningfully

linked. What do you think about that?

James: Yeah um um it's -- it's true ex- it's true for people with stokes

because um they have to uh find a new identity. And they um b-

they – they t- d- didn't n- didn't imagine they would ever be uh

like this but um … (2 s) when you um when you suddenly f- find

out you're going to have a uh I know you don't – you don't ever f-

think you're going to have a stroke, but uh when you do, you have

to um uh f- f- you have to think about your – your n- new life.

Interviewer: Tell me about the statement: Sharing my story gave me time to

think about how my life has changed and stayed the same.

James: Yeah, um it's b- i- it's – it's um really true that I um have um uh t-

big change f- from uh my life before and after and I – this st- this

story thing helped me um concentrate – I mean not concentrate but

um imagine my life in the future.

Dennis expressed how proud he was of himself, and that the process allowed him to find

a confidence in himself that he did not have prior to beginning the project. In the excerpt

below he describes how he feels he can do anything now. And that the project allowed

him to develop tools to gain this confidence.

Interviewer: Do you see yourself any differently after creating and sharing your

story?

Dennis: I'm proud of myself. I think. You know? Make me. Make me. I

can, I can. You know? I can I can do anything I want to. You

know? You got you got the tools to do, you can do it.

In another excerpt Dennis proclaims that he realized he can talk to people and exhibited a

new found confidence in himself. He is now viewing himself, his identity, as someone

who has the ability to talk to people.

Dennis: You know I – I found out yesterday that I – I c- I could talk /pə/

[to] people now you know. It's and th- the chance to talk /ʊ/ [to]

people just – yes no, you know? People blow it off XXX just – yes,

no, whatever you know because /pidə/ [people that] know me, they

still – they don't talk s- uh talk – talk uh that much, you know?

And no uh now I – I know that I can talk. It take time you know uh

I'm uh better and better every day. I think, you know? So I – I'm

pretty /hæboʊt/ [happy about] that whole thing, you know.

James also highlighted the importance of providing an opportunity to imagine the

future and how his aphasia and physical limitation caused by the stroke impact him.

James also mentions he 'will be alright' which supports the post-traumatic growth

concept. During the story construction sessions and in his actual story, James

communicated about how he used to build boats before his stroke and aphasia and that

his goals were to build another boat this time with his son.

Interviewer: What was meaningful for you about this story creation?

James: Um well f- um it was um it was good to um get a perspective on

my life and – and fina- remember w- w- where w- where I was

going and um what I'm going to do next and uh I didn't think about that too much, you know.

Interviewer: Before you started this?

James: Yes I just um um was going along waiting for the next day and um pla- making plans but no- never thinking about um w- what I was going to do and um.

Interviewer: So not thinking about the future really.

James: Yeah, yeah.

Interviewer: Thinking about the day to day plans.

James: Yeah. Um yeah um and I me- uh also h- h- how my uh speak and my uh physical ab- limitations were going to um affect things af- as I go along but um I – I think I'm – I'm going to be alright but um um yeah I – I th- I – yeah.

Dennis described the importance of the co-construction process in providing a new perspective on his life. Below he shares how his life is different now from before the stroke, and that is a blessing, despite the fact that not everything worked out like he had planned. He shared that he is regretful that that his wife had to prolong her retirement because he no longer can work due to the stroke and aphasia but concludes that he has come to terms that life is different than he had planned, and it's a great life. Oyserman and colleagues (2011) described different types of identities signifying membership in a group. Here Dennis is somber about losing his work identity and that his wife is now in the role of provider but has gained a newfound identity in his role as a family member.

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Dennis: Well it helped me. I think. To put my story. You know. I keep

saying we we had it all. I I I don't want to say that. Because we

had a good life. We still have a great life. You know health is fine.

All kids are great. Grandkids great. It's what what else do you

need. You know. It's just. My really. It's just I really /p/ /p/

/pætʃɪn/ /pætʃɪn/ [unsure]…You know? Life seems so different

right now. Just look, look, look now that. You know? You thought

you thought you want it all, but you didn't. You don't need it all.

All you need is your family, kids, grandkids, friends. All the stuff

all the stuff just just life. Work is just just have have a job, have to.

You know? Without you're screwed anyway. Yeah you have. You

need money, but it's it's everything's just stuff. All all you need is

your family. You know? Because those friends are fine, but the

only thing really you need your family. You know? Life with that.

And it's just me, it's stuff you need but you don't don't have it."

Don- don't have all, you don't need it all. Yeah you don't have to

have it all and. Don't have it. Say it, I can't say it. It's just my life

is so happy right now. I wish I wish Kathy could retire. You know?

The plan was I work, she'd be retired by now.

Post-traumatic growth. A second subordinate theme of *More than a Story* was

post-traumatic growth. Reflection after a life changing event, such as having stroke and

aphasia, can provide an opportunity for meaning reconstruction (Neimeyer, 2001). Each

participant reiterated that the time provided during this story construction process was

beneficial in gaining a new perspective on life. This is supported in the literature as post-traumatic growth (Sherratt, 2014).

In this next passage, James explained that this was an emotional experience for him and that having this experience may reduce his anxiety in the future since he addressed some of these concerns during the 'My Story' process. Specifically, James was referring to a time during the co-construction process when he was troubled by the thought that when he was working, his stress level impacted his relationship with his wife. This had been on his mind since he had his stroke. When he initially brought up the concern, I asked him if he had ever talked to his wife about that time to learn her perspective. He reported he hadn't, so I suggested that he perhaps ask her. During our next co-construction session when we were reviewing to the point in the story about his job stress, I asked him if he had talked to his wife about her perspective. He replied that he had and that she did not notice his stress level impacting the family in the same way that he did. I asked James how he felt about that and he said he was relieved. He alludes to this again during the final interview which is highlighted in the passage below.

James: Yeah I – I um have run into d- um emotional t- things in uh this –
             the -- in the course of this um work that I didn't have um before
             um th- you asked me to do this… Yeah um yeah I di- I got a lot of
             emotion out of this…

Interviewer: Is that an okay thing?

James: Yeah, I think so…Um yeah 'cause I'll i- it's – in – I mean it's um
             in my um psyche or something and uh um n- it's coming out and

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uh um and deal with it and in fusha- in the future I won't ha- have

s- so much um anxiety because I've um resolved it kind of.

In post-traumatic growth, the clinician plays a critical role in this identity reconstruction, helping persons with aphasia to "discover that alongside losses, there may be gains" (Sherratt, 2014, p. e73). It was apparent that the participants valued the relationship with the researcher and that having a chance to talk with someone who understood them and their aphasia was an important part of the process. Below Dennis explains this importance.

Interviewer: What did you like about this process? What was meaningful about it?

Dennis: I I I loved /ɛvri/ [everything] /baʊt/ [about] because I got I had the chance to talk to somebody. Somebody knows about me, knows, know what /hæps/ /hæps/ [happened to] my my speech. You know the speech you /yndəstænd/ [understand] you understand what happened to me. You know? What's going on now. It's been it's been great. It's been so I had I had fun.

Interviewer: That's great. I did too.

Dennis: You know? Every every time I came /kir/ [here] I so see excited to come here. So I had fun. The whole thing was fun. You've change, you've change change my life. You change change everything about what I do what I do now. Talking, speaking. Change me I I I can I can do it you know. I did [didn't] I knew [know] I could do it

until someone says someone says wow I can. You know? So, you you really changed change my life. So thanks you so much.

During the co-construction process, Dennis had shared a story about a clinician who had "lost the joy for their job." He was angry and upset that this clinician had wasted his time and perhaps negatively impacted his opportunity for recovery during a critical time in his rehabilitation. When Dennis first brought up the story during our co-construction process he didn't want to talk about that part of his rehabilitation. When I asked why, he began to explain that he was angry that he did not receive the level of care that he deserved. During the course of the co-construction sessions we reframed his negative story in to a message to clinicians about the importance of being present with each client. Below, Dennis talks about this experience.

Dennis: He told me, told me to say thank you for the XXX people, XXX people. The therapy'

Interviewer: Saving people?

Dennis: But listen people's that's people's life. You know. Only so many limited times.

Interviewer: Oh the therapist message.

Dennis: Yeah. He thank thank you [me] for that you know. Thank you know. I'm happy told, told him about that you know. People people will remember that stuff you know because it's it's someone's someone's life you know.

They they need it. So a lot of time, limited time. Don't waste me [my] my time. So if you're burned out, get out you know. That's a good story. A good message.

Interviewer: I'm glad he said that to you.

Dennis: Yeah. I did say, /di/ [he] I'm glad I'm glad you told me that because good, good ideas you know.

Interviewer: Yeah, absolutely. Because we were a little nervous with how do we frame that.

Dennis: Yeah how say it without saying names. You know what, and ah you know what. She is a /laɪs/ [nice] lady. She's a [Yep] /meɪzɪŋ/ [amazing] woman. But his [her] husband passed away. She she was not there. Hurt them, hurt them…To her. Their plans get retired you know. But the husband passed away. Then the whole thing blown up but her, by then. F that you she's like. You know? Just wait. What time? ….It's was [wasn't] her fault. Her life got different too and made made her sad and lost the joy, lost the joy. For people, not for people for speech. Her job.

Interviewer: And that and that impacted you?

Dennis: Yes it did. Really in a bad bad way. You know? In a bad way. Really did. Just you know XXX don't care anymore whatever. She don't care, I don't care. Done with it. Whatever you know. Then whatever. Have a good life. Thanks see you later you know.

Interviewer: Yeah which is yeah which is sad.

Dennis	It is.
Interviewer:	Those early times are important for building skills.
Dennis:	Yes. That was that was /bər/ /pɜrs/ [first] first time go there you know. That's the time to do it then. You know? And I didn't. It it hurt me. You know? Hurt other people too, she hurt people too. So happy that there's someone new there now.

While his anger is still apparent, through the co-construction, Dennis was able to have an opportunity to reframe this experience and find empowerment by sharing his story about the important role that clinicians play in the lives of clients. This is an example of what Kenyon and Randall (1997) refer to as *restorying*. Specifically, restorying attempts to capture the purpose of enhancing one's sense of possibility through the telling and retelling of stories. Clinicians can play a powerful role as agents of restorying. Randall (1996) asserted that the clinician's goal is to help the client change his or her life narrative from passive to active to help the individual restory his or her life (Randall, 1996). Listening and caring can assist clients profoundly as they weave life stories that are healthier and more livable. This fits well with Sherratt's (2014) description of the active role a clinician plays in providing perspective to support the post-traumatic growth in persons with aphasia.

Co-constructing 'My Story' was a positive emotional experience. The theme *co-constructing 'My Story' was a positive emotional experience* captured the participants' enjoyment in taking part in constructing and sharing a story about their life which was exhibited by all three participants. I will begin with a detailed passage from Dennis. This theme of enjoying the process of co-constructing and sharing his story in this passage

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demonstrates that story co-construction and storytelling were meaningful and had a positive impact on his identity. The process also showed him that he can have fun, something he hadn't really experienced since before his stroke.

> Dennis: You know I had nothing but fun about it. You know it's so – it's so fun, I /kʊdə/ [couldn't] /wɪʔ/ [wait to] /gɪtʃ/ [get] here every week, you know. The stor- the whole story was a- was amazing. Blessing, so blessed. /əz/ [it's] such a blessing that you – you really touched my heart…It's – it's so – I had fun. I haven't had fun for years. I have – I have fun but not…

In his excerpt, it is clear that Dennis demonstrated delight in the experience, anticipation for each session, and value in the therapeutic relationship. Three subordinate (explanatory) themes supported this super-ordinate theme. The subordinate themes included *having fun*, *reflection on the past was valuable*, and *I've still got it and it feels good*. Each subordinate theme will be reviewed in detail.

 Having fun. Having fun was a subordinate theme of *co-constructing 'My Story' was a positive emotional experience* which was predominantly shared by all three participants. Participants reported enjoying the co-construction sessions and the celebratory sharing event. Each gave the impression that it was fun to talk about themselves and their lives, in the past, present and future. The following exchange with Dave, who had the most severe expressive aphasia of the three participants, demonstrated his positive energy during the project.

> Dave: Ah uh w- uh uh XXX uh XXX uh uh uh uh um. [writing on page]
>
> Interviewer: Exciting. [reading off page]

Dave: Right, right, right, right.

Interviewer: It was exciting.

Dave: Right, right, right.

Spouses of the participants also noticed that participants were having fun. In this excerpt below, Dennis explains how he found joy in the process and that his wife, Kathy, also remarked that his happiness from participating in the project resulted in a noticeable change in his affect at home. He also remarked that he is sad to have the project end and wonders what will be next.

Dennis: That was fun of [for] me. I had fun here.

Interviewer: Yeah, I enjoyed it too. Yeah.

Dennis: I told Kathy, I said, I said now what, you know? I had much. I had so much fun here. You know? That was. I'm sad to say it's done. You know? It's fun.

Interviewer: Yeah, well next steps.

Dennis: She had told me, you know she's she's probably told you too that, you know, Dennis has been so happy s- working with you, so happy, he make, he came home happy all the time. You know? It was, it was fun.

Reflection on the past was valuable. A second subordinate theme of *co-constructing 'My Story' was a positive emotional experience* was the value of reflecting on the past. This isn't to say that all reflection was about happiness, fun, joy, but that spending time thinking about the past was beneficial to moving forward. Dave communicated that recalling the past, such as talking about his father who had passed,

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spending time in the nursing home after his stroke, and thinking about previous pets brought up memories he hadn't thought of for quite some time. Despite this, he felt it was beneficial to reminisce.

One outcome of his reminiscence was that Dave's wife learned new things about his life, from when he was a child and also happenings during the time of his rehabilitation from the stroke that opened up new opportunities for communication. This new opportunity for communication was shared by all three participants, who spoke with their family to clarify details of their story that they weren't able to remember from the stroke. Dennis provides an example which is representative of this for all participants.

Interviewer: We thought about different parts of your life. What was that like?

Dennis: Yeah, it give me a chance to /sɪnk/ [think] about it at home. This more sense I more things, I put but stuff in it. It has don't want to tell you every little thing, but the more Karen Karen want last night a couple things about. Honey, /mɛmbər/ [remember] /mɛmbər/ [remember] when we were at the hospital and this happened? And this? Nah I fo- forgot it. Well some of its funny stuff. I was out anyway.

Make them laugh, I've still got it and if feels good. A third subordinate theme of *co-constructing 'My Story' was a positive emotional experience* was *make them laugh, I've still got it and it feels good*. Each participant commented that it was enjoyable and validating to be able to tell funny stories and have the audience react positively with laughter. Dennis also noticed this theme and commented that all three participants shared funny stories. And they all have a good life too.

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Dennis: You know? I hope they, I hope they saw something you know

               what. You know what? Funny stories and is ah you know had a

               good life and they did too. I hope they, I hope they liked it too.

               They should like the stories too.

For Dave, this was something important that he mentioned at least four times during the

interview as well as numerous times during the post-session interviews. Dave told a story

about being so thirsty that he snuck water from his roommate's cup at the nursing home

when he wasn't allowed to eat or drink anything and getting caught by the nurse after he

began coughing. This was a story that he hadn't told anyone before, including his wife,

Gwen. He had kept this narrative to himself for four years since his stroke, and it was

important to him that he had a chance to share it. And he clearly enjoyed sharing it.

While not able to be transcribed with words, upon review of one of the video tapes of a

post-session interview, it is apparent to the viewer just how much fun Dave was having

with sharing the story about sneaking the water. The following excerpt provides an

example of this during the interview.

Interviewer: Did this give you any opportunity for you to learn anything new

               about yourself?

Dave: Right, uh … (3 s) um … (4 s) um uh uh uh I /hæbənt/ [haven't] um

               uh /tæbənt/ [haven't] uh Gwen uh uh [laughs] uh uh uh /poɹiɪz/

               [four years] /boɹ/ [four] years I – I uh /sævənt/ [haven't] uh uh uh

               bo- uh uh uh uh /pɑɾɚ/ [water] /pfɑɾɚ/ [water]

Interviewer   4 years with the water story and you kept it a secret.

Dave: [Laughs]

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Interviewer: [Laughs]

James also remarked on how good it felt to have people interested in hearing his story and that it was reinforcing to have the audience laugh along with him. The following excerpt highlights his remarks:

James: Well um I felt um um that um the people were i- really interested and um um when I was doing that I – I had uh um I was trying to um … (2 s) make a story that they would understand and uh um they were pretty good and um and I – I was surprised at um how much they um they reacted to some things. Like when they – everybody laughed at um something but I don't know what they were laughing at so um I guess they were pretty good.

Interviewer: You felt like their laughter was [James: 'Yeah'] in support of you?

James: Yeah

Being perceived as a 'fun guy' was important to Dennis' identity, both before the stroke and now. He stated:

Cause that's it's not different now, but I can I can talk, I can talk with people, I can you know I can have fun. I used I use fun guy. I used to be. Still am. Just different know. You know? I'm so blessed I have great life. You know? Without the toys and stuff. Now don't need it just stuff. You know? What matters is family.

Hope. The third major theme of hope was important to all participants. The co-construction experience seemed to empower each participant to provide a new level of

confidence not only in their communication skills but in themselves. Dennis expressed that through this process he found hope and also that he realized he can do anything

> Dennis: I think about today. I just just told you a minute ago. You know. I know now there's hope. I'm be I'm going to make it you know. I'll be okay. I'll get better and better. And and take time, but I'm getting better and better. And I I can do it. You know? I can I can I can do anything. I know I can do it now.

Three subordinate themes, *resilience, providing hope to others,* and *advocacy for public awareness of aphasia* are detailed below.

    Resilience. *Resilience* was the first subordinate theme to support the theme of *hope*. Aphasia can have a devastating impact on the lives that it touches. Having aphasia puts a person at high risk for depression and can negatively impact quality of life (Lam & Wodchis, 2010). The co-construction process allowed participants to be successful in communicating important aspects of their life. Each participant emphasized the importance of resilience in their own unique way. For Dave, that meant sharing his philosophy on life, 'never give up'. This is examined in the following passage.

> Dave: Uh /twajwɚ/ [never] /ɪz/ [give] /ɪz/ [give] up. /tʃɛwɪwɝ/ [never] /ɪz/ [give] up. Uh /tsɛwɪwɝ/ [never] i- uh
>
> Interviewer: Something it up? [trying to identify the words]
>
> Dave: Uh um um okay uh um /tsɛwɝ/ [never] /ɪz/ [give] up um [pointing to words on paper]
>
> Interviewer: Learned today. [reading paper] What did…
>
> Dave: Uh I uh uh. Okay uh okay um [pointing to notepad]

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[P2 writing on paper]

Interviewer: Never give up. [reading writing on paper]

Dave: Give up. [choral speech with Interviewer] Okay.

Interviewer: I gotcha, yeah. Never give up, yeah. Um so did this process today

                help you kind of think about that?

Dave: Right, right, right, right, right.

The acts of co-construction and storytelling were not the only inspiring aspects of

this process. Listening to others' stories also emerged from the data as relevant. When

asked what it was like to listen to the other stories, Dennis said 'Yeah it's it's it's cool

that's there is another life after stroke you know.' This underlines the positive impact of

each of the stories and the importance it had for those who listened to the stories. James

reiterates this in the excerpt below where he discusses how listening to the other stories

reminded him that everyone has to grab ahold and start living again.

Interviewer: Did listening to stories help you learn about how other people with

                aphasia rebuild their lives?

James: Yeah, yeah um it did um everybody has to find somewhere –

                something to uh uh grab ahold of and um start living again.

Interviewer: Mm hm.

James: And that's w- they uh uh um the other guys do. Yeah and so yeah

                it was interesting to see them, yeah.

Likewise, Dennis remarked at how surprised by and proud he was of Dave's story.

Dennis didn't realize that Dave was able to talk and thought that his wife was going to

tell the story for him.

Dennis: Um it's cool stories. You know? You never know people's lives.

            You know? Happened in their life, you know? Cool. Cool stuff.

            I'm happy they shared with that. You know? I enjoyed it. I so so

            proud of Dave. So proud of him you know. Well that's Dave. You

            [did] crazy job. You know. It came out so good thank you for that.

            Thank you for sharing that you know. It's so cool you know. Like I

            said I didn't I didn't know he could /kɔk/ [talk]. And Dave did it.

            That was cool. I was so proud of him. I was I was that was fun cool

            to see it. He he gets it out. You know? Sound right, gets it out.

            Good job.

While the participants knew one another from attending the same aphasia support

group, they did not know each other well, nor did they have any contact outside of the

group attendance before the 'My Story' Project participation. Despite this, at the time of

the group sharing celebratory event, and during the final interviews, they remarked on

how inspirational each story was. Dave, whose aphasia was the most significant, received

the most remarks about his performance and story from the other two participants.

Providing hope to others. A second subordinate theme of *hope* was *providing

hope to others*. This theme primarily came from Dennis, although Dave provided a few

comments to support this theme. Overall, Dennis was motivated that sharing his story

might inspire others with aphasia to find hope. Dennis reiterated that he hoped if even

one person who heard his story was helped it was worth it to him.

Dennis: I know I would hope that somebody helps. Helps me somehow.

            You know you and me. To help help somebody.

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Interviewer: So your message can be heard by other people?

Dennis: Yeah I hope so. You know somebody see it and say. How how can I say this? I mis- I hate to say that the amazing story. It's not a story. All the story is that there's hope. To me. I hope someone help.

This theme of helping others was a part of Dennis' identity, both before and after his stroke. During the co-construction sessions he shared that he was from a small town and that he was brought up to help people when they need help. It was a part of who he is that hasn't changed since the stroke. During his actual 'My Story' presentation he shared a story about saving his neighbor's life and rescuing him from a burning house. Dennis was clear that helping others is just a part of who is.

Dennis: Had stroke I'm still same person before. I'm still proud of my family. Kathy smelled smoke one day and went went outside and saw the neighbor's house burning down. My daughter called 911. Then look at the house anybody in there. Went in and found him, put him in the /hoʊl/ [house] and same person I do the same thing.

Sharing his story and helping others was beneficial to his identity as well. Another aspect of providing hope to others was that it takes time to get better. Both Dennis and Dave emphasized this message. Below Dave provides his advice.

Interviewer: So what would you tell other people with aphasia about the My Story project?

Dave: Oh okay.

Interviewer: What would you tell them?

Dave: Huh … (4 s) um … (2 s) uh /ti/ [be] /testɪn/ [patient] uh /ti/ [be]

                /tetɪn/ [patient] um uh.

Interviewer: Patience? Be patient?

Dave: Ri- right, right, right.

Interviewer: Mm hm, yeah.

Dave: Uh um … (2 s) and /tsuɹ tə fɛdɚ/ [things will get better] /twedədɚ

                tɛdɚ/ [things will get better] uh uh.

Gwen (Dave's Spouse): Things will get better [whispered]

Dave: Uh uh.

Dennis spoke frequently about wanting his story to help others and also to talk with

others who have aphasia that he knows from the support group he attends. There was a

younger man who recently joined the support group that Dennis felt compelled to talk

with and provide him with hope. Below is an excerpt which is representative of his

passion for helping others.

Dennis: So hope hope it help help help somebody, ah like young fella.

                Finds out. See me. I was, I was mute. I couldn't talk at all. Now

                two years, two years. Two and half years. I can talk now. A bit. So

                hope I hope I hope him he knows there's hope. You know. Without

                hope. You know then what? I hope it help him.

     Advocacy for public awareness of aphasia. A third subordinate theme of *hope*

was *advocacy for public awareness of aphasia*. This theme was unique to Dennis.

Although Dave and his wife did share Dave had plans to tell his story at his stroke

support group where his neurologist would be present this wasn't a central theme to his

experience. Dennis however, repeatedly stated that sharing his story was one way of advocating aphasia awareness and perhaps inspiring others to share their stories. He also stated that aphasia needs better public awareness, like autism. Dennis' grandson has autism. Dennis also felt strongly that aphasia needs a more recognized logo in order to gain advocacy. During one post-session interview, he pulled up his shirt sleeve and showed me his arm, with tattoos including the autism logo featured prominently, and stated, that he wanted to add an aphasia tattoo, but that the logo needed to be improved, 'better art,' before he was going to commit. The following exchange highlights this. Dennis even challenged and teased his speech-language pathologist [SLP] and graduate student clinician, [student] to design an improved logo.

> Dennis: Uh Uh. Aphasia sign. Needs art, better than that you know.
>
> Interviewer: Yeah
>
> Dennis: I tol
>
> Interviewer: We need an upgrade?
>
> Dennis: Something you know? I have a. I told her [SLP] [I want a] new tat-tattoo with something something bet- better than that. You know the mouth thing with the words in it. Sounds. Uh.
>
> Interviewer: The jumblely words?
>
> Dennis: Something. Tell [SLP], you guys, [student] you're a kid figure it out. You know. Yo- You're a genius. Figure it out.
>
> Interviewer: I love that. I love that. So what'd they say?
>
> Dennis: Well, I say don't any of your friends have art? Get going you know. She laughed. To help somebody and others. You know?

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Interviewer: So I guess what I'm hearing is helping the people saying the story, but also educating others.

Dennis: Yes

Interviewer: About what aphasia is.

Dennis: Yes

Interviewer: And how they can communicate with people who have aphasia.

Dennis: Yeah, not only just just my story, but everybody. Help pe- people better. You know? Be a little more. Little more ah. I can't, the word can't get it out but people.

Oyserman and colleagues (2011) described different types of identities including social identities in involving the knowledge that one is a member of a group, in this case the group is those who have aphasia. In wanting to have an aphasia tattoo, Dennis demonstrated his acceptance of this new identity. Tattoos can be a form of narrative identity, telling a story through the body (Kosut, 2000). This also demonstrated that Dennis has pride in aphasia as a part of his identity in that he desires to have a tattoo to display his aphasia.

Advocating for aphasia awareness is important in providing an environment which supports people who have aphasia in communicating and living their life. Dennis felt strongly that sharing his story with others might be helpful in increasing awareness about aphasia. In the exchange below, he describes how he openly discloses his aphasia when encounters the public.

Dennis: People do- do- don't /feɪʒə/ [aphasia]. People don't really know what it is even. You know? That's what I tell right away. Tell them

right away. Listen I had a stroke can't talk that well, have /feɪʒə/ [aphasia], so hang on, I'll get it out. You know? People care, don't care. I don't care. You know? I'm going, I'm going to get it out so hang on. Most people are cool about it. You know? Oh no problem, my brother had a stroke, or my uncle stroke, or my mom stroke. So it … turns out to be, oh my mom mom mom mom my mom had a stroke you know. People say tell about stuff about that you know.

Interviewer: Yeah, it opens up a conversation.

Dennis: Yeah. Tell people just be patient, you know? You know? Give people a chance you know. I'm just same, I'm just person you know. I can talk, so I'm not dumb. Take time. Don't judge me. Because I can do it. You know? So that helps somebody talk with people. No idea how how how to help people other people. How to help them. But we we about we know what it is. You know? How do you tell them? How do we get out about it?

In this excerpt, he emphasizes that it is important to tell others he encounters in the public how they can better communicate with him and how he hopes this act of advocacy can help others who have aphasia. Dennis also shared that revealing to others about his stroke and aphasia often opens up a commonality as the person he is talking to may know someone who has had a stroke and may then show empathy in supporting his communication.

Communication Confidence

   While this study was qualitative in nature, the CCRSA was used to measure communication confidence pre- and post-participation in the 'My Story' Project to determine if any changes were noted in each participant. Scores for each participant are outlined in Table 4.2.

Table 4.2

Self-Ratings on the Communication Confidence Rating Scale for Aphasia (CCRSA) by Participant Before and After the 'My Story' Project

		Dave				James				Dennis			
		Before		After		Before		After		Before		After	
	CCRSA Item	RS	CS	RS	CS	RS	CS	RS	CS	RS	CS	RS	CS
1	Talk with people	20	1	50	2	40	2	40	2	80	3	90	4
2	Stay in touch	70	3	70	3	60	3	80	3	100	4	100	4
3	Follow news or sports	90	4	90	4	90	4	90	4	100	4	100	4
4	Follow movies	40	2	80	3	70	3	70	3	60	3	80	3
5	Speak on phone	10	1	20	1	50	2	40	2	20	1	50	2
6	Understand you	20	1	30	2	40	2	60	3	80	3	90	4
7	Include in conversations	20	1	50	2	40	2	60	3	50	2	60	3
8	Speak for yourself	30	2	30	2	30	2	40	2	80	3	100	4
9	Make own decisions	100	4	70	3	90	4	90	4	100	4	100	4
10	Talk about finances	60	3	80	3	90	4	70	3	20	1	70	3
	Total	460	22	570	25	600	28	640	29	690	28	840	35

Note. RS = Raw Score; CS = Converted Score. CS values of 1 indicated no or minimal confidence and values of 4 indicated high confidence.

Following the CCRSA protocol, raw scores were rescored to converted scores (CS) using a 4-point scale as follows: 0, 10, 20 = 1; 30, 40, 50 = 2; 60, 70, 80 = 3, and 90, 100 = 4 (Babbitt, et al., 2011). Values of 1 indicated no or minimal confidence and values of 4 indicated high confidence. Results revealed each participant to increase both their overall raw and converted scores on the CCRSA. The mean raw score change from before and after was 100 with a range of 40 to 150. The mean converted score change from before and after was 3.67 with a range of 1 to 7. Each participant increased their converted score by 1 for items #6: *How confident do you feel that people understand you when you talk?* and #7: *How confident do you feel that people include you in conversations?*

As a part of the qualitative interview, self-reported CCRSA scores from before and after the 'My Story' Project were shared with each participant. Participants were asked to speculate as to why the change occurred. Analysis of interview transcripts revealed that while none of the participants could verbalize a specific reason for the changes in scores, they did each appear surprised at the increase in their own ratings. Dennis, who had the largest numeric score change of the three participants, stated *"It changed my – changed my life I guess….I talk better. The whole thing helped me talk better…"* And later in the interview when continuing to review the CCRSA scores Dennis said, *"The whole thing made me prouder….made [me] more proud of myself. You know not just speeching [speaking] but just made me prouder of myself."*

Cautionary Notes

As previously stated the intent of IPA is exploratory, not explanatory (Larkin & Smith, 2010). This study was not about measuring outcomes but rather observing the

process of co-constructing a personal narrative from the view of the participants. Therefore caution must be heeded in making generalizations about the results reported here. The paper is intended to provide an example of what the experience was like for these particular participants with aphasia.

As with any therapeutic intervention, co-construction of personal narratives should not be viewed as a technique for all clients. Ruth and Kenyon (1996) cautioned that guided narrative approaches are not necessarily for everyone, nor should storytelling be viewed as the sole technique for processing a life event. Likewise this advice should be heeded when determining who with aphasia might be a candidate for co-constructing a personal skills and training in communicating with people who have aphasia. Selecting clients who are intrinsically interested in sharing their story is of utmost importance.

As noted in some of the excerpts, some of the content revealed during co-construction sessions brought about intense emotional feelings to participants. Researchers and clinicians who are not trained in mental health need to be acutely aware of when to refer to a mental health specialist should the intensity of the sharing experience warrant such a referral. Additionally it is important to do frequent check-ins with the client and to have a conversation with them about how they are feeling about the process.

Research and Clinical Implications

Co-constructing a personal narrative with persons who have aphasia can provide an opportunity to positively re-construct identity and provide an outlet to begin to think about future life and goals. Results from the participants were overwhelming positive in that the story was more than a story, but brought opportunity to have post-traumatic

growth. Also that they had fun. And that having fun in and of itself was a positive change. This project provided not only an opportunity to co-construct a story, but also an opportunity to make meaning out of the changes in their life since having aphasia. But this project wasn't only about co-constructing a story. Additionally important was the relationship between the clinician and the client, which was more equalitarian than a traditional client/clinician relationship. Researchers and clinicians need to identify such opportunities to work in a collaborative relationship with persons with aphasia to support positive changes in identity and provide an opportunity to foster hope. Also of importance was the opportunity to hear others' stories. The participants in this study reiterated the benefits of hearing and relating to other person's stories. They also found inspiration and hope in hearing about other people's lives with aphasia.

Dennis brings up a valid concern in when he states, "I told Kathy [his wife], I said, I said now what, you know? I had much. I had so much fun here. You know? That was. I'm sad to say it's done. You know? It's fun." His point is compelling in that the formal presentation should not be seen means to as an end but rather as opening a door to generate continued opportunities for to not only sharing the story but also to exploring what life goals are important to the storyteller. Additional opportunities to share the story also provide yet another experience to provide new perspective to both the story teller and the listener. Revisions or additions to the story may demonstrate changes in identity from the original story and would be interesting to study longitudinally.

While story retell was not a planned part of the 'My Story' Project, each presentation was videotaped and copies of both the video and PowerPoint slides (electronic and paper versions) were provided to participants. I did ask each if they

thought they would continue to share their story. Without prompting, Dave, who exhibited the most significant communication challenges of all participants, and his spouse, Gwen, already had plans to share the story the day after the final interview with their stroke support group. They were excited that Dave's neurologist would be attending the group. James and Dennis didn't have clear ideas of who they would share their story with again. After probing and providing a few ideas for future sharing, such as sharing with the aphasia support group they were recruited from or that future sharing didn't need to be a formal presentation, Dennis stated he might share with his family members who didn't attend the formal presentation, and he stated that 'they can watch the movie.' James was agreeable to the suggestion but wasn't sure if he would share his story again.

The act of co-constructing and telling a personal narrative about life with aphasia is a deeply personal matter. The 'My Story' Project attempted to provide a framework for researchers and clinicians to use in supporting persons with aphasia who are interested in co-constructing a story about their life. This article focused on the experience of the person with aphasia in that process. The 'My Story' Project was just one method for co-constructing a personal narrative. Future research should include expanded opportunities for co-constructing narratives and the experience of the storytellers. Additionally, the benefits of hearing other people's stories should be examined.

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CHAPTER V

A SUMMARY OF IDENTITY, CO-CONSTRUCTION OF PERSONAL
NARRATIVES AND THE PERCEIVED IMPACT OF TELLING ONE'S STORY

Aphasia can have a chronic and devastating impact on the lives of the people it touches, including the possibility of a change or disruption in identity (Brumfitt, 2008; Shadden, 2005). The disruption in language may impact the ability to create and tell stories. It also may impact confidence in communicating which may reduce the ability of the person with aphasia to participate actively key life decisions (Babbitt & Cherney, 2010). Stories are one way to construct and reconstruct meaning. Language is a tool that is used to create stories (Shadden, Hagstrom, & Koski, 2008). The power of language contributes to the construction of identity as a person (Ruth & Kenyon. 1996).

This dissertation research comprises a series of three studies in which I explored key aspects related to whether speech-language pathologists (SLPs) view themselves as having a role in reconstructing identity in adults with aphasia, and if so, what practices they used, including narratives, to support identity. I also developed and piloted a protocol, the 'My Story' Project, for co-constructing personal narratives with adults who have aphasia. Finally I explored the viewpoint of the participants who co-constructed 'My Story' personal narratives to determine the perceived impact of co-constructing and telling one's story.

SLPs Views on their Role in Supporting Reconstruction of Identity in Adults with Aphasia

Speech-language pathologists play an essential role in providing the rehabilitation of language and communication in people who have aphasia. Although researchers (Brumfitt, 2008; Kagen, et al. 2008; Simmons-Mackie & Elman, 2011) have argued the

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importance of addressing identity as an integral part of speech-language therapy, no studies to date have measured whether SLPs view themselves as having a role in supporting identity in working with people who have aphasia. Therefore, I designed and implemented a survey to explore the views of SLPs to determine whether indeed they viewed aphasia as having an impact on identity, whether they viewed themselves as having a role to support identity, and how familiar they were with methods for supporting the reconstruction of identity after the onset of aphasia. The survey also explored whether SLPs used personal narratives as one method of reconstructing self-identity in persons with aphasia.

All of the SLPs who participated in the survey regarded aphasia as having a negative impact on self-identity. These results are not surprising as having aphasia has been documented as negatively impacting quality of life (Lam & Wodchis, 2010). However an unexpected result was the number of SLPs who perceived aphasia as also having a mild degree of positive impact. This juxtaposition of viewing aphasia as having both a negative and positive impact on identity may open a door for concepts such as hope (Bright, Kayes, McCann, & McPherson, 2013), restorying (Kenyon & Ruth, 1997), and post-traumatic growth (Sherratt, 2014). Hope (Bright et al., 2013) and post-traumatic growth (Sherratt, 2014), which have been explored in persons with aphasia were identified as themes of having participated in the co-construction process.

The majority of SLPs surveyed reported themselves to have a role in supporting the reconstruction of identity in persons who have aphasia. Despite this the majority of respondents reported targeting identity indirectly vs. explicitly in speech-language treatment, if they targeted identity at all. Additionally, approximately 40% reported

having had no educational activities in identity and in personal narratives. These results

indicate a potential gap between the perceived role in supporting identity and existing

educational activities and may account for infrequent use of techniques used to support

identity in treatment. It appears that, although SLPs identified themselves as having a role

in supporting reconstruction of identity, they are not well-equipped with adequate training

or tools to do so. This finding has ramifications for the training of SLPs who provide

services to persons with aphasia. Specifically, providing access to interdisciplinary

training in identity and personal narratives may be beneficial to support SLPs or other

providers interested in targeting identity directly in treatment and ultimately providing

services that support the well-being of the person with aphasia in a client-centered

manner.

Development and Piloting of 'My Story' Protocol

In an effort to address the gap of SLPs having a perceived role in supporting

identity reconstruction in persons with aphasia and but having limited existing

educational activities and tools to support identity identified in the survey, I developed

and piloted a protocol, 'My Story,' to systematically co-construct personal narratives in

adults with aphasia. The protocol had two parts: 1) Guiding Principles for Clinicians Co-

Constructing 'My Story' a Personal Narrative with Persons with Aphasia; and 2) Protocol

for Co-Constructing 'My Story' a Personal Narrative for Persons with Aphasia. The

protocol was a total of 6 individual 90-minute sessions with me as the clinician-

researcher. These sessions were designed to co-construct and share a personal narrative.

Specifically, the narrative included: "Who I was before my stroke and aphasia;" "My

stroke and aphasia;" "Who I am today;" and "My future goals." A seventh and final

group session, including a focus group, was held where the 'My Story' personal narratives were shared with all participants and their invited guests.

The aims of this qualitative collective case study were to describe, analyze and critique the protocol and 'My Story' products that resulted from this co-constructive process for three primary participants. Story construction can provide an opportunity for creating sense out of loss and reconstruction of identity (Neimeyer, 2001). The 'My Story' Project provided a supported opportunity for participants to reflect on their lives and to think about the future. The co-construction process also allowed for participant-researchers to organize the events of their life, including the events surrounding the stroke, and to make meaning of these events. Participants reported the experience to be highly positive. The project supported the concept of living successfully with aphasia (Chapey et al., 2008; Holland, 2006) in that it provided participants an opportunity to examine their life and share it with persons that were important to them. An intentional aspect of the project was to focus on their life, not on the stroke or aphasia. While stroke and aphasia were a component of the story, this was not the defining point of their story identity, but rather one part of their story.

Participants Experiences in the 'My Story' Project

Another aim in this study was to explore the experience of the 'My Story' Project from the perspective of the persons with aphasia, their family members who were invited to hear the stories and participate in a focus group with the participants with aphasia, and the clinician-researcher. Analysis of feedback data from the three participant-researchers revealed three themes: *value in co-construction process, providing perspective,* and *we had fun*.

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Family members who listened to the stories at the celebration event and participate in a focus group immediately following the focus group, indicated the process to be a positive one. Spouses of the story tellers also expressed interest in constructing their own stories, as it was difficult at times not to interfere with the story construction of their significant other.

As the clinician researcher, I shared the themes of *value in the co-constructive process* and *having fun* identified by the participants. I found myself providing a dual role of researcher and clinician. A significant part of the clinician role was that of counseling. The value of being present and listening intently to each participant-researcher was critical as the importance was about being heard and validating the content of the story, which often was accompanied by an emotional response from the participant-researcher.

Additionally, my role as a clinician-researcher in providing organization to the order and sequencing of story events and offering clinical supports during the 'My Story' sessions and presentations was reported to be beneficial by the participants. At times my role was to provide an opportunity for restorying. In restorying (Kenyan & Randall, 1997) the clinician plays a critical role in identity reconstruction by helping persons with aphasia by providing opportunities to examine negative experiences and to reframe them in a more positive light. I experienced this during the 'My Story' project.

Participants' Perceived Impact of Participating in the 'My Story' Project on Identity and Communication Confidence

Finally, through semi-structured qualitative interviews, the experience of the participants who completed the 'My Story' Project was explored using interpretative phenomenological analysis (IPA) to examine the self-reported changes resulting from participating in the 'My Story' Project. Results of IPA analysis revealed three super-

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ordinate themes, each of which had two to three subordinate themes. The first super-ordinate theme was *More than a story: My life came back to life*. Two subordinate themes supported this super-ordinate theme. They included: *My life came back to life and post-traumatic growth*. The next super-ordinate theme was *Co-constructing 'My Story' was a positive emotional experience*. Three subordinate themes that supported this theme included: having fun, reflection on the past was valuable, and I've still got it and it feels good. The third super-ordinate theme was *Hope*. The process of co-construction provided a supported opportunity for the person with aphasia to examine their life, including imagining the future and determine goals contributed to this theme of hope. Three subordinate themes that were found to support this theme included; *resilience*, *providing hope to others*, and *advocacy for public awareness of aphasia*.

Additionally of interest was whether participating in the 'My Story' Project to co-construct personal narratives had an impact on self-reported communication confidence ratings. The Communication Confidence Rating Scale for Aphasia (CCRSA, Cherney & Babbitt, 2011) was administered before and after participation in the 'My Story' Project. Participant-researcher's overall scores improved on the CCRSA. Participants were surprised at their increased scores in rating their own communication confidence. This research provided support for the meaningfulness of co-creating a personal narrative in contributing to positive identity changes and communication confidence.

Limitations

This dissertation research is not without limitations. The survey was completed by a small number of SLPs. Further, the SLPs had self-reported interest in providing aphasia services which may impact the generalizability of the results. Despite this, the survey did

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provide preliminary information about SLPs views of aphasia, identity, and personal narratives, which was not previously available in the literature. The qualitative studies were conducted with a limited number of participants who had mild to moderate aphasia. Cautions must be taken when applying these outcomes to other persons with aphasia and clinicians who attempt to implement this process. Because the same clinician-researcher designed and implemented the co-construction process for the 'My Story' Project, this is a potential source of bias. Participant-researchers or audience members in the focus group may not have been able to express their thoughts with complete openness since they knew that the clinician-researcher who designed and implemented the project was the same person who was collecting feedback on the process.

Summary

Shadden and Hagstrom (2007) proposed integrating the use of personal narratives with the Life Participation Approach to Aphasia (LPAA, Chapey et al., 2008) as a method to support persons with aphasia in regaining a sense of coherence to their life following stroke and aphasia. Although there is interest in using narrative approaches to reconstruct identity with adults with aphasia (Shadden, 2005; Shadden & Agan, 2004; Simmons-Mackie & Elman, 2011), less has been written about specific methods clinicians can use in supporting adults with aphasia in constructing personal narratives as part of reconstructing their identity.

This dissertation research provided preliminary evidence that SLPs do view aphasia as having an impact on identity and view themselves as having a role in supporting identity reconstruction. Additionally, this research provided preliminary evidence of the positive impact that co-constructing personal narratives can have with

adults with aphasia which may in turn impact identity positively. It is hoped that the 'My Story' Project will inspire others to explore this avenue of clinical research to strengthen the evidence and methods available for clinicians to use narratives to support adults with aphasia in adjusting to their life.

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Appendix A

Survey Questions

Survey Questions

Before going further, we need to determine if you qualify for the study.
1. **Are you a certified and/or licensed speech-language pathologist (SLP)?**
    o   Yes
    o   No (If no, will be linked to a screen that says "Thank you for your participation.")
2. **Have you worked with at least 10 adults with aphasia over the past two years?**
    o   Yes
    o   No (If no, will be linked to a screen that says "Thank you for your participation.")

The first part of the survey asks about your views on self-identity and aphasia. In these questions think of "clients" as adults with aphasia on your caseload and self-identity as "who we are, where we are coming from, and where we are going."
3. **To what degree do you think that having aphasia has a NEGATIVE impact on a person's self-identity?**
    o   Strong degree of negative impact
    o   Moderate degree of negative impact
    o   Mild degree of negative impact
    o   No degree of negative impact
4. **To what degree do you think that having aphasia has a POSITIVE impact on a person's self-identity?**
    o   Strong degree of positive impact
    o   Moderate degree of positive impact
    o   Mild degree of positive impact
    o   No degree of positive impact
5. **How familiar or unfamiliar are you with activities designed to support clients' reconstruction of self-identity?**
    o   Highly familiar
    o   Familiar
    o   Somewhat familiar
    o   Neither familiar or unfamiliar
    o   Somewhat unfamiliar
    o   Unfamiliar
    o   Highly unfamiliar
6. **Which type of preservice or inservice education have you completed that highlighted supporting the reconstruction of self-identity when working with adults with aphasia? (Select all that apply)**
    □   Colleague
    □   Continuing education workshop
    □   Journal Article(s)
    □   Personal goal to learn more from multiple sources
    □   Textbook
    □   University coursework

☐   Other (Please specify)

☐   None

If you selected other, please specify: _____

7. **What therapeutic role (if any) do you perceive the following professionals to have in supporting adults with aphasia to reconstruct their self-identity? (Select one for each)**

	Primary Role	Secondary Role	Tertiary Role	No Role
Clergy				
Occupational Therapists				
Physicians				
Physical Therapists				
Psychologists				
Psychiatrists				
Social Workers				
Speech-Language Pathologists				
Other (please define)				

If you selected other, please specify: _____

8. **Considering your own work with adults with aphasia over the past two years, how frequently did you engage in activities with the EXPLICIT goal to help them to reconstruct their self-identity?**
    o   Always (with all my clients with aphasia)
    o   Most of the time (with most of my clients with aphasia)
    o   About half the time (with about half my clients with aphasia)
    o   Hardly ever (with less than a quarter of my clients with aphasia)
    o   Never (with no clients with aphasia)

9. **Considering your own work with adults with aphasia over the past two years, how frequently did you engage in activities with the INDIRECT goal to help them to reconstruct their self-identity?**
    o   Always (with all my clients with aphasia)
    o   Most of the time (with most of my clients with aphasia)
    o   About half the time (with about half my clients with aphasia)
    o   Hardly ever (with less than a quarter of my clients with aphasia)
    o   Never (with no clients with aphasia)

10. **If you had to prioritize the following treatment areas for your clients with aphasia, how would you rank them, using 4 for the most important and 1 for the least important? (Place a number from 1-4 by each treatment target. Use each number only once).**
    _____ Augmentative and alternative communication
    _____ Reconstruction of self-identity
    _____ Social communication and participation
    _____ Specific language skills (expressive and receptive language)
    Comments: _____

11. **What are the top THREE reasons you would engage in activities designed to support your client's reconstruction of self-identity? (Select up to 3 choices)**

- ☐ To provide more person-centered treatment
- ☐ To address functional needs
- ☐ To address communication needs
- ☐ To address language needs
- ☐ To address concerns of the client
- ☐ To address concerns of a significant other
- ☐ Other (Please specify)
- ☐ I would not engage in activities designed to support my client's reconstruction of self-identity

If you selected other, please specify:_____

12. **What additional factors would influence your decision to engage in activities designed to support your client's reconstruction of self-identity? (Select all that apply)**
    - ☐ Type of aphasia
    - ☐ Severity of aphasia
    - ☐ Stage in adjustment to aphasia
    - ☐ Motivation of client
    - ☐ Personality of client
    - ☐ Preference of client
    - ☐ Preference of significant other
    - ☐ Other (Please specify)
    - ☐ No factors influence me to engage in activities designed to support my client's reconstruction of self-identity

    If you selected other, please specify:_____

13. **What do you perceive as barriers to engaging in activities designed to support your client's reconstruction of self-identity? (Select all that apply)**
    - ☐ Time constraints
    - ☐ Funding or reimbursement restrictions
    - ☐ Limited awareness of supporting reconstruction of self-identity
    - ☐ Lack of education in supporting reconstruction of self-identity
    - ☐ Limited comfort level in supporting reconstruction of self-identity
    - ☐ Greater effectiveness of other methods
    - ☐ Resistance from client
    - ☐ Resistance from significant other
    - ☐ Language problems due to aphasia
    - ☐ Limited relationship of supporting reconstruction of self-identity to speech, language, and communication
    - ☐ Other (Please specify)
    - ☐ I do not perceive any barriers to engage in activities designed to support my client's reconstruction of self-identity

    If you selected other, please specify:_____

The second part of the survey asks about your views on helping adults with aphasia construct personal narratives of their "life stories" before and after the onset of aphasia as part of speech-language treatment. Life-story personal narratives are a way for people begin to put their lives together by reconstructing the past and

imagining the future as an ongoing narrative that depicts who they were, are, and will be – and how the past, present, and future are meaningfully linked.

14. **How familiar or unfamiliar are you with constructing life-story personal narratives in working with adults with aphasia?**
    o Highly familiar
    o Familiar
    o Somewhat familiar
    o Neither familiar or unfamiliar
    o Somewhat unfamiliar
    o Unfamiliar
    o Highly unfamiliar

15. **Which type of preservice or inservice education have you completed that highlighted use of life-story personal narratives in working with adults with aphasia? (Select all that apply)**
    □ Colleague
    □ Continuing education workshop
    □ Journal Article(s)
    □ Personal goal to learn more from multiple sources
    □ Textbook
    □ University coursework
    □ Other (Please specify)
    □ None
    If you selected other, please
specify:_____

16. **What are the top THREE reasons you would use life-story personal narratives as a part in working with an adult with aphasia? (Select up to 3 choices)**
    □ To provide more person-centered treatment
    □ To address functional needs
    □ To address communication needs
    □ To address language needs
    □ To address concerns of the client
    □ To address concerns of a significant other
    □ Other (Please specify)
    □ I would not use life-story personal narratives as a part of speech-language treatment
    If you selected other, please specify:_____

17. **What additional factors would influence your decision to use life-story personal narratives with adults with aphasia? (Select all that apply)**
    □ Type of aphasia
    □ Severity of aphasia
    □ Stage in adjustment to aphasia
    □ Motivation of client
    □ Personality of client
    □ Preference of client
    □ Preference of significant other

☐ Other (Please specify)
☐ No factors influence me to use personal narratives
If you selected other, please specify:_____

18. **What do you perceive as barriers in using life-story personal narratives in working with adults with aphasia? (Select all that apply)**
☐ Time constraints
☐ Funding or reimbursement restrictions
☐ Limited awareness of using life-story personal narratives
☐ Lack of education in using life-story personal narratives
☐ Limited comfort level using life-story personal narratives
☐ Greater effectiveness of other methods
☐ Resistance from client
☐ Resistance from significant other
☐ Language problems due to aphasia
☐ Limited relationship of using life-story personal narratives to speech, language, and communication
☐ Other (Please specify)
☐ I do not perceive any barriers in using life-story personal narratives
If you selected other, please specify:_____

19. **Considering your own work with adults with aphasia over the past two years, how frequently did you use life-story personal narratives?**
o Always (with all my clients with aphasia)
o Most of the time (with most of my clients with aphasia)
o About half the time (with about half my clients with aphasia)
o Hardly ever (with less than a quarter of my clients with aphasia)
o Never (with no clients with aphasia)

20. **To what degree have you found the language problems of your clients to interfere with ANY ATTEMPTS to construct personal narratives?**
o Strong degree of interference
o Moderate degree of interference
o Mild degree of interference
o No degree of interference
o I have never attempted to construct personal narratives with my clients with aphasia

The third part of this survey asks about your perceptions of connections between supporting reconstruction of self-identity AND using life-story personal narratives, as well as your experience and confidence for incorporating these components in your treatment.

21. **How confident are you in your clinical skills to use life-story personal narratives as activities designed to support your client's self-identity?**
o Highly confident
o Fairly confident
o Somewhat confident
o Not at all confident

22. **Considering your own work with adults with aphasia over the past two years, how frequently did you use life-story personal narratives AS AN ACTIVITY DESIGNED TO SUPPORT YOUR CLIENT'S RECONSTRUCTION OF SELF-IDENTITY?**
    o Always (with all my clients with aphasia)
    o Most of the time (with most of my clients with aphasia)
    o About half the time (with about half my clients with aphasia)
    o Hardly ever (with less than a quarter of my clients with aphasia)
    o Never (with no clients with aphasia) (If never is selected will advance to question 24)
23. **If you have used life-story personal narratives designed to support reconstruction of self-identity with clients on your caseload, please describe your experience.**
24. **To what extent do you support or oppose SLPs engaging in life-story personal narratives designed to support a client's reconstruction of self-identity?**
    o Strongly support
    o Somewhat support
    o Neither support or oppose
    o Somewhat oppose
    o Strongly oppose
25. **Before taking this survey how frequently had you considered engaging in life-story personal narratives designed to support a client's reconstruction of self-identity with clients on your caseload?**
    o Always (with all my clients with aphasia)
    o Most of the time (with most of my clients with aphasia)
    o About half the time (with about half my clients with aphasia)
    o Hardly ever (with less than a quarter of my clients with aphasia)
    o Never (with no clients with aphasia)
26. **To what degree has taking this survey influenced the likelihood that you would choose to use or not to use life-story personal narratives as an activity to support reconstruction of self-identity in your future clinical practice?**
    o Much more likely to use
    o Somewhat more likely to use
    o Neither more likely or less likely to use
    o Somewhat less likely to use
    o Much less likely to use

The final part of this survey is to find out some information about you, your education and your work experience.
27. **Which one work environment best describes your current employment?**
    o Acute Care
    o Aphasia Specialty Clinic
    o Community Based
    o Home Health
    o Inpatient Rehabilitation

- o   Nursing Home/Extended Care Facility
- o   Outpatient
- o   Private Practice
- o   University Clinic
- o   University Research and/or Teaching
- o   Not currently working
- o   Other (Please specify)

  If you selected other, please specify: _____

28. **What additional settings are you currently working in? (Select all that apply)**
    - ☐   Acute Care
    - ☐   Aphasia Specialty Clinic
    - ☐   Community Based
    - ☐   Home Health
    - ☐   Inpatient Rehabilitation
    - ☐   Nursing Home/Extended Care Facility
    - ☐   Outpatient
    - ☐   Private Practice
    - ☐   University Clinic
    - ☐   University Research and/or Teaching
    - ☐   Not currently working
    - ☐   Other (Please specify)
    - ☐   None, I am not currently working in any other settings

    *If you selected other, please specify:*_____

29. **What is the estimated number of adults with aphasia you have worked with over the past two years? _____**

30. **How many years of experience do you have working with adults with aphasia?**

31. **How many years of experience do you have working as an SLP?**

32. **Approximately what percentage of your current caseload is made up with adults with aphasia?**

33. **Which year did you complete your formal master's level training in speech-language pathology?**

34. **What additional education and training distinctions do you have beyond your master's training, ASHA certification, and/or state license? (Select all that apply)**
    - ☐   ASHA Award for Continuing Education (ACE Award)
    - ☐   Board Certification in Neurologic Communication Disorders (BC-NCD) through the American Neurologic Communication Disorders and Sciences
    - ☐   Clinical Doctorate Degree
    - ☐   Doctor of Philosophy Degree (Ph.D.)
    - ☐   Doctor of Education Degree (Ed.D.)
    - ☐   Additional Master's Degree
    - ☐   Other (please specify)
    - ☐   None

35. **In what year were you born? _____**

36. What is your gender? (Select one)
- o Male
- o Female

37. Are you of Hispanic, Latino, or Spanish origin? (Select one)
- o Yes
- o No

38. What is your race? (Select all that apply)
- ☐ American Indian or Alaska Native
- ☐ Asian Indian
- ☐ Black, African American
- ☐ Chinese
- ☐ Guamanian or Chamorro
- ☐ Japanese
- ☐ Korean
- ☐ Native Hawaiian
- ☐ Other Asian
- ☐ Other Pacific Islander
- ☐ Samoan
- ☐ Vietnamese
- ☐ White
- ☐ Some other race (please specify)

If you selected some other race, please specify:_____

39. Please provide any additional comments about this survey in the box below.

Thank you for your time in participating in this study. Your input is greatly appreciated. This completes the survey.

Appendix B

Initial Email Invitation Recruitment Flyer

An Invitation to Participate in a Research Project

Hello! My name is Katie Strong.

I am a Ph.D. student at Western Michigan University.

This is an invitation to participate in a research project.

It is called the **'My Story' project**.

The 'My Story' project will involve **creating a story about your life**.

I am looking for **people who have aphasia** who are interested in working with me on this project.

Here is a little bit about the **'My Story' Project**:

- We will work together to create a story about your life.
- You will share the story with others in a group celebration.
- We will meet again to talk about what it was like to share your story after the group celebration.
- We will meet 2x a week over 4 weeks for 90 minute sessions.
- You will need to have your own transportation to the sessions held on MSU's campus in East Lansing. Parking passes will be provided.

The 'My Story' project is being conducted as part of Katie Strong's dissertation at Western Michigan University.

There are no fees for participating.

If you are interested in learning more about participating in this project, **please contact**

Katie Strong
517-410-2888
katie.a.strong@wmich.edu

Appendix C

Consent Documents

Western Michigan University
Interdisciplinary Health Sciences Ph.D. Program
Kalamazoo, MI 49008

Katie A. Strong, M.A., CCC-SLP
Doctoral Student Investigator

Nickola Wolf Nelson, Ph.D., CCC-SLP
Faculty Advisor

**Co-Construction of Personal Narratives in Supporting Identity
and Communication in Adults with Aphasia**
Consent Form
Participants with Aphasia

You are invited to participate in a research project entitled **The 'My Story' Project.** This research is intended to study a process of creating and sharing a story about your life.

What are we trying to find out in this study?
- We are creating a process 'My Story' to try and find out whether creating and sharing a story about your life is helpful to you.

**If sharing stories   has   any benefits?
about your life**

=

Who can participate in this study?
- You can participate if you are between 40-75 years of age and have had a stroke with mild to moderate aphasia at least 2 years ago.

Where will the study take place?
- Individual sessions will be held in Room 215 of the Oyer Speech and Hearing Building on the campus of Michigan State University in East Lansing, Michigan. The group celebration session will be held in Room 101 of the Oyer Speech and Hearing Building on MSU's campus.

What is the time commitment for participating in this study?
- Your participation will take between 12-15 hours of your time.

What will you be asked to do if you choose to participate?
- You will be asked to attend a total of 8 sessions for the project (two per week).
- In the first session you will do some activities that are a part of the *Western Aphasia Battery-Revised* and you will answer some questions on a communication confidence scale. We will also take the first steps in telling your story and learning about how we will use the computer and PowerPoint software to help tell your story.
- The next five 90-minute sessions will be used to create and practice telling your story.

These will be private sessions with Katie Strong, M.A., CCC-SLP. Katie is a licensed speech-language pathologist holding the Certificate of Clinical Competence from the American Speech-Language-Hearing Association and who is a WMU doctoral student. All sessions will be videotaped and transcribed for research purposes.

- The 7th session will be a group celebration to share the story with two other people who have aphasia and their significant others. A total of up to 15 people will attend this celebration event.

- Prior to this session, you will invite 1-2 people who are important to you to attend this session. This session will include a group discussion about the 'My Story' project. It will also be videotaped and transcribed for research purposes.
- The 8th will be a final private session with Katie to talk about what you thought about the 'My Story' project. You will answer some questions on a communication confidence scale. This also will also be videotaped and transcribed for research purposes.

What information is being measured during the study?
- We will be measuring your communication confidence. Also we will be asking your opinion about the 'My Story' project process.

What are the risks of participating in this study and how will these risks be minimized?
- As in all research, there may be unforeseen risks to the participant.
- You may get tired during this process.

We will take breaks should you become tired, or stop the session should you determine you are too tired to continue.

We will be talking about your life, which may be emotional at times.

Should you have strong feelings come up and want to talk with a mental health professional about your participation in this project. You will be provided with a list of agencies or you can contact your preferred provider.

- You will be informed if any additional personnel are to be present other than Katie Strong. You will be asked to give your verbal permission prior to the entry of the additional personnel.

What are the benefits of participating in this study?
- There are no direct benefits for participating.
- Some people get a good feeling knowing that they are helping others.
- You will be provided with a copy of your story upon completion of the 'My Story' project.

What are the costs associated with participating in this study?
- There will be no charge for participating in 'My Story' the sessions.
- You will be asked to provide your own transportation to the sessions.

Is there any compensation for participating in this study?
- No. There is no financial compensation for your participation.

Who will have access to the information collected during this study?

- Katie Strong and her dissertation committee will have access to the information collected during this study. Her major advisor, Dr. Nelson, will keep a separate master list with the names of the participants and the code numbers in a locked office in the WMU College of Health and Humans Services Building (Room 2584). Once the data are collected and analyzed, the master list will be destroyed. Any reports of the results of the study will not identify you unless you indicate a preference for your real first name to be used. You can decide whether any part of your story that has pictures can be shared with others.

- Your confidentiality will be protected as much as possible.

  However this project involves sharing personal information about your life with others. You will decide what you want to share in your story and who it will be shared with. You can use pictures to share about your story. You can decide which pictures to use. If you are not willing to do this, then participating in this project may not be for you.

- Other people will be sharing their stories which will also contain personal information. By signing this form, you are agreeing to protect other people's privacy. That means agreeing not to share any details about their stories outside of the group.

- You will be asked to respect the confidentiality of each presenter by not sharing the information heard in the stories with others who do not attend the celebration event.

- Information collected from this study will be used as a part of Katie Strong's dissertation. The results will be submitted for publication and may be presented at conferences. You can choose if you would like your own first name to be associated with your or if you want to use a false name.

What if I decide to stop participating in this study?

- You can choose to stop participating in the study at any time for any reason.
- You will experience NO consequences or penalties if you choose to withdraw from this study.

If you have any questions at any time, you can contact the primary student investigator, Katie Strong at 517-410-2888 or katie.a.strong@wmich.edu. You may also contact the Chair, Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research at 269-387-8298 if questions arise during the course of the study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

My signature represents that I am willing to participate in this study that includes all of the following.

I will:
- Work with Katie Strong as a participant/researcher in developing the 'My Story' protocol over 5 sessions, in which I will share my opinion about the activity.
- Develop a story about my life that will include personal identifying content (which I can asked to be removed for any sharing after the event).
- Share my story with 1-2 people who are important to me as well as 2 other people who have aphasia and the people they invite to hear their story.
- Protect other people's privacy by not talking about their stories outside of the group celebration.
- Talk about the experience in a one-hour personal interview after the group celebration.

When Katie Strong is reporting on this research, I would rather have her use _____ my first name OR _____a false name in telling my story.

Video and audio tape recordings will be used during this project. For permission to use these video and audio recordings beyond this research project, please refer to the attached Audio and Video Use Permission Form.

I have read this informed consent document. The risks and benefits have been explained to me. I agree to take part in this study.

With this signature, I also retain the right to decide which pieces of my story can be shared with others and what I want to have removed.

_____

Please Print Your Name

_____   _____

Participant's signature   Date

Audio/Video
Use Permission Form

As a participant in this research project, videotape/audiotape recording of you will be recorded during your participation in the study.

Please indicate below what uses of this recorded material you consent to allow us to use for scientific purposes. Please place a check mark by all that are applicable. Your responses will not affect your participation in the study and the recordings will only be used in way that you agreed to by the check marks indicated. You will not be identified by name with the recordings.

If you do not initial any of the spaces below, recordings of you will be destroyed.

Please indicate the type of informed consent
_ Videotape _Audiotape

(*AS APPLICABLE*)

 The videotape/audiotape can be shown/played as part of a presentation given at a scholarly conference.
Please initial: _____

 The videotape/audiotape can be shown/played in classrooms to students.
Please initial: _____

 The photograph/videotape/audiotape can be shown/played as part of a presentation to faculty, staff, and students.
Please initial: _____

I have read the above description and give my consent for the use of the photograph/videotape/audiotape as indicated above. I understand that the recordings will not be used for any purposes other than those I have indicated above.

Participant Name _____

SIGNATURE _____ DATE _____

Western Michigan University
Interdisciplinary Health Sciences Ph.D. Program
Kalamazoo, MI 49008

Katie A. Strong, M.A., CCC-SLP
Doctoral Student Investigator

Nickola Wolf Nelson, Ph.D., CCC-SLP
Faculty Advisor

**Co-Construction of Personal Narratives in Supporting Identity and Communication
in Adults with Aphasia**
Consent Form
Significant Others

You are invited to participate in a research project entitled **The 'My Story' Project.** This
research is intended to study a process 'My Story' of creating and sharing a story about
the individual in your life with aphasia.

What are we trying to find out in this study?
- We are creating a process 'My Story' to try and find out if sharing a story about
  life with aphasia is helpful.

Who can participate in this study?
You can participate if you are invited by someone who is participating in the 'My Story'
project.

Where will the study take place?
- The study will take place in Room 101 of the Oyer Speech and Hearing Building
  on Michigan State University's Campus in East Lansing, Michigan

What is the time commitment for participating in this study?
- It will take about 2 hours of your time.

What will you be asked to do if you choose to participate?
- You will be asked to attend a session called sharing 'My Story.' Three people
  with aphasia and their guests, including the person who invited you to attend will
  be sharing their stories. This session will include a group discussion about the
  'My Story' project. It will also be videotaped and transcribed for research
  purposes.
- 'My Story' personal narratives may contain personal information about the
  presenter. You will be asked to respect the confidentiality of each presenter by not
  sharing the information heard in the stories with others who do not attend the
  celebration event.

What information is being measured during the study?
- We will be asking your opinion about the 'My Story' project process.

What are the risks of participating in this study and how will these risks be minimized?
- No known risks, but as in all research, there may be unforeseen risks to the participant.
- You will be informed if any additional personnel are to be present other than Katie Strong. You will be asked to give your verbal permission prior to the entry of the additional personnel.

What are the benefits of participating in this study?
- No direct benefits, but some people get a good feeling knowing that they are helping others.
- You may also enjoy hearing the 'My Story' personal narratives.

What are the costs associated with participating in this study?
- There will be no charge for participating in 'My Story' session.
- You will be asked to provide your own transportation to the session.
- Participating will take 2 hours of your time.

Is there any compensation for participating in this study?
- No there is not any compensation for your participation.

Who will have access to the information collected during this study?
- Nickola Wolf Nelson, the primary investigator, and Katie Strong, the student investigator, will have access to the information collected during this study. They will keep a separate master list with the names of the participants and the code numbers. The master list will be stored in the locked Interdisciplinary Health Sciences Office Suite in the WMU College of Health and Humans Services Building. Once the data are collected and analyzed, the master list will be destroyed. Any reports of the results of the study will not identify you.
- All the information obtained during the study will be confidential. This means that your name will not appear on any papers on which this information is recorded. Your name and other personally identifiable information will be deleted and replaced with codes on all documents.
- Information collected from this study will be used as a part of Katie Strong's dissertation. The results will be submitted for publication and may be presented at conferences. Your identity will be kept confidential by assigning a different name or initials to your responses.

What if I decide to stop participating in this study?
- You can choose to stop participating in the study at any time for any reason. You will not suffer any prejudice or penalty by your decision to stop your participation. You will experience NO consequences personally if you choose to withdraw from this study.

Should you have any questions prior to or during the study, you can contact the primary student investigator, Katie Strong at 517-410-2888 or katie.a.strong@wmich.edu. You may also contact the Chair, Human Subjects Institutional Review Board at 269-387-8293 or the Vice President for Research at 269-387-8298 if questions arise during the course of the study.

This consent document has been approved for use for one year by the Human Subjects Institutional Review Board (HSIRB) as indicated by the stamped date and signature of the board chair in the upper right corner. Do not participate in this study if the stamped date is older than one year.

I have read this informed consent document. The risks and benefits have been explained to me. I agree to take part in this study.

_____

Please Print Your Name

_____   _____

Participant's signature   Date

Appendix D

Invitation to Attend 'My Story' Group Celebration

You are invited to attend a special group celebration called

‘My Story’

A story about my life

This celebration will take place on (INSERT DATE at (INSERT TIME).
The celebration will last about 2 hours.
During the first hour we will listen to 3 ‘My Story’ presentations. Following the presentations, we will have a group to talk about the ‘My Story’ project.

Refreshments will be provided.

This group celebration is a part of a research project for Katie Strong's dissertation project: Co-Construction of Personal Narratives in Supporting Identity and Communication in Adults with Aphasia. You will be invited to sign a consent form for the discussion following the presentations. You may decline signing the consent if you do not wish to participate in this part of the activity.

Appendix E

Guiding Principles for Clinicians Co-Constructing 'My Story' a Personal Narrative with
Persons with Aphasia

Guiding Principles for Clinicians Co-Constructing 'My Story' a Personal Narrative with Persons with Aphasia

Philosophical and Theoretical Orientation

Aphasia is a loss of language due to acquired brain injury after a stroke or head injury. People with aphasia may have difficulty communicating their thoughts verbally, thinking of words they want to say, writing their thoughts, understanding directions, or reading. The construction of personal narratives can provide an opportunity for healthy adjustment to threatening life events, such as stroke, by assisting those affected to search for meaning, make sense of what happened to their lives, and redefine their identity, including who they are from the current day forward (Shadden, Hagstrom, & Koski, 2008).

Recent literature has increased attention to the impact and importance of identity in working with persons with aphasia (Brumfitt, 2008; Ellis-Hill & Horn, 2000; Hersh, 2009; Shadden, 2005; Worrall et al. 2010). Taylor (1994) provided a definition of identity as "who we are, and where we are coming from" (p. 33). Evidence suggests that identity is altered following stroke even among individuals who have no significant cognitive, communicative, or perceptual residual difficulties (Ellis-Hill & Horn 2000). It might be expected that individuals with aphasia following stroke would have even more significant changes in identity. McAdams (1996) argues that we learn to think of our own identity through a narrative process. In other words, a person might use language to make sense of the chaos and life alterations associated with a stroke. Yet, aphasia, by definition, involves compromised narrative process and language ability. Brumfitt (2008) identified language as a necessary tool for defining one's identity and that it plays a vital role in understanding other people's definition of oneself as a part of the process of self-definition. When discussing guided autobiography techniques, Ruth and Kenyon (1996) cautioned that such approaches are not necessarily for everyone, nor should storytelling be viewed as the sole technique for processing a life event. The 'My Story' process is not a type of psychotherapy not should be a substitute for psychological services. The 'My Story' project is designed for any care provider who has as a tool to be used in supporting language in an effort for a person with aphasia to develop and tell a personal narrative. It is not intended as a replacement for psychotherapy or other types of psychosocial counseling methods.

Guiding Principles for Co-constructing 'My Story' with Persons with Aphasia

1. The aim is to co-construct a personal narrative that can be communicated in a way that will be understandable to other people the person with aphasia considers important.

2. Although the process of co-constructing the personal narrative is a shared experience, the person with aphasia shall have ownership of the ideas and story created.
3. The intent of the protocol provided for co-constructing 'My Story' is to provide enough support to create the story but enough flexibility to evoke meaningfulness for each individual person with aphasia.
4. The co-constructed story will be short in nature (approximately 10 minutes). The story may be the beginning of a larger story for the person with aphasia, but this process of therapeutic co-construction should have a clear beginning and ending.
5. Seven sessions will be dedicated to co-creation of the story; the first session will outline 'My Story process' and will take approximately 15-20 minutes. This is followed by four 90- minute sessions for co-construction, one 90-minute practice session, and one session to share the story.
6. Before or during the 'My Story' process, an authentic audience should be identified by the author as a target to share the story (e.g., spouse, children, friends, or others important to the author).
7. The researcher/clinician shall reveal that this is a learning experience for both the client and the clinician.
8. The researcher/clinician should embrace aspects of positive psychology and a coaching model to emphasize "What's right with you" rather than "What's wrong with you" (Holland, 2007). Co-construction of the narrative should be a positive experience, even if it may be emotional at times.
9. The researcher/clinician shall be a good listener and act as a guide during the process.
10. Concepts from Supported Conversation for Adults with Aphasia (SCA) such as use of communication ramps (e.g., spoken and written key words, gestures and body language, hand drawings, and pictures), reflection (i.e., repeating the client's message) and expansion (i.e., adding what you think the client may be trying to say) and summarization (e.g., pulling things together at the end of a longer discussion) will be used to support conversation on complex topics (Kagen et al., 2001).
11. Values and Principles from the Writing Lab Approach (Nelson, Bahr, & Van Meter, 2003) may be helpful in framing the approach to supporting an author who has aphasia.

    The Writing Lab Approach's BACKDROP Principles have been modified below in Table 1 with the 'My Story' personal narrative process in mind.

Table 1: BACKDROP Principles from *The Writing Lab Approach* (Nelson, Bahr, & Van Meter, 2003).

B – Balance

- Accepting clients where they are while scaffolding them to reach higher levels.
- Keeping targeted objectives in mind while looking flexibly for teachable moments is the essence of individualized instruction.
- Protocol-prescribed and client-centered activities and outcomes should be kept in balance.

A – Authentic Audience

- Awareness of an interested audience is an essential element for good communication.
- Clients need opportunities to create and share stories for authentic purposes and audiences.
- Clinicians should show primary interest in a client's ideas and secondary interest in technical skills and correctness.
- Caregivers and community values are important, and concerns about topic choices and technical correctness should be addressed.

C – Constructivist

- Making sense of language and making learning stick both require active, reciprocal involvement in the construction of meaning.
- Constructivist instruction is designed intentionally to mediate experiences so that clients can make discoveries on their own with scaffolding.

K – Keep it simple

- Integrated instructional practice present wonderful learning opportunities but also create danger of cognitive overload.
- Planning should include cognitive load of students.

D – Dynamic

- The implementation of 'My Story' protocol should remain dynamic.
- By using BACKDROP principles to guide them, clinicians can avoid the pitfalls of a static approach, which may become mundane and boring to clinicians and clients alike.
- Dynamic implementation keeps the model responsive to varying conditions, strengths, and needs.

R –Reflective practice

- Reflective practitioners keep journals and analyze data in order to reflect on what works and what does not work and to improve their practice.

O – Ownership

- Authors should have ownership for their ideas, decisions, and personal goals.
- Self-generation of topics is possible for all clients.
- Authors should have a sense of control and responsibilities about 'My Story' decisions.
- Success occur when client authors share their story with people who are important to them as much as with their clinicians.

P – Patience

- Long term payoffs justify interim patience.
- Focusing on process as well as product yields better communicators as well as better products, even though it takes more time.
- Granting clients try ownership leads to better critical thinking, independent learning, and responsibility for personal choices in the long run.

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Appendix F

Protocol for Co-Constructing 'My Story' a Personal Narrative

'My Story'

A story about my life

Together we will create a **story** about **your life**.

You can **share the story** with people important to you.

Before we begin, I want to **thank you** for your help with this project.

'My Story'

This is an opportunity to create a **story of your life**.

A life story is a way for people to begin to put their lives together by reconstructing the past and imagining the future as an ongoing story that depicts who you were, are, and will be.

I am interested in hearing your story. I want to help you to develop your story in a way that you can **share it with people** who are important to you.

This story will be selective and will not include everything in your life.

Instead, we will focus on what you want to share about your life.

I think you will **enjoy** the process of creating your story.

This **workbook** is designed to help us create your story.

Getting Started: Tips for writing 'My Story'

Before we begin your story, there are a few tips that are important for you to know.

Tip 1:

This is **YOUR** story.

A way for you to tell to other people about **who you are**.

I will help you to tell it, but it should be **your ideas**.

Tip 2

This process is a **learning experience** for _both of us_.

We will work together to tell your story.

What we learn may help others.

💡 Tip 3

Your story will have **4 chapters**.

You probably have more to say, so please to think about what you want to share when we are together.

You can always add more to your story once we are finished.

💡 Tip 4

We will use a **computer** and **PowerPoint** to create your story.

You don't have to know how to use the computer or PowerPoint.

I will use the computer if that is easier.

You can focus on what you want to share.

Tip 5

You may get **tired** during this process.

We will take **break**s should you become tired.

You can decide to **stop** the session if you are too tired to continue.

Our schedule

We will meet **8** times together.

7 sessions will last 90-minutes.

One session will be about 2-hours

Outline of our schedule

Session 1:   Review process for 'My Story' project

Session 2:   Work on Chapters

Session 3:   Work on Chapters

Session 4:   Work on Chapters

Session 5:   Work on Chapters

Session 6:   Practice telling 'My Story'

Session 7:   Share your 'My Story' with others

Session 8:   Talk about the process of the 'My Story' Project

Sessions 2 to 6 – Creating 'My Story'

We will meet 2 times a week to create your story.

To help organize our sessions, we have agreed upon the following times and dates for each session.

Session	Date	Time
2		
3		
4		
5		
6		

If you need to **change a session**, please let me know so we can find a different time.

Session 7 – Group Celebration - Sharing 'My Story'

Our 7th session will be a time for you to share your story.

Two other people who have aphasia will also share their stories at that time. Their families may be there.

The date of Session 7 will be

_____

at _____.

Session 8 – Reviewing the 'My Story' project process

Our final session will be to talk about what it was like to participate in the 'My Story' project.

The date of Session 8 will be

_____

at _____.

"To Do" List for 1ˢᵗ Session

Before my 1ˢᵗ session for 'My Story' I need to:

1. Think about who I will invite to hear 'My Story'

2. Decide what pictures or other items I will bring to

   the session to help tell 'My Story'

   - Who I was before my stroke and aphasia

   - My stroke and aphasia

   - Who I am today

   - My future / goals

Appendix G

Post-Session Interview

Post-Session Interview

1. How much of the story represents **your words and ideas**?

0	10	20	30	40	50	60	70	80	90	100
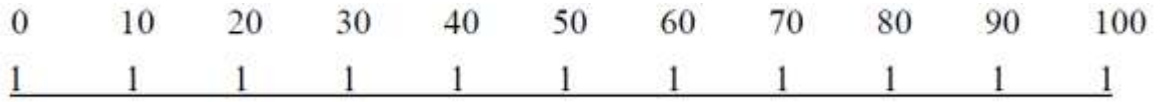
None of my
words and ideas
ideas

Some of my
words and ideas

All of my
words and

2. What did we **learn** today that would **help other people** doing something similar?

3. What worked **well**?

Yes

4. What should we **change**?

No

5. Do you have anything else you want to share about the process?

Appendix H

'My Story' Experience Focus Group Moderator's Script

'My Story' Experience Focus Group Moderator's Script

Introduction (5 minutes)
Thank you for coming today. As you know, I'm Katie Strong. My role is to guide the discussion today about the 'My Story' project.

Today I am here not as an expert or to share my opinion, but to hear from each of you. I want to hear your honest opinions about the 'My Story' project. There are no right or wrong answers. The discussion will last about an hour.

I want everyone to be able to participate, including the story tellers and guests. If anybody needs extra time to share their ideas we will wait I've provided some paper and pens on the table. Feel free to use them to communicate or if anyone wants to use them in making comments.

I want everyone to feel comfortable talking about their ideas. Don't be afraid of telling the group what you think, even if it sounds like you disagree. I will be looking around to be sure that everyone gets a chance to talk.

There are just a few rules. Don't interrupt one another. And also, be respectful of each other's comments even if you disagree. If one of you is talking a lot, I may call on someone else who we haven't heard much from. Okay?

One more important thing—I also ask that each of us be respectful of the confidentiality of everyone in this group by not sharing the information discussed today with others who do not participate in this group discussion.

I am taping this discussion to capture all of the information. The tapes will help me in writing my dissertation and other research reports. They will be used for these purposes only. Everything you share is confidential. Any personally identifying information will be removed from the reports. Also, please remember you can choose not to answer a question at any time and that your participation in this focus group is completely voluntary and you can leave at any time.

Feel free to get up, help yourself to the snacks or use the bathroom. Finally, please turn off your cell phones or turn them to silent mode so they do disturb the discussion.

Warm Up (5 minutes)

1. Let's begin by finding a bit about each of you. Please tell us
    a. Your first name
    b. And if you didn't already share a story, tell your relationship to the person whose story you came to hear today.

First I'd like to hear from those of you who shared your story today. Let's talk a bit about your thoughts on the 'My Story' project. (25 minutes)
2. When I shared my story I felt _____.
3. Having other people listen to my story made me feel _____.
4. I liked _____.
5. I didn't like _____.
6. My suggestions to make this better are _____.
7. Another way I could share my story is _____.

Now I'd like to hear from those of you who were invited to hear today's 'My Story' presentations. Reaction to 'My Story' presentations. (15 minutes)
I'm interested in learning about your thoughts on the stories that were shared today.
8. What were your reactions to today's stories?
9. What did you learn from the stories?
10. What suggestions do have about this process?

Finally, I'd like to hear from everyone about their thoughts on the 'My Story' project. (10 minutes)
11. What is your opinion about the value of time spent on the 'My Story' project?
12. What could be done to improve the 'My Story' project?
13. What other ideas do you have for creating stories for people with aphasia?

Wrap Up (5 minutes)
Thank you for sharing your thoughts with me about 'My Story. This information will be used to help us revise and improve the program.

To summarize…. (Moderator to give a quick overview of focus group discussion).

Thanks again for your participation with the 'My Story' project.

Appendix I

'My Story' Experience Focus Group: Aphasia Friendly Format PowerPoint

My Story Group Discussion

Today's Group

Everyone is welcome to participate

TAKE YOUR TIME

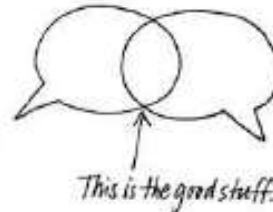If anybody needs extra time to share their ideas we will wait

Paper and pens are on the table.

Feel free to use them to communicate or make comments.

Sharing our ideas

- Everyone should feel comfortable talking about their ideas

- Don't be afraid to tell the group what you think, even if you disagree

- Everyone gets a chance to talk

This is the good stuff.

Group Rules

DOS

Share your ideas and opinions

Respect each other's comments even if you disagree.

Respect the confidentiality of others

DON'TS

Interrupt

Dominate the group or talk all the time

Disrespect what other people say

Session will be videotaped

- Videotape will be used for ONLY for Katie's dissertation and reports
- Everything you share is confidential
- Any personally identifying information will be removed from reports
- Your participation is voluntary
- You can choose to not answer any questions
- You can leave at any time

Help yourself to snacks

Or use restroom at any time

PLEASE
Silence your cell phone

Introductions

- Please tell us
  - Your first name

  AND

  - If you didn't share a story
    - your relationship to the person whose story you came to hear today

HELLO
my name is

Next let's hear from our storytellers...

1. When I shared my story I felt _____.

2. Having other people listen to my story made me feel _____.

3. I liked _____.

4. I didn't like _____.

5. My suggestions to make this better are _____.

6. Another way I could share my story is _____.

What Do You Think?

Now let's hear from our audience members

1. What were **your reactions** to today's stories?
   a. To the person who invited you today
   b. To the others that shared their stories

2. What did you **learn from the stories**?

3. What **suggestions** do you have about this process?

Finally…let's hear from everyone

1. What is your opinion about the value of time spent on the 'My Story' project?

2. What could be done to improve the 'My Story' project?

3. What other ideas do you have for creating stories for people with aphasia?

your ideas

THanK YoU!

Appendix J

Post-Project Semi-Structured Interview "My Story' Experience

Post-Project Semi-Structured Interview "My Story' Experience

Interviewer Guide

Congratulations! You did it!

You created your story and shared it!

Today I want to hear your thoughts about what this process meant to you.

_____

I am taping this discussion to capture all of the information you provide.

The tape will help me in writing my dissertation and reports and will be used for this purpose only.

_____

Important reminders:

- You can choose **NOT** to answer a question at any time.
- Your participation in this interview is completely **voluntar**y.
- You can **stop** at any time.

_____

Take your time answering any of the questions.

If you have any challenges communicating, I will support you in sharing your ideas.

Paper and pens are on the table.

_____

General probes for interviewer:

- Tell me more about that.

- What was that like?

- Could you explain to me what you mean by that?

- I'm not quite sure I understood…Could you tell me some more about that?

- You mentioned…Could you tell me more about that? What stands out in your mind about that?

- This is what I thought I heard…Did I understand you correctly?

- So what you're saying is…

Section 1: First let's talk about the process about developing your story.

1. What was it like to participate in creating a story about parts of your life?
   a. Probes
      i. What did you like? (meaningful)
      ii. What didn't you like? (hard or difficult)
2. What was it like to set aside time to think about parts of your life?
   a. Probes
      i. Was it helpful? Painful? Emotional?
3. Was it difficult to choose what parts of the story to create and share?
   a. Probes
      i. List of aspects of the process (show list to participant – on separate paper)
         1. Deciding what to share
         2. Deciding the chapters
            a. Who I was before my stroke and aphasia

        b. My stroke and aphasia
        c. Who I am today
        d. My future / goals
    3. Finding photos or other items that helped to share the story
    4. Sharing personal information with Katie
    5. Deciding who to invite to hear the story

4. Now let's talk about practicing the story. What was it like to practice sharing your story with me?
    a. Probes
        i. Was this necessary? Unnecessary? Helpful? Not helpful?

5. Did it make a difference that we knew (or didn't know) each other well before we started this project?
    a. Probes
        i. If yes, what kind of difference did it make?
   ii. List of phrases for cues (didn't matter, was important, wasn't important)

Section 2: Now let's talk about the process of sharing of your story and listening to other stories.

1. What was it like to share your story?
    a. Probes
        i. Did sharing your story bring up feelings?
            1. Good feelings? Bad feelings?
            2. Tell me more
        ii. Was sharing your story helpful for you in thinking about your life?
            1. If so, how? OR If not, how?

2. How did you expect others to react to your story?
3. How did others actually react?
4. What was it like listening to the other stories?
    a. Probes
        i. How did listening to others' stories make you feel?

           1. Probe…(will provide a visual listing of emotions/feelings)
      ii. What benefits did you find in listening to others tell their stories?
      iii. Did listening to stories help you to learn about how other people with aphasia rebuild their lives?
           1. If so, how? OR If not, please describe.
5. Do you think you will continue to share your story with others?
   a. Probes
      i. If so, who will you share it with?
      ii. Will you continue to add to your story?
           1. If so, what will you add?

Section 3: Some people think that **sharing stories** is a way to help people think about **who we are, where we are coming from, where we are going and how the past, present, and future are meaningfully linked.**
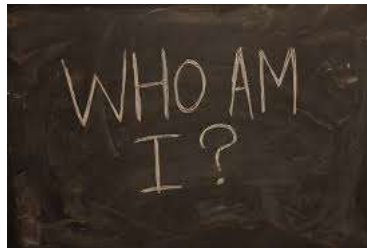
1. What do you think about that?
   a. Probes
      i. Did you learn anything new about yourself as part of this project? If so, tell me about it.
           1. Did participating in the 'My Story' project change how you think about yourself?
      ii. Do you see yourself any differently after creating and sharing your story? If yes, how so?
           1. Did this process help you to view yourself more positively? If yes, How so?
2. Tell me about the following statements.
   Sharing my story
      • gave me time to think about how my life has both changed and stayed the same with stroke and aphasia.

- provided a way to explain my stroke and aphasia to **myself.**
- provided a way to explain my stroke and aphasia to **others.**
  a. Probes
       i. How do you feel about using the 'My Story' approach to think about how your life has changed with stroke and aphasia?
  b. Did participating in this project help you to find a way to explain your stroke and aphasia to:
       i. yourself?
       ii. others?

Section 4: Next, I'd like to hear your thoughts on helping others with aphasia.

1. What would you tell other people with aphasia about the 'My Story' process?
2. How might this help other people with aphasia?
3. My suggestions to improve the 'My Story' process are
   _____.
   a. Probes
        i. What ideas to you have for improving this process?
        ii. What do you think this is good for?
            1. What it feels like to have a stroke?
            2. What it feels like to have aphasia?
            3. Helping people think about who they are?
            4. Other ideas?

Section 5: Finally, I'd like to hear your thoughts about your confidence in communicating. Remember you had taken this scale (show it to them) twice? Once at the start of our time together and once as we wrapped up your story.

I wanted to ask you about a few of your answers.

It looks like the first time you took this you answered XXX and then the next time you answered XXX. Do you have any thoughts on why you answered differently?

Personalize each questions depending on differences for each.
_____

Wrap up ---

This concludes our interview today. I want to thank you for your participation in this project. Here is a copy of your story for you to keep.

Appendix K

Post-Project Semi-Structured Interview "My Story' Experience Participant Visual
Supports

I am taping this discussion to capture all of the information you provide.

The tape will help me in writing my dissertation and reports and will be used for this purpose only.

Important reminders:

- You can choose **NOT** to answer a question at any time.
- Your participation in this interview is completely **voluntar**y.
- You can **stop** at any time.

Take your time answering any of the questions.

TAKE YOUR TIME

If you have any challenges communicating, I will support you in sharing your ideas.

Paper and pens are on the table.

Before we get started today, I would like for you to complete the **Communication Confidence scal**e again.

0	10	20	30	40	50	60	70	80	90	100

Not

Confident

Moderately

Confident

Very

Confident
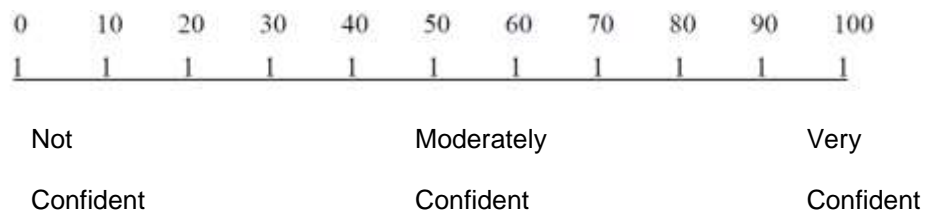
Section 1:

First let's talk about the process about developing your story.

- Deciding what to share
- Deciding the chapters
  - Who I was before my stroke and aphasia
  - My stroke and aphasia
  - Who I am today
  - My future / goals
- Finding photos or other items that helped to share the story
- Sharing personal information with Katie
- Deciding who to invite to hear the story

Section 2:

Now let's talk about the process of sharing of your story.

Section 3:

Some people think **that sharing stories help people** with stroke and aphasia **think about their identity**. In other words, who they are as a person.

What do you think about that?

Sharing my story

- gave me time to think about how my life has both changed and stayed the same with stroke and aphasia.

- provided a way to explain my stroke and aphasia to **myself.**

Section 4:

Next, I'd like to hear your thoughts on helping others with aphasia.

Section 5: Finally, I'd like to hear your thoughts about your confidence in communicating. You had taken this scale twice. Once at the start of our time together and again today.

I have enjoyed working with you and having the honor of hearing your story.

Appendix L

Lansing Area Aphasia Support Group Permission Letter
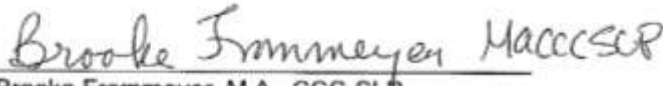
July 23, 2014

Dear Members of HSIRB at Western Michigan University,

Please accept this letter of support from the Lansing Area Aphasia Support Group the research project Co-Construction of Personal Narratives in Supporting Identity and Communication in Adults with Aphasia. We are willing to allow Katie Strong to recruit participants from the membership of our group for this research project.

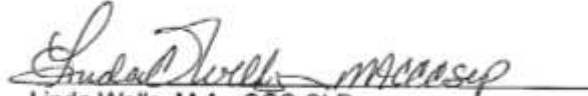If you have further question or concerns, please do not hesitate to contact us.

Sincerely,

Brooke Frommeyer MacccSP   7/23/14
Brooke Frommeyer, M.A., CCC-SLP   Date
Group Facilitator of Lansing Area Aphasia Support Group
Speech-Language Pathologist, Sparrow Hospital
brookefrommeyer@gmail.com

Saralyn Rubsam MacccSP   7/23/14
Saralyn Rubsam, M.A., CCC-SLP   Date
Group Facilitator of Lansing Area Aphasia Support Group
Speech-Language Pathologist, Hope Network
srubsam@hopenetwork.org

Linda Wells MacccSP   7/23/14
Linda Wells, M.A., CCC-SLP   Date
Group Facilitator of Lansing Area Aphasia Support Group
Speech-Language Pathologist, Origami Brain Injury Rehabilitation Services
linda.wells@origamirehab.org

Appendix M

MSU Permission for Use of Meeting Facilities

MICHIGAN STATE
UNIVERSITY

July 22, 2014

To,

HSIRB Review Board

Western Michigan University

Subject: Use of meeting facilities at Michigan State University

This letter is to confirm that Katie Strong will have access to meeting space at the Oyer Speech and Hearing Building on Michigan State University's campus to conduct interviews for research. This research is for her dissertation project entitled **Co-Construction of Personal Narratives in Supporting Identity and Communication in Adults with Aphasia.** I understand this project is also overseen by Dr. Nickola Wolf Nelson, her faculty advisor and Dr. Mary Lagerwey. This support is contingent upon approval of the research protocol by Western Michigan University's Institutional Review Board.

Feel free to contact me if you need additional information regarding this matter.

Sincerely,

Rahul Shrivastav, Ph.D.
Professor and Chair
rahul@msu.edu

College of
Communication Arts
& Sciences

Department of
Communicative Sciences
and Disorders

1026 Red Cedar Road
Room 109, Oyer Speech &
Hearing Building
East Lansing, MI 48824

517-353-8780
Fax: 517-353-3176
comdis.msu.edu

Appendix N

WMU HSIRB Approval

WESTERN MICHIGAN UNIVERSITY

Date: January 31, 2012

To: Nickola Nelson, Principal Investigator
        Katie Strong, Student Investigator

From: Amy Naugle, Ph.D., Chair

Re: HSIRB Project Number 12-01-25

\This letter will serve as confirmation that your research project titled "Supporting Identity in Aphasia: A Survey of Speech-Language Pathologists" has been **approved** under the **exempt** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note that you may **only** conduct this research exactly in the form it was approved. You must seek specific board approval for any changes in this project. You must also seek reapproval if the project extends beyond the termination date noted below. In addition if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: January 31, 2013

WESTERN MICHIGAN UNIVERSITY
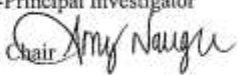
Date: September 2, 2014

To: Nickola Nelson, Principal Investigator
Katie Strong, Student Investigator for dissertation
Mary Lagerwey, Co-Principal Investigator

From: Amy Naugle, Ph.D., Chair

Re: HSIRB Project Number 14-08-05

This letter will serve as confirmation that your research project titled "Co-Construction of Personal Narratives in Supporting Identity and Communication in Adults with Aphasia" has been **approved** under the **expedited** category of review by the Human Subjects Institutional Review Board. The conditions and duration of this approval are specified in the Policies of Western Michigan University. You may now begin to implement the research as described in the application.

Please note: This research may **only** be conducted exactly in the form it was approved. You must seek specific board approval for any changes in this project (e.g., *you must request a post approval change to enroll subjects beyond the number stated in your application under "Number of subjects you want to complete the study*)." Failure to obtain approval for changes will result in a protocol deviation. In addition, if there are any unanticipated adverse reactions or unanticipated events associated with the conduct of this research, you should immediately suspend the project and contact the Chair of the HSIRB for consultation.

Reapproval of the project is required if it extends beyond the termination date stated below.

The Board wishes you success in the pursuit of your research goals.

Approval Termination: September 1, 2015