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Resilience in Aphasia:
Perspectives of Stroke Survivors and Their Families

by

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ABSTRACT

This study investigated factors associated with resilience in individuals with aphasia. Resilience is a phenomenon demonstrated when a healthy system of adaptation is present across several levels including individual or personal, family, community or society, in response to exposure to adversity such as communication impairment. Resilience was examined as it is perceived by individuals who have experienced aphasia, and by their families and caregivers. Sub-factors associated with successful outcomes for individuals with aphasia were identified through a qualitative approach using content analysis of personal interviews with persons who have experienced aphasia, their families, and caregivers. These sub-factors were grouped thematically to constitute the following major factors associated with the demonstration of resilience: support networks, person-first, and thinking positively. These factors represent the views of people with aphasia and their caregivers who participated in this study, and parallel factors associated with resilience that have been identified in previous research with related populations.

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1.0 INTRODUCTION

Resilience is a behaviour that is considered to be exhibited in the face of adversity when there is a healthy system of adaptation across several levels of influence, including individual or personal, family, and community or society. Systematic investigation of this phenomenon was first conducted primarily in the field of social work, by researchers including Garmezy (1974), Anthony (1974), Murphy and Moriarty (1976), Rutter (1979), and Werner and Smith (1982). They focused their efforts on identifying children in difficult situations who were coping well, or even surpassing expectations of normal development, despite significant threats to their health and well-being. From this early research it was determined that resilience is not an uncommon occurrence. Further, it was found that the presence of certain factors is correlated with demonstration of resilient outcomes. This led to the development of the resilience framework, and a foundation for subsequent research investigating positive adaptation.

Resilience is the process by which an individual demonstrates positive adaptation in the face of adversity. Frequently, it is operationalized as a subjective description of ‘doing ok’, from the perspective of the individual in question. Further, the demonstration of resilience is variable across situations and therefore does not represent a personal attribute, but rather a behaviour that may or may not be demonstrated. Key tenets of the resilience framework include elements called protective and vulnerability factors, which either facilitate or impede resilient outcomes, respectively, in response to negative experiences. Although there has been some variation in how resilient outcomes are operationally defined, it can be generally stated as ‘showing competent functioning despite exposure to adversity’ (Masten & Powell, 2003).

Much of the early work by researchers interested in resilience focused on identifying potential vulnerability and protective factors in children who had been exposed to a range of adverse development situations. Research in resilience has since expanded by focusing on the mechanisms underlying vulnerability and protective factors, as well as through the application of the resilience paradigm in other fields to identifying vulnerability and protective factors in a wide range of populations (Luthar & Cicchetti, 2000).

The resilience framework has been very minimally extended to the field of health sciences, and in particular to aging populations (Hildon, Smith, Netuveli, & Blane, 2008; Harris, 2008; Glymour, Weuve, Fay, Glass, & Berkman, 2008). The framework has significant potential in this field, as it allows for a holistic representation of individuals’ progress by defining successful outcomes as demonstrating behaviours that result in adaptive functioning, rather than complete recovery from impairment. This is applicable to many populations, including individuals with aphasia.

Aphasia is an acquired neurological communication disorder that affects the ability to produce and/or comprehend linguistic information, and can be differentiated from impairments of motor planning or the execution aspects of speech. It is a multimodality impairment that affects both receptive and expressive language ability. The impairment is independent of more general cognitive impairment, and may result in general or specific language deficits. Most often aphasia results from stroke, although it may also be caused by events such as traumatic brain injury, or in some cases specific degenerative disorders (see Davis, 2007 for a review of stroke and aphasia).

The majority of people with aphasia will experience at least some recovery from aphasia, with some showing marked improvements, though deficits may still be present (Code, 2001). From this, it may be deduced that while many people with aphasia show significant improvements in language abilities, as well as use of additional communication strategies, few will recover all of their previous language skills entirely. However, it is possible that many individuals, including those who maintain significant impairment despite intervention efforts, may demonstrate positive adaptation in response to their aphasia and function competently.

This study sought to identify protective factors associated with positive adaptation in individuals with aphasia following stroke, from the perspective of the individuals themselves and their family members and caregivers.

At the time of this study, there had been only very limited attempts to apply the concept of resilience to individuals who have experienced stroke (Glymour, Weuve, Fay, Glass, & Berkman, 2008) and none that had examined it from the perspective of the individuals with aphasia. Resilience was examined from the perspective of individuals who have experienced aphasia, and their families and caregivers. Factors believed to be associated with successful outcomes for individuals with aphasia were identified through content analysis.

2.0 LITERATURE REVIEW

2.1 Historical Foundations of Resilience Theory

Current research structured within the resilience paradigm is the product of work in the 1970's in the field of social work, which focused on children who demonstrated positive social and psychological adaptation under adverse conditions. The foundations of Resilience Theory are based on work by Garmezy (1974), and were further developed in the work of Anthony (1974), Murphy and Moriarty (1976), Rutter (1979), and Werner and Smith (1982).

Garmezy's initial research was largely focused on investigating positively functioning individuals with schizophrenia and their children. This research suggested that there were individuals with schizophrenia who demonstrated competent social functioning, despite a predisposition to social maladaptation. Furthermore, Garmezy found that many of the children of individuals with schizophrenia were developing normally in spite of exposure to adversity in their developmental environments (Luthar, Cicchetti, & Becker, 2000). Findings such as these led other researchers to reconsider the idea of children who demonstrated resilience as rare exceptions, and they began to investigate this population and the common traits they shared. The resilience framework, as it is defined in the literature today, grew out of this early interest in identifying factors associated with positive outcomes despite exposure to adverse situations or experiences.

In 1973, Garmezy began Project Competence, a series of studies that furthered the investigation of children exposed to adverse developmental environments, focusing on competency, adversity, and resilience (Masten & Powell, 2003). This project highlighted the importance of resilience research and the applicability of this concept to the development of social policy, as well as to intervention and prevention programs (Masten & Powell, 2003). Luthar & Cicchetti, (2000) argue for preventative measures, fostering resilience in individuals who are at risk for negative consequences, rather than waiting for these negative consequences to manifest. Anthony (1974) described children who show positive psychological outcomes, despite exposure to strongly adverse psychological situations. Research interest focusing on what Anthony referred to as “invulnerable” children (Anthony, 1974, p. 3) continues, although the term ‘resilient’ replaced the term ‘invulnerable’.

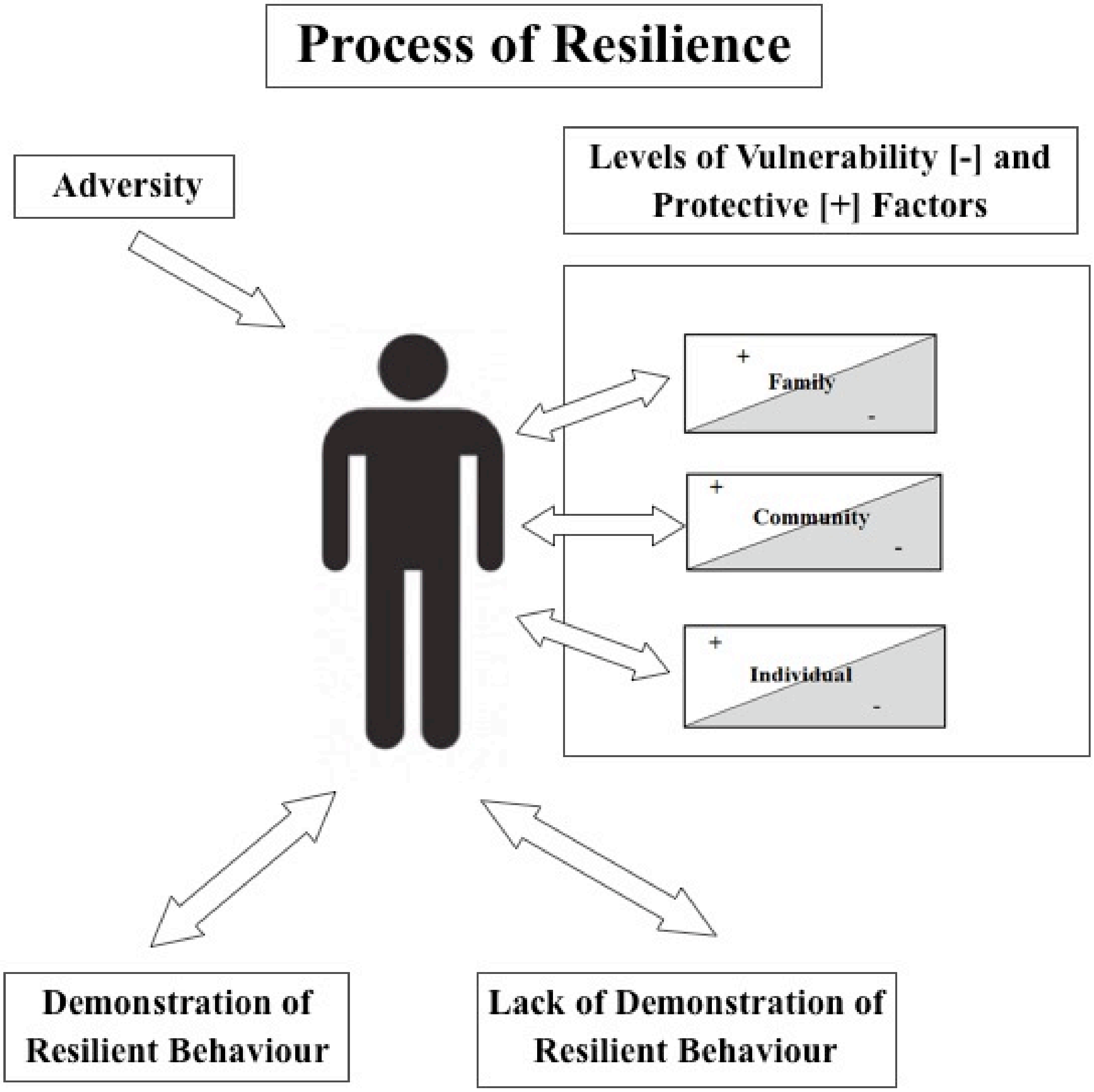
Research to determine protective factors was expanded as other researchers extended the framework to children in a range of developmentally adverse situations. Murphy and Moriarty (1976) focused their research efforts on children in “relatively stable” (p. 3) communities who were exposed to stress and demands typical in an average town in the ‘Bible Belt’ of America. Werner and Smith (1982) investigated resilience in children in impoverished and dysfunctional family situations in Hawaii who were at high risk of developing social and academic problems. Rutter (1993) focused research efforts on children who demonstrated resilience in several contexts, including high stress environments and in families with parents suffering from mental illness. Examples of factors identified in these studies include “an internal locus of control or having a positive relationship with at least one adult” (Luthar and Cicchetti, 2000, p. 859). Although these researchers investigated children in diverse environments, the vulnerability and protective factors they identified were generally consistent, adding evidence to support the generalizability of the resilience framework.

2.2 Resilience

Resilience refers to behavioural “patterns of positive adaptation in the context of significant … adversity” (Masten & Powell, 2003, p. 4). A key tenet of the resilience framework is that the demonstration of resilient behaviours is not extraordinary. It arises from the functioning of normal developmental processes that protect against adversity, in the presence of protective factors, and/or the absence of vulnerability factors. Early researchers investigating resilience in children touted these individuals as exceptional; however, further investigation has shown that resilience is, in fact, a relatively common process referred to by Masten as “ordinary magic” (Masten, 2001, p. 227).

Although initial research efforts strove to identify specific personality characteristics in individuals that demonstrated resilience, resilience is presently seen as a dynamic process. To this end, resilience is not a personal quality or individual attribute, but rather couched in behavioural terms such that a person can demonstrate positive adaptation in spite of significant adversity within a situation (Masten & Powell, 2003). To be resilient in one situation does not imply that an individual will be resilient in all situations. Conversely, if one does not show resilience in a given situation, it does not suggest that resilience can not be shown in another situation. It is this aspect of the construct of resilience that offers promise for providing a framework to view individuals’ coping as dynamic over time.

Research efforts in resilience have focused largely on the identification of vulnerability and protective factors, such as particularly in the context of child development. Further research may now investigate the mechanisms of these factors. For example, positive self-esteem has been identified as a protective factor (Rutter, 1993). Therefore, it is important to investigate how certain individuals maintain positive self-esteem in the face of adversity, such as in an abusive family situation. For example, It may be that involvement in activities such as team sports or a religious study class is the mechanism behind maintenance of healthy self-esteem. The identification of the mechanisms behind protective factors like high self-esteem facilitates intervention efforts, as personal and contextual changes can be made in order to foster the development of protective factors (Rutter, 1993). The process of resilience is shown in Figure 1:



T. M. Paslawski (person communication, Oct 26, 2009)

Figure 1. *Process of Resilience*

2.3 Definitions of Positive Adaptation

Rutter (1993) views positive adaptation as the positive end of a continuum of outcomes that are possible for individuals exposed to adversity. Positive adaptation, or competence, can be thought of as multidimensional in nature, with differentiated domains of educational, emotional, and behavioural (Luthar, Cicchetti, & Becker, 2000). According to Luthar and Cicchetti (2000), positive adaptation can be defined as a behavioural demonstration of psychosocial competence (Luthar & Cicchetti, 2000). Further, these researchers suggest that a specific definition of positive adaptation should be determined by taking into account a particular adverse condition (Luthar & Cicchetti, 2000). Masten, who employs the term "competence" (p. 2) to refer to positive adaptation, has suggested that rather than using social aptitude or other related achievements, the absence of psychopathology or the limited manifestations of negative effects following exposure to adversity can be seen as positive adaptation (Masten & Powell, 2003). Supporting the concept of positive adaptation as dynamic, previous research has shown that children who demonstrate competence in one domain may not demonstrate competence in other domains (Luthar et al., 2000). For example, Luthar (1991) found that children who showed resilience in the domain of social competence, despite exposure to high stress developmental environments, were more likely to experience depression and anxiety than children who were not exposed to this developmental adversity.

2.4 Definitions of Adversity

Adversity refers to a detrimental environment in which an individual has an increased likelihood of maladaptation or negative psychological outcomes (Luthar & Cicchetti, 2000). Adversity can be classified in terms of severity and onset, and can be operationalized in many ways. Severity of adversity can be thought of as mild, moderate, or severe, and onset can be distinguished as chronic or acute (Garmezy, 1983). Adversity has been operationally defined in diverse ways, including low socioeconomic status, low birth weight, abusive family situations, or medical conditions such as stroke (Masten, 2001; Werner, 1971; Glymour, Weuve, Fay, Glass, & Berkman, 2008). As explained by Masten (2001), it is possible to posit an absolute vulnerability factor, such as being in a fire, but many vulnerability factors are in fact one end of a positive-negative continuum of possibilities. Masten (2001) describes this by using the example of the type of parenting that a child is exposed to, which could be simplified into a continuum from ‘good parenting’ to ‘bad parenting’. In this case, bad parenting would likely act as a risk factor, but good parenting may represent both the absence of this particular adversity as well as a possible protective factor that would function in the presence of a different adverse situation (Masten, 2001). Furthermore, risk factors can summate and the presence or absence of one risk factor may be negatively or positively correlated with the presence of others (Luthar & Cicchetti, 2000).

2.5 Vulnerability and Protective Factors

Vulnerability factors heighten the risk of negative consequences following exposure to adversity (Masten, 2001). When a constellation of these factors is present, particularly in the absence of protective factors, the likelihood that an individual will demonstrate positive adaptation despite risk exposure is decreased (Masten, 2001). In contrast, protective factors decrease the likelihood of negative effects of exposure to adversity (Luthar & Cicchetti, 2000). If an individual experiences adversity, but has sufficient protective factors, the consequences of the adversity will be reduced in many cases. Elements such as community, family, and individual influences may manifest as either vulnerability or protective factors, or both (Luthar & Cicchetti, 2000). For example, family may act as a protective factor for one individual in the case that the family provides emotional support; however, in another case family may act as a vulnerability factor if it is a source of stress.

The effects of vulnerability and protective factors may be considered using either a variable-focused approach or a person-focused approach (Masten, 2001). In a variable-focused approach, the relationships between adversity, competence, and possible protective factors involved are examined (Masten & Powell, 2003). This can shed light on the application of resilience theory to intervention by giving information about the number and quality of protective resources necessary for positive outcomes (Masten & Powell, 2003). In a person-focused approach, researchers study the lives and personal attributes of individuals who have been identified as having demonstrated resilience, so that a comparison may be made with individuals who have not shown resilient outcomes in the face of adversity (Masten & Powell, 2003). This methodology is particularly sensitive to naturally occurring patterns of resilient functioning, although it is less useful than variable-focused approaches in determining mechanisms of protective factors (Masten & Powell, 2003).

2.6 Resilience in Health Sciences

The resilience framework has significant potential in the field of health sciences. Given the differences between clinical populations and children in developmentally adverse environments, it is important for research to investigate the process of resilience as it applies specifically in health sciences. Further, the heterogeneity of different clinical populations must be considered, and therefore investigation of the process of resilience within individual clinical populations is warranted at this preliminary stage of the research in this area.

The resilience framework lends itself to informing our understanding of prevention and intervention, by conceptualizing behavioural, psychosocial, and biological outcomes as dynamic. For example, within this paradigm it is assumed that a patient who is demonstrating resilience at a given stage of recovery may still be at risk of showing unsuccessful adaptation at a later stage. A later focus of resilience research in health sciences will likely focus on understanding the mechanisms behind protective factors so that this information may be applied to intervention. However, the initial task of identifying the protective factors within specific contexts and populations must first be addressed. The resilience framework has only been recently applied to adult populations in health sciences in a limited number of studies related to aging, dementia and stroke (Hildon, Smith, Netuveli, & Blane, 2008; Harris, 2008; Glymour, Weuve, Fay, Glass, & Berkman, 2008). Research in health sciences that has employed the resilience framework shows that this framework has potential in this field.

2.7 Resilience in Aging Populations

Hildon, Smith, Netuveli, and Blane (2008) investigated resilience, operationalized as “good quality of life” (p. 726) using a quality of life scale, the CASP-19, in aging populations. This study looked at resilience in the context of social ties and the effects of death or illness of a loved one, the experience of retirement, and the experience of physical and mental illness. The researchers concluded that social ties were particularly salient, with support from social networks and relationships emerging as recurrent themes in their study. Interestingly, they found that retirement was experienced differently by the group who had positive outcomes in aging than by the group who demonstrated negative outcomes. Specifically, those who had resilient outcomes rarely classified retirement as negative, unless it was elicited by health issues. In contrast, those who had negative outcomes in aging classified retirement as a negative experience (Hildon et al., 2008). However, in the context of illness, subjects who experienced resilience in aging generally described less severe health issues that were less limiting to daily activities in comparison to the health issues of those that experienced negative outcomes in aging (Hildon et al., 2008). The researchers concluded that "the process of constructing and reinterpreting past events in light of more recent ones was essential to developing resilience...because…seemed to clarify the meaning of adverse experiences" (Hildon et al., 2008, p. 738).

Harris (2008) suggests that the resilience paradigm, as compared to the successful aging paradigm, may be more prudent in gerontology as it is applicable to all older adults "regardless of social and cultural backgrounds or physical and cognitive impairments" (Harris, 2008, p. 43), and may provide a more realistic picture of patients' outcomes. Within a successful aging paradigm, positive outcomes are defined as lack of impairment or disease, whereas within the resilience framework successful outcomes would be regarded as positive adaptation despite the presence of adversity. Harris (2008) argues that patients with early stage dementia may demonstrate resilience, despite the fact that the presence of Alzheimer disease is not traditionally considered part of "successful aging". In her study, resilience was operationalized by the subjective judgement that someone is "doing OK" (Harris, 2008, p.49), as determined independently by the participant and any family members present at the interview, the healthcare professional who provided the referral, and the researcher. She presented two case studies of patients with early stage Alzheimer disease (AD) that showed resilience in aging, and identified several factors contributing to successful outcomes, including a positive attitude, coping strategies, self-esteem, productivity, and religious beliefs. She also identified several protective factors, including a healthy marriage, positive role models, and supportive family. In addition, several risks and vulnerabilities were identified, including medical concerns, living alone, concern for caregiver well being, lack of family support, and financial concerns (Harris, 2008).

Glymour, Weuve, Fay, Glass, and Berkman (2008) investigated the relationship between social ties and cognitive recovery to determine whether or not social integration promotes resilience in a cognitive domain. In this study, resilience was operationalized as successful cognitive outcomes, including cognitive recovery and cognitive maintenance following stroke. They looked at number and type of social ties, distinguishing three separate categories: intimate ties, other personal relationships, and social engagement, as well as emotional and instrumental support. They found that emotional support and social ties at baseline independently predicted cognitive summary scores six months post stroke (Glymour et al., 2008). Furthermore, emotional support predicted greater improvements in cognitive summary scores within the six months following the stroke, although results indicated that baseline social ties did not predict greater improvement in function in the six month period post stroke (Glymour et al., 2008). Given that no other social exposures predicted improvements in cognitive functioning, it was concluded that emotional support may promote resilience within a cognitive domain, while social ties provide cognitive reserve that protects against impaired cognition after stroke (Glymour et al., 2008).

2.8 Research Question

Given that there was no previous research investigating resilience in aphasia, this study sought to identify protective factors associated with positive adaptation in individuals with aphasia following stroke, from the perspective of the individuals themselves and their family members and caregivers. These factors were identified from the perspective of adults with aphasia following stroke, and their family members and/or caregivers. Although many protective factors associated with resilient functioning in children have been identified previously, there was no research that systematically investigated protective factors within the context of adults with aphasia following stroke. The information in this study was derived from responses to semi-structured interview questions prompting reflection on personal and contextual factors that fostered positive adaptation for these individuals.

3.0 METHODOLOGY

3.1 Introduction

The purpose of this study was to identify protective factors that facilitate positive adaptation in individuals with aphasia following stroke, from the perspective of the individuals themselves and their family members and caregivers. Resilience was examined from the point of view of the individuals with aphasia themselves, as well as family members and/or caregivers of people with aphasia. Factors believed by the respondents to be associated with the demonstration of resilience by individuals with aphasia were identified through analysis of the interviews.

Harris (2008) states that the two primary methodologies used in resilience research are person-focused approaches and variable-focused approaches. Person-focused approaches are described as using case studies to identify individuals who have demonstrated resilience in the face of a specific risk factor, and comparing them to individuals who have been exposed to similar risk but not shown resilient outcomes. This approach lends itself more to the identification of risk and protective factors, rather than understanding the mechanisms behind these factors. In contrast, variable-focused approaches are more suited to investigating mechanisms of resilience, in contexts where risk and protective factors have already been established. In this approach, the focus is on relationships between factors associated with resilient outcomes, and relating them to the principal components of the resilience framework (Harris 2008).

To date, the factors associated with resilient outcomes in persons with aphasia have yet to be identified. As such, this study used a person-focused approach to identify "actual patterns of resilience that occur naturally in the lives of people" (Harris, 2008, p. 47). Resilience was defined as a participant's own feeling of having demonstrated positive adaptation, as participants self identified as having shown resilient outcomes. Consistent with qualitative description methods (Sandalowski, 2000), analysis followed a qualitative content analysis approach, and identified factors associated with successful adaptation that represent the views and experiences of the participants.

3.2 Method

Through the use of qualitative description (Sandalowski, 2000), this study sought to obtain a clear description of factors that facilitate successful adaptation in individuals with aphasia, from the perspective of people with aphasia, and their family members and caregivers. The advantage of this approach is that "basic qualitative description is not highly interpretive in the sense that a researcher deliberately chooses to describe an event in terms of a conceptual, philosophical, or other highly abstract framework or system" (Sandalowski, 2000, p.336). Rather, this approach strives to obtain a veridical description of an experience or phenomenon, without colouring the description with a specific theoretical or philosophical influence.

3.3 Data collection

Data was obtained using individual semi-structured interviews with participants. Individuals with aphasia and any family members or caregivers that were present were interviewed together. Participants were interviewed in their homes, unless they indicated a preference for an alternate setting, in which case interviews were conducted in a laboratory in Corbett Hall at the University of Alberta. Each interview took approximately 60-90 minutes of the participants' time. Interviews were video- and audio-recorded and then transcribed verbatim by the interviewer, as per the recommendation of Easton, McComish and Greenberg (2000). At the time of transcription, all identifying information were replaced by ID numbers and/or pseudonyms to preserve confidentiality. In addition to the recordings, the interviewer took field notes related to context to supplement the recorded data to clarify transcription. The audio- and video-recordings were used together to provide rich transcripts. For example, transcripts would include statements such as ‘participant gives a thumbs up’ instead of ‘participant makes a gesture’.

The questions used in the interview (refer to Appendix A) were based on the following broad levels of factors identified in the literature as contributing to resilience: (a) individual or personal, (b) family, and (c) community.

3.4 Participants

This study originally sought to recruit seven participants, consistent with recommendations by Guest, Bunce, and Johnson (2006), and the thesis advisory committee. Following recruitment, nine individuals with aphasia who self-identified as having demonstrated resilience following stroke expressed an interest in participating in the study. Interviews were arranged for all nine participants. Participants self-selected with regard to eligibility to participate in this study; participants determined whether they felt that that they had demonstrated resilient outcomes following the onset of their aphasia. Whether or not participants were accompanied by a caregiver was left to the participant’s discretion. One participant was accompanied by an unrelated caregiver with whom he had a personal connection, four participants were accompanied by their spouses, one participant was accompanied by a parent, and three participants participated in the interview alone. The average age of participants was 57 years, with a range from 47-73 years[1]. All participants were from Edmonton or surrounding urban centres.

3.5 Inclusion Criteria

All participants indicated that they had been diagnosed with aphasia resulting from stroke. Confirmation of the diagnosis and etiology was not requested. Participants were not screened for cognitive status, nor for expressive or receptive language abilities. Participants were asked to self-select for eligibility to participate in the study based on their having demonstrated resilience. For the purposes of recruitment, resilience was defined as ‘having a good outcome after my stroke and communication difficulties’, based on Masten’s (2001) definition of resilience as a good outcome despite significant threat to adaptation.

3.6 Recruitment

This study employed non-random purposive sampling. Purposive sampling can be employed to “select a sample that is representative of a larger population” (Levin & Fox, 2000, p.160). More specifically, criterion sampling was used to recruit individuals who meet a specific criterion, having had “a particular life experience” (Given, 2008, p.697) Following approval by the University of Alberta Human Research Ethics Board, recruitment letters were given to Speech-Language Pathologists working with adult stroke patients at the Corbett Clinic at the University of Alberta. Speech Language Pathologists were requested to give copies of the recruitment letter (Appendix B) to potential participants who were receiving services at Corbett Clinic at the time of recruitment. The recruitment letter outlined the purpose of the study and the

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[1] Averages based on data from 8 participants, as accurate date of birth was unavailable for one participant.

criteria for participation in the study. Individuals who were interested in participating and who felt they met the criteria for the study were instructed by the recruitment letter to contact the student researcher's supervisor, Dr. Paslawski, on a private University of Alberta phone line and leave their contact information. Interested participants were contacted by the researcher to answer any questions they had about the study, to verify their interest in participating and, if appropriate, to arrange an interview time. Two participants indicated to their clinicians that they wished to have further information about the study but did not feel comfortable using the telephone. These individuals asked their Speech-Language Pathologists to arrange a meeting with Dr. Paslawski or the student researcher to provide more information in person. These meetings were arranged at Corbett Clinic. No interviews were set up during these face-to-face information sharing meetings, but interested individuals were instructed to contact Dr. Paslawski at a later date if they had further questions or were interested in participating in the study.

3.7 Consent

At the beginning of the interview, consent forms which outlined the purpose and parameters of the study were reviewed with the participants and signed prior to proceeding with the interview (Appendices C and D- Consent Forms 1 and 2, for individuals with aphasia and for family members and/or caregivers, respectively). The original signed consent forms were kept by the researcher in a locked cabinet at the University of Alberta and a copy was given to each of the participants for their records.

3.8 Interview Location

Five interviews were conducted in the lab at the University of Alberta, and four interviews were conducted in the participants' homes.

3.9 Protection of Confidentiality

Each interview was assigned an ID number. The master list with participants' names and ID numbers was kept in a locked cabinet separate from the other data associated with the study. All other data associated with the study, including transcription, used ID numbers and pseudonyms. The audio recordings and transcripts were only accessible to the researcher and Dr. Paslawski. Data were stored in a locked cabinet in the Department of Speech-Language Pathology at the University of Alberta, separate from the master list, and will be destroyed 5 years after completion of the study as required by the Health Research Ethics Board.

3.10 Data Analysis

3.10.1 Transcript Verification

The transcript verification sampling ratio was two or more minutes for every ten minutes, with a minimum of three checks and an average of five checks per interview. Successful verification of the transcripts was operationalized as 95% accuracy of agreement between listeners. This spot-checking follows the recommendations of Easton et al. (2000) and meets the guidelines for transcript accuracy recommended by MacLean, Meyer and Estable (2004). Transcripts were then analysed to determine themes in the data in order to answer the research question, using the qualitative data analysis software ATLAS.ti.

3.10.2 Definition of Terms

Researchers have highlighted the ambiguity of the term ‘theme’, noting that the term often refers to rather nebulous concepts present within a data set (Ryan & Bernard, 2006). Guest et al. (2006), define themes as recurrent concepts found within text, and highlight the importance of themes being evidenced in the data (Guest et al., 2006). To this end, Guest et al. (2006) define codes as the “formal renderings” (p. 77) of themes present in the data. This concept is disambiguated by the researchers’ statement that “codes are applied to the data (often electronically), whereas themes emerge from the data” (Guest et al, 2006, p. 77). In this study, codes determined by the data represent sub-factors associated with the demonstration of resilience by people with aphasia following stroke. Major factors associated with resilience in aphasia identified in this study represent thematically grouped sub-factors.

Data analysis employed content analysis to determine qualitative themes appearing in the data. Content analysis allows for data to be reduced to more manageable content categories, based on recurrent themes found within the data (Weber, 1990). Coding followed an inductive approach, with themes being derived from the data. Initial themes were loosely based on the following broad factors identified in the literature: (a) individual or personal, (b) family, and (c) community. Themes were refined and the codes enriched to organize the data as patterns emerged (Silverman, 2000). Themes that were present across six or more interviews were formalized into codes that were applied to the data, in accordance with the recommendations for theoretical saturation by Guest et al. (2006), to produce a set of themes applicable to all of the participants’ interpretations of the experience of demonstrating resilience in response to aphasia following stroke.

Following recommendations by Berg (2001), a second coder analysed the interviews to ensure reliability and reproducibility of the coding system. The themes identified by the second coder largely corresponded with the original themes taken from the data. Any differences in coding were discussed by the two coders to reach consensus regarding how best to represent the data. Analysis by the second coder resulted in the addition of two new codes. All of the codes determined by the data were then compared to factors identified in the literature to be associated with resilient outcomes in populations other than people with aphasia, such as people with Alzheimer disease. Sub-factors represented by codes were then grouped into 3 major categories that represented factors associated with resilience in this population found across participant data. Because this is preliminary research in resilience in aphasia, sub-factors were preserved within major themes rather than collapsed to prevent data reduction.

3.11 Reliability and Validity

The validity of themes that emerged from the data was ensured through triangulation of data sources and analyst triangulation (Patton, 1999). Specifically, triangulating data sources was accomplished by taking into account the responses of nine individuals with aphasia and their caregivers. Reliability was accomplished through analyst triangulation, by having two researchers independently analyze the data and compare their findings.

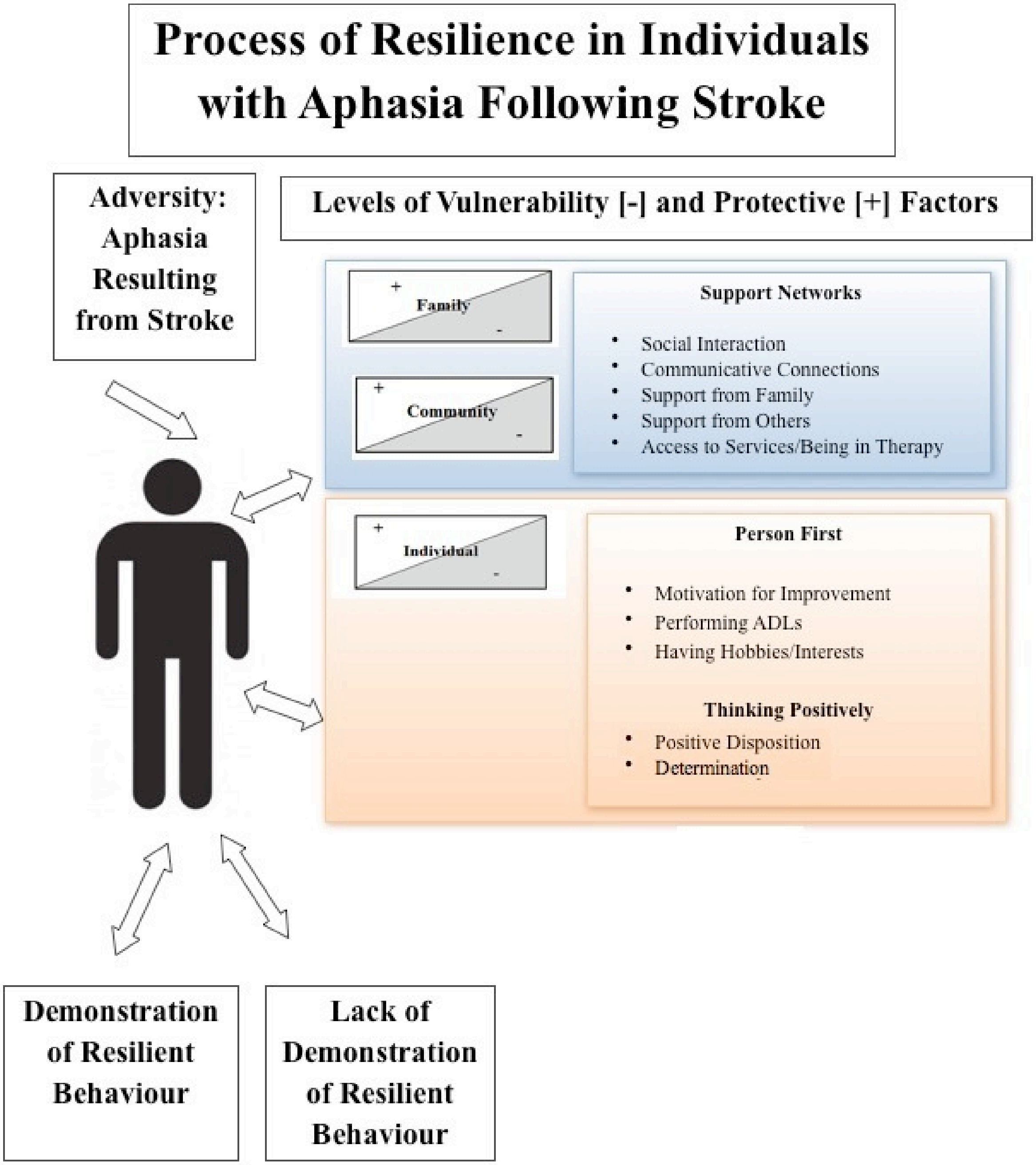
3.12 Summary

This study employed a person-focused methodological approach to further understandings about how individuals with aphasia who are recovering from stroke experience resilience. This research identified protective factors associated with positive adaptation in individuals with aphasia following stroke. Data was collected from semi-structured interviews with people with aphasia and their caregivers. Qualitative content analysis was used to analyse the data. Themes present in the data of six or more participants were formalized into codes that were applied to all of the transcripts. These codes represent sub-factors believed to be associated with the demonstration of resilience. Codes were then verified by a second coder and grouped thematically into major factors associated with the demonstration of resilience by these individuals.

4.0 RESULTS

4.1 Introduction

This study sought to identify protective factors associated with positive adaptation in individuals with aphasia, from the perspective of adults with aphasia following stroke, and their family members and/or caregivers. Protective factors were identified from responses to semi-structured interview questions, which shed light on personal and contextual factors that fostered positive adaptation with aphasia. Analysis of the data revealed three major factors associated with the demonstration of resilience following stroke: support networks, person-first, and thinking positively. Each of these major factors comprises a set of related sub-factors that recurred in the data across participants. For analysis, responses were not separated according to whether they were stated by the person with aphasia or the family member/caregiver, as the interviews were conducted with both individuals at the same time when a caregiver or family member was present. Therefore, these results represent the combined viewpoints of persons with aphasia and their family members and caregivers. Factors are identified as operating at one or more of the three broad levels of individual or personal, family, or community. Figure 2 illustrates the interaction of these factors in the demonstration of resilience:



T. M. Paslawski (person communication, Oct 26, 2009)

F*igure 2.* Process of Resilience in Individuals with Aphasia Following Stroke

4.2 Support Networks

‘Support networks’ is a major factor pertaining to emotional, social, and instrumental support received by an individual. This factor operates at the levels of family and community. Following are the sub-factors that constitute the major factor ‘support networks’.

4.2.1 Social Interaction

‘Social interaction’ refers to interactions with people in the community that the individual with aphasia may or may not have a personal relationship with. This sub-factor includes casual social interactions such as at a grocery store, or in a more formal situation such as participating in a bridge tournament at a local seniors centre. In seven out of nine interviews, it was reported that ‘social interaction’ was an important element that contributed to resilience. It is notable that although many of the other sub-factors, such as ‘communicative connections’ or ‘support from family’ also involve social interaction, ‘social interaction’ is justified as an independent sub-factor because it encompasses simple interactions in which emotional support is not provided, or a communicative connection is not made. For example, when asked about what was helpful following the stroke and the onset of the aphasia, one participant stated, “*And this day we usually go for supper and eat because everybody’s there, is there.”* Another participant, when asked “what makes [coping with aphasia] okay at home” responded, “*Could be a lot of the neighbour, as well, coming over… and from there, before and after my stroke, and even right now I have friends over there as well, so I continue on.”* Another participant told the researcher that very shortly after being discharged from the hospital following his stroke, he attended a social sporting event that he had been a part of annually. For one participant, ‘social interaction’ was achieved through time spent out walking with a friend and with that friend’s grandchildren.

Finally, one participant highlighted ‘social interaction’ as a contributor to his positive adaptation with aphasia and also demonstrated strong motivation to participate socially in the community, for example by expressing an interest in working as Santa Claus at the local mall.

4.2.2 Communicative Connections

‘Communicative connections’ was defined as the interaction between an individual with aphasia and a communication partner with whom a personal connection has been established. In this study, a personal connection was conceptualized as a relationship where individuals are personally and emotionally invested in one another. In six out of nine interviews, participants made statements related to ‘communicative connections’. A ‘communicative connection’ may be formed with individuals such as a spouse, family member, friend, or employed caregiver. When talking about an interaction with an individual who would visit the home to work on impaired abilities such as language and memory, one participant, who was a caregiver, informed the researcher that *“she used to come every day [during the program]. Now she’s just trying to be nice to them because they like her.”* One participant further highlighted the importance of establishing a ‘communicative connection’ with a speech-language pathologist, explaining that after her spouse was discharged from the hospital, they specifically contacted one of the speech-language pathologists they had worked with at the acute care centre and arranged to continue seeing her privately. One participant reported that since the birth of a grandchild, his spouse with aphasia has shown increased vocabulary because the child expects the same communication from his grandmother with aphasia as everyone else, and she attempts to provide that.

Other participants described ‘communicative connections’ that were made with individuals who have had similar experiences. This included both interactions between people who have aphasia following stroke, as well as interactions between loved ones of people with aphasia following stroke. Communication involving information exchange, for example regarding available rehabilitation services, was also involved in this interaction. One participant described an experience wherein *"they had, again people, folks like her…who would talk to us about, and then understanding the whole thing, this stroke business…and the recovery process, so yeah it's connecting with other people."* Another participant stated the following:

> *It's easier for anyone, her included, to sit with this people that have had the same sort of problem, or the same experiences…and not feel uncomfortable with how you try to communicate with them…and you know that, that person is struggling with the same communication skills as you are and then you adapt much better. Plus I think, the some of the ones that have different skills, can teach the other ones.*

One participant highlighted the importance of 'communicative connections' by informing the researcher that one of the biggest struggles his spouse faced was the short sessions spent with any one speech-language pathologist. This participant felt that as soon as his spouse with aphasia got to know the therapist and felt comfortable, services with that individual were no longer available.

4.2.3 Support from Family

'Family support' comes from sources such as spouses, children, parents, and extended family. This support may be social, emotional, or related to participation, interaction, and performing activities of daily living. One form of emotional support that was discussed by a spouse of a participant with aphasia was treating the person with aphasia as the same person as before the stroke. This is exemplified by the following quote:

> *And ah, and I, I've always you know viewed [spouse] as [spouse], not as '[spouse], this poor boy that had a stroke'...or this victim, or this...person that is different somehow than the rest of us…I have just always see [spouse] as [spouse].*

'Support from family' was present in the transcripts of all of the participants in this study. One participant expressed that "*the biggest struggle, ah was when I went down to ah [city in USA], ah speech therapy, umm and umm I missed my plane…(laughs) so I ah phoned [spouse], and ah she walked me through it.*" This participant also stated that, "*My family is my family…and she, they stuck by me.*" Another participant informed the researcher that his sister assisted him with activities of daily living (ADLs), such as dealing with finances or attending medical appointments. In response to a question about what was most helpful at home following stroke and onset of aphasia, one participant pointed to her daughter's names in her communication book, and said "helping".

4.2.4 Support from Others

'Support from others' includes support from friends, unrelated caregivers, and co-workers. As with support from family, support from others may be social, emotional, or related to participation, interaction, and performing ADLs. In five interviews participants discussed support from friends, in two interviews participants discussed support from unrelated caregivers, and in one interview support from co-workers was discussed. One participant stated, *"My friends ... they're good friends ... stuck by me ... even though I couldn't talk."* Another participant stated that *"they [friends] take him like he is, and they're…it doesn't seem to make any difference. The same with our [sports] group. You know, they're just supportive."* In response to a question about what was helpful at home, one participant pointed to his unrelated caregiver. Support from an unrelated caregiver was further described by another participant, who stated *"this lady comes in the morning… and helps [person with aphasia] person, with the personal in the morning…because it is very difficult."* Another participant stated the following, with regard to his relationship with his co-workers, one participant stated that *"from there, before and after my stroke, and even right now I have friends over there [at the participant's workplace] as well, so I continue on."*

4.2.5 Access to Services/Being in Therapy

This sub-factor refers to access to multiple types of services and therapy, including physical therapy, occupational therapy, medical services, and speech-language pathology services. 'Access to services/being in therapy' was cited as a contributor to positive adaptation following stroke in all of the interviews. One participant stated, *"We wanted to live in [another major urban centre in Alberta], actually…but, the services were here." Another participant said, "You know, interaction and communication…that's what she [spouse with aphasia] needs…for speech... that's what she needs."* Another participant stated, *"I think he was saying because of the speech therapy he [participant with aphasia] 's doing okay",* to which the participant with aphasia agreed. One participant repeatedly showed the researcher a business card from one of the services she attends, while her spouse confirmed the importance of accessing this service. Finally, one participant highlighted the importance of receiving a service related to counselling for people who have survived a stroke and their family members.

4.3 Person-First

’Person-first’ pertains to a person with aphasia’s sense of self-determination and preserved self-identity. This factor operates at the level of individual or personal. The following sub-factors constitute the major theme of person-first:

4.3.1 Motivation for Improvement

‘Motivation for improvement’ refers to intrinsic motivation to improve impaired abilities. This motivation can be manifested in ways such as willingness to participate in therapy or through individual home practice in areas such as word learning. In all nine interviews, participants in this study expressed motivation for improvement. One participant stated to a spouse with aphasia, *“Mainly, you’re working very hard, and you want to, you want to get better. You want to speak, that’s what you want to do…and communicate better.*” Another participant stated, *“I want to get myself even better than I, that I had before.*” One participant expressed his motivation for improvement by stating, *“I wanted to be [like the] next guy…improve myself”.*

4.3.2 Performing ADLs

Performing activities of daily living refers to performing tasks such as household duties like cooking and cleaning, self-care, and working. In six out of the nine interviews, participants in this study discussed performing ADLs in response to the question “Why are you doing okay?”. One participant expressed that *“I ah, put a BBQ together…one hand. And I rake the lawn…umm, umm laundry.”* Another participant discussed being able to get out with the help of a scooter to get groceries. One participant discussed how his spouse with aphasia can now use credit cards and sign her name. Working is another aspect of performing activities of daily living. One participant stated that, *"I think that is one of the … best thing that I have done after my stroke, was umm, back to work."*

4.3.3 Having Hobbies/Interests

'Hobbies and interests' refers to activities or subject matters that a person is involved with for pleasure, such as an interest in hockey or gardening as a hobby. Although almost everyone has hobbies and interests, this was considered a protective factor because participants cited their hobbies and interests in response to questions about why they are doing ok. 'Having hobbies/interests' was discussed in seven out of nine interviews. One participant stated *"You [the participant with aphasia] were doing some wood working there [at the rehabilitation hospital] too."* Another participant told the researcher that she began pursuing new hobbies, such as kayaking, following the stroke and the onset of the aphasia. In response to a question about what was helpful in the community, one participant told the researcher about a service that facilitates hobbies such as painting and computers.

4.4 Thinking Positively

'Thinking positively' is a major factor pertaining to the person with aphasia's outlook for the future, as well as the way in which the present situation is perceived. This factor operates at the level of individual or personal. The following sub-factors constitute the major factor of thinking positively:

4.4.1 Positive Disposition

Positive disposition refers to having a positive attitude, a happy/easy going disposition, a sense of humour, and an ability to accept changes following stroke and aphasia. In seven interviews, participants cited positive disposition as a key aspect of being able to adapt to aphasia following stroke. In response to the question *"What about you made you successful,"* one participant said *"happy."* Another participant, in response to a question inquiring about what advice would be helpful for someone with aphasia following stroke, said, *"determination and good attitude, and what more can I say?"* One participant stated the following:

> *But I, her, your attitude now, if I hear you right, the times you've told me (laughs)…is, you almost died, life's too short...to be miserable. You enjoy what you've got. Make every moment counts... that's her philosophy at this point.*

Another aspect of positive disposition that was considered was sense of humour. Sense of humour refers to the person with aphasia's ability to both produce and understand humour, and share humour with others. One participant stated, *" Oh yeah, and he [the participant with aphasia]'s a comedian too."* In response to a question about what was helpful following the stroke, one participant responded, *"Sense of humour… bit twisted, but was a sense of humour."* Acceptance of changes resulting from stroke and aphasia also reflects positive disposition. In this regard, one participant stated that "*It's umm, it's one of these things. It's not, nobody's fault, or whatever, it just happened, so I just trying to the best that I could do*."

4.4.2 Determination

This sub-factor refers to the person with aphasia's commitment to efforts at improving, despite challenges such as slow progress, and willingness to attempt difficult tasks. In six out of nine interviews, participants discussed determination. In response to a question about advice that would be useful for a person with aphasia, one participant responded, *"Umm, ah, don't give up, yup. "*Another participant said, *"Umm it's the same thing, when I, after my stroke and back in the, or going to the, at [former workplace], I started at the bottom. Umm, and I continue, continue up."* One participant described the following situation:

> *Also what I go in.., if I go into customers, and to figure out, to figure out how we're going to fix this, they have…they have a problem, so… they don't have enough people to, to do that. So they asked me to go out, on-site, and talk with the customer, to figure out how, what, what we can do…so…that's quite challenging.*

4.5 Summary

The purpose of this study was to answer the research question: What factors facilitate positive adaptation in individuals with aphasia following stroke, from the perspective of the individuals themselves and their family members and caregivers?

Table 1 outlines the factors that were identified:

Protective Factors	Sub-Factors
Support Networks	Social Interaction Communicative Connections Support from Family Support from Others Access to Services/Being in Therapy
Person-First	Motivation for Improvement Performing ADLs Having Hobbies/Interests
Thinking Positively	Positive Disposition Determination

Table 1. Summary of Protective Factors and Sub-Factors

These factors and sub-factors represent the collective perspectives of adults with aphasia following stroke, and their family members and/or caregivers. This study identified three major factors associated with the demonstration of resilience following stroke: support networks, person-first, and thinking positively, each of which are composed of related sub-factors that were present in interviews across participants. The factors are identified as operating at one or more of the three broad levels of individual or personal, family, or community.

5.0 DISCUSSION

5.1 Introduction

This study examined protective factors associated with positive adaptation in individuals with aphasia, through analysis of semi-structured interview questions prompting reflection on personal and contextual factors. Factors associated with resilience in aphasia identified in this study are consistent with protective factors identified previously in resilience research.

5.2 Protective Factors

Results of this study parallel factors previously identified in literature investigating resilience in health sciences, as illustrated by the following tables:

Protective Factors	Protective Factors Identified in Previous Literature	Sub-Factors Identified in the Transcripts
Support Networks	Social lntegration (intimate ties, other personal relationships, social engagement) (Glymour et al., 2007)	Social Interaction Communicative Connections
	Received Emotional Support (Glymour et al. 2007) Received Instrumental support (Glymour et al, 2007) Social Support Networks (Harris, 2008)	Support from Family Support from Others
	Community resources (Harris, 2008)	Access to Services/Being in Therapy

Table 2. ‘Support Networks’ in this Study and in Previous Research

Protective Factors	Protective Factors Identified in Previous Literature	Sub-Factors Identified in the Transcripts
Person-First	High Sense of Self-Efficacy (Luthar & Cicchetti, 2000)	Motivation for Improvement Performing ADLs Having Hobbies/Interests

Table 3. ‘Person-First’ in this Study and in Previous Research

Protective Factors	Protective Factors Identified in Previous Literature	Sub-Factors Identified in the Transcripts
Thinking Positively	Positive Attitude (Harris, 2008) Fighting Spirit (Harris, 2008)	Positive Disposition Determination

Table 4.‘Thinking Positively’ in this Study and in Previous Research

Because the factors identified represent a continuum, with a positive and a negative pole, they can therefore act as either protective or vulnerability factors. This was exemplified within the interviews. One participant identified her relationship with her mother as a protective factor, because her mother provided both emotional support and support with ADLs. In contrast, another participant identified her relationship with her mother as a source of stress, as she described experiencing particular difficulty and feelings of frustration when communicating with her mother.

5.3 Clinical Implications

The resilience framework has potential positive clinical implications. It can be inferred from this study that the resilience framework highlights the importance of multiplicity of support, in terms of the benefit of the presence of several protective factors. Although there is not yet enough foundational research to support an investigation of the relationship between the numbers and types of protective factors present and the relative risk for failure to demonstrate resilience, it is notable that all of the participants in this study identified multiple protective factors in their environment. In this sense, it may be argued that it is not adequate to provide a client or patient with one type of support, such as ‘access to services’ or ‘support with ADLs’, and further, that the presence of several protective factors will augment the likelihood of positive adaptation following stroke and aphasia. Multiplicity of support may also be applied in the sense of supports to multiple people in the environment of the individual with aphasia. An example of how this may be put into practice would be counselling for those associated with the person with aphasia, such as the caregiver, therapist and employer, and not just for the person with aphasia themselves.

It is expected that further investigation of sub-factors may uncover other relevant clinical implications. For example, the protective factor ‘communicative connection’ suggests that the communicative interaction of the speech-language pathologist may be more beneficial to the client if a personal, meaningful connection is established. It implies that speech and language therapy may be more effective when provided by speech-language pathologists who have established a personal connection with the patient they are working with. Although determining the underlying mechanisms of the identified protective factors is beyond the scope of this study, further research may address these questions.

While it is recognized that this work is in the early stages of development, it is conceivable that the resilience framework could be used to identify individuals who are lacking protective factors, and are therefore at risk for not showing positive adaptation following stroke. This highlights the role of this framework as a tool for identifying those at risk for not demonstrating resilient behaviours, rather than as a prognostic indicator.

5.4 The Resilience Framework as a Complement to the WHO ICF Model of Functioning

The application of the construct of resilience to populations with aphasia is further motivated by the present movement in health sciences to consider patients from a more holistic perspective. Evidence of this movement is found in models such as the World Health Organization (WHO), International Classification of Functioning, Disability, and Health model (ICF model) (WHO 2001). The construct of resilience is compatible with the ICF model, in that both frameworks take into account the role of both internal and external factors, ultimately taking a strengths-based approach.

The ICF describes an individual's health and health-related states. The model consists of two basic parts: functioning and disability, and contextual factors. Each of these parts is further divided into two different components. The first encompasses body functions and structures, and activities and participation. The second encompasses environmental factors and personal factors (WHO, 2001). Key tenets of the ICF model include possibility for components to be presented in terms of positive or negative terms, and the multidimensional nature of components, insofar as they each encompass several domains (WHO, 2001). The model strives to facilitate a holistic perspective of an individual, moving away from an impairment-based medical model. When this model is employed to assess a patient's ability to participate, the inclusion of factors additional to a diagnosis and pathophysiological impairment permit a veridical representation of the patient.

The WHO ICF model and the resilience framework are similar in that both models take into account factors outside of the traditional medical model that affect impairment and they recognize a continuum from positive to negative with respect to the impact that the factors have on an individual. However, there are also differences between the WHO ICF model and the resilience framework, and as such the two can be used concurrently to obtain a holistic profile of a patient and that patient's process of recovery. In the WHO model, impairment is determined by limitation in participation. In the resilience model, impairment is determined by an individual's perception that they are not coping. The resilience model suggests that a patient may have demonstrated resilience, despite the presence of limitations on ability to participate in certain activities. Contrarily, an individual may not be doing okay, or have failed to show a resilient outcome, despite improvements in ability to participate. The WHO model is very useful for determining and evaluating treatment goals that maximize participation and minimize the impact of the impairment on daily life. The resilience framework gives a picture of how well an individual is coping with impairment, despite limitations to participation in certain activities. Although how well a person is able to maintain participation and how well they are coping may be related, the resilience framework may explain why certain patients demonstrate resilience and others do not, despite similar abilities to participate socially and in activities.

5.5 A Biological Framework for Resilience

Traditionally, vulnerability factors are psychosocial or behavioural factors that may be demonstrated by an individual within a specific situation. However, some researchers have proposed a biological conceptualization of the phenomena, expanding the operational definitions of vulnerability and protective factors to include biological factors (Curtis and Cicchetti, 2003; Cicchetti and Blender, 2006). According to Curtis and Cicchetti (2003), possible contributing biological factors to resilient outcomes include genetics, neuroendocrinology, and immunology, emotion, cognition, and neuroplasticity, all of which are subject to the influence of environment and experience. Similarly, Cicchetti and Blender (2006) posit a relationship between the process of neuroplasticity and resilience, citing evidence from the neural response to stress reactivity.

There is great value in investigating the role of biology in resilience. As noted by Luthar, Cicchetti and Becker (2000), there is a reciprocal interaction between biological and psychological factors, and therefore it is logical to posit that both of these factors are implicated in the process of resilience. Furthermore, as the body of research in the area of resilience grows it is vital that a multidisciplinary approach is integrated into the framework so that the potential of this paradigm is not limited (Luthar, Cicchetti and Becker, 2000).

5.6 Limits and Challenges of the Study

Given that the resilience framework had yet to be applied to people with aphasia following stroke, a qualitative methodological approach that fostered development of theory from the data was appropriate. By using qualitative methods to investigate the phenomenon of resilience in people with aphasia, rich information was obtained and data reduction at this early stage in the research process was minimized (Morse and Richards, 2002). However, there were some limitations to the methodological approach required to obtain the least restricted data possible.

Although inclusion criteria specified that all participants must have aphasia secondary to stroke, the diagnosis and medical history was not confirmed. Further, the recruitment letter stated that participants must feel that they have demonstrated resilience in the face of their aphasia. In many cases, it was a caregiver that called to confirm the person with aphasia’s interest in the study. This study did not control for who actually contributed to the self-selection. Therefore, it is not possible to determine in this study if the person with aphasia truly felt they had demonstrated resilience, or if the judgment was made by a caregiver or family member.

Because a ‘wide net’ was cast with regard to recruitment, participants ranged greatly in terms of communicative ability. The decision to include a variety of people with aphasia following stroke, as opposed to selecting participants that represent a certain aphasic profile was driven by a desire to avoid limiting the variability within this population from which these factors were identified. One implication of this decision was that participants relied on their caregivers to varying degrees in order to communicate responses to interview questions and share their experiences. Given this, it was not possible to differentiate between caregiver responses that express their own opinion, and caregiver responses intended to convey thoughts and ideas that they believe represent what the person with aphasia would say if they were able.

5.7 Suggestions for Future Research

This study is a preliminary investigation of the application of the resilience framework to individuals with aphasia. This work must be expanded and refined to determine the protective and vulnerability factors applicable to this population. In this study, there were a number of ‘emerging’ protective factors that were not formalized as codes as they did not appear frequently enough to qualify as such. However, they are relevant in that they represent the views of the participants of this study, and are related to sub-factors that were identified, and are worthy of further investigation.

One such ‘emerging protective factor’ was ‘interactions with individuals who have had similar experiences.’ This refers to interactions between people who have aphasia following stroke, as well as interactions between loved ones of people with aphasia following stroke.

Information exchange, for example regarding available rehabilitation services, is involved in this interaction. Although this code did not appear in enough of the transcripts to constitute a sub-factor, in four out of nine interviews participants spoke about the importance of interactions with other people who have had similar experiences in coping with aphasia. In two cases, interaction with individuals who have had similar experiences occurred in a counselling setting. One participant described an experience wherein *"they had, again people, folks like her…who would talk to us about, and then understanding the whole thing, this stroke business…and the recovery process, so yeah it's connecting with other people."* Another participant stated the following:

> *It's easier for anyone, her included, to sit with this people that have had the same sort of problem, or the same experiences…and not feel uncomfortable with how you try to communicate with them…and you know that, that person is struggling with the same communication skills as you are and then you adapt much better. Plus I think, the some of the ones that have different skills, can teach the other ones.*

Another 'emerging protective factor' was 'having an advocate'. In two of the nine interviews participants felt that having an advocate was important for coping with aphasia. Within the context of this study only spouses were cited as filling an advocate role, although it is possible that that individuals such as a spouse, friend, caregiver, or therapist could fill the role of advocate for a person with aphasia following stroke. Advocacy pertains to active support of another individual, through actions such as facilitating access to services and fostering the ability of that individual to participate socially. When asked about what advice would be useful for someone experiencing aphasia, one participant responded, *"Yeah, I'd say umm I'd say get an advocate."* Another participant felt similarly, stating that, *"I think with aphasia you can't get through it without, without an advocate…you know, someone with your best interest in mind."*

Using maintained skills, which refers to skills that the participant possessed before the stroke and aphasia, did not qualify as a sub-factor; however, participants talked about using skills that were maintained in spite of the stroke and aphasia in four out of nine interviews. One participant stated that, *"he [the individual with aphasia] still can cook…he could also still do BBQ…yeah, and yeah cook his breakfast and everything on the stove."* Another participant discussed going on a canoe trip. Another variation of using maintained skills is volunteering. Volunteering refers to any unpaid work performed by the person with aphasia in which their actions benefited others. One participant described an experience wherein *"to get out of the house and start to interact with the community she [the participant with aphasia] decided to become a volunteer at a thrift store…so she went and sorted clothes and stuff at the thrift shop."*

In four out of nine interviews, 'strategies to compensate for speech challenges' was discussed. This includes strategies that facilitate successful communication, such as using writing instead of spoken language, and also strategies that may assist the person with aphasia to cope with the communication difficulties, such as taking a break or taking a deep breath. With regard to the use of compensatory strategies, one participant said that, *"it's [the use of compensatory strategies] something that we're trying to work to, minimize the strength of the aphasia I guess."*

Counselling was another 'emerging protective factor' that was identified. This sub-factor refers to the many forms of counselling that caregivers or people with aphasia may receive. In two of the interviews, participants highlighted the importance of services that addressed coping issues, such as managing caregiver burden or adjusting to changing roles. One participant described the following experience:

> *You know, some people, you know you ask questions of who's gone ahead of you three years and four years and they say to you... this could happen, could happen… doesn't mean it will happen. So, that was very helpful. Anything at all. Anything that will...say listen, here's a little flag for that. There's a possibility that flag might come up. It might not…and so then you're aware of it.*

Another participant informed the researcher about a stroke survivors support group that they attended, stating that, "*I think it [the stroke survivor support group] was one of the most beneficial things that happened to us, because when you get out of hospital you know nothing. You're just out*".

In addition to investigating other possible protective factors associated with resilience, future research should consider other factors that address the challenges of doing qualitative research with a population with communication impairment. From this preliminary research, some suggestions for screening in future studies of this nature have come to light. In an effort to ensure that it is the person with aphasia who feels that they have demonstrated resilience, rather than a caregiver, one aspect of screening could have the person with aphasia give a definition of resilience before answering whether or not they feel they have shown positive adaptation. Further screening could involve an expressive and receptive language screening test to provide the researcher with a better idea of the meaningfulness of responses.

In future studies, the information from initial studies could be used to create other forms of interview questions, such as multiple choice, which could be answered by people with aphasia who have a variety of communicative abilities. This study chose to use open ended questions as there were no previous indications of what factors would be identified, and therefore any multiple choice questions would be biased by the researcher's hypotheses. In studies with fewer open-ended questions, there may be less need for caregiver support for people with aphasia to participate in the interview. This would facilitate separate analysis of responses from people with aphasia and caregivers.

Once protective factors implicated in the process of resilience in this population have been identified, further research can focus on the mechanism underlying these factors. As discussed previously, the first step in applying the resilience framework to people with aphasia following stroke lies in identifying protective and vulnerability factors to provide a foundation for research in this area. This study focused specifically on the identification of protective factors, but further research may investigate factors associated with negative outcomes, or lack of adaptation following stroke and aphasia. After these factors have been established, future research could investigate the underlying mechanisms in an effort to understand how these factors work. Investigating factors associated with the demonstration of resilient outcomes from the perspective of other healthcare professionals, such as occupational therapists, physical therapists, or nurses, could also enrich the present data in this area.

The resilience framework has potential for application to a variety of populations in health sciences. For example, the framework could be applied to people with communication impairment from other etiologies, such as degenerative disease or traumatic brain injury. This hypothesis is supported by the correspondence between factors identified in this study, in the context of people with aphasia following stroke, and factors identified in previous literature with related populations, such as people with Parkinson or Alzheimer disease.

5.8 Summary

The factors associated with resilience identified in this study correspond to factors identified previously in the literature. There are clinical implications to the use of the resilience framework, including employing the concept of multiplicity of support in patient care and guiding interactions between patients and clinicians to maximize potential for positive adaptation despite aphasia., It is anticipated, with further research support, that the framework could eventually be used to identify individuals at risk for not demonstrating resilient outcomes in the face of aphasia. This framework is compatible with the WHO-ICF model of functioning, and the two may be used together to provide holistic patient descriptions.

This study identified three major factors associated with resilience in aphasia: support networks, person-first, and thinking positively. These factors represent the point of view of people with aphasia and their caregivers and family members. This research provides a starting point for future research in applying the resilience framework in health sciences, and specifically to populations with aphasia.

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Appendix A: Interview Questions

This study is about people who are successful or are doing okay after they've had a stroke and experienced a communication difficulty (aphasia).

1. What made you sign up for this study? Why are you doing okay?
2. Tell me about your experience after your stroke when you were having difficulties with communication (aphasia).
    - What have been the struggles that you experienced?
        - At home
            - With your family?
            - With friends?
        - Tell me what kinds of things you did outside of home
            - What struggles did you experience in those situations?
            - Did you work after your stroke?
                - What struggles did you experience there?
3. Tell me why you were successful or did okay after your stroke. Can you tell me what made things better for you?
    - What things made you okay at home?
    - What things made you okay at work (or whatever the person did outside of the home)?
4. Are there things about you that you think make you successful? Tell me about that/them.
5. Are there things about your family and friends that help you be okay? Tell me about that/them.
6. Are there things in your community or in the city that helped you be okay? Tell me about that/them.

7. If there was something you could have changed about your experience after your stroke, something that would have helped you be more successful, what would that be?
8. What advice would you give to someone else with a similar experience, having a stroke and communication difficulties?

Appendix B: Recruitment Letter

You are being asked to consider taking part in a research study called: "Resilience in Aphasia- Perspectives of Stroke Survivors and their Families." **Please read this letter carefully, and feel free to ask any questions you might have.** Questions can be addressed to*:*

Dr. Teresa Paslawski
Department of Speech Pathology and Audiology
University of Alberta
Phone: (780) 248-1218

What is this study about?

This research project is interested in identifying factors that help people to adapt successfully following stroke resulting in aphasia.

Am I eligible to be in this study?

We are interested in interviewing people who believe they have successfully adapted, following stroke and resulting aphasia. This does not mean that the skills that were affected because of the stroke have fully recovered. Rather, we believe that successful recovery is simply 'doing well' despite the effects of the stroke.

How will I be involved?

I am asking to interview you because you have experienced a stroke resulting in communication difficulties. There are no right or wrong answers to any of the questions that will be asked. The researcher wants to know what you think and what you experienced. The interview will last from 1 to 1 1/2 hours, and will take place in your home, if you are comfortable with having a University of Alberta researcher visit you. The researcher will come to your home at a prearranged time that suits you best. You are welcome to have any family members or caregivers present at the interview and to participate in the interview if they wish.

What if I am not sure whether or not I would like to participate?

You are welcome to contact Dr. Teresa Paslawski at (780) 248-1218 if you are not sure that you would like to participate, but want to ask more questions. By calling, you are in no way obligated to participate, and no information about you will be kept if you choose not to participate in the study. If you do choose to participate, you don't have to answer any questions you are uncomfortable with. You can stop participating in this study at any time for any reason, and you don't have to give a reason. Choosing to leave the study will not affect your access to, or continuation of, services provided by public agencies such as Universities, hospitals, social services, schools, and therapists. If you choose to withdraw, your information will be deleted from the study and destroyed.

If you are interested in participating, or would like to ask any questions about this study, please contact

Dr. Teresa Paslawski
Department of Speech Pathology and Audiology
University of Alberta
(780) 248-1218

Thank you for taking the time to read this letter and consider participating in this study.

Appendix C: Consent Form A

You are being asked to be a part of a research study called: “Resilience in Aphasia- Perspectives of Stroke Survivors and their Families.” **Please read this form carefully, and feel free to ask any questions you might have.**

What is this study about?

The researcher is asking to interview you because you have experienced a stroke resulting in communication difficulties. I would like to find out about your experiences related to your communication difficulties after your stroke and your thoughts about what has helped you be successful.

There are no right or wrong answers to any of the questions. The researcher wants to know what you think and what you experienced. The interview will last from 1 to 1 1/2 hours.

Potential Benefits:

I believe what you have to say about your experiences is important; however, there are no direct benefits to you in participating in this study. What you have to say could help others learn about what is helpful for people with similar experiences as you. The information that comes out of the interview will be put together with the information from others who also take part in this study and a report will be written that discusses this information. This report may help other people learn about what you have experienced.

Parts of this report will be written up by students who are in a Master’s program in Speech Language Pathology at the University of Alberta. The information may also be presented at conferences and may be published in journals.

Risk or Deception:

Participants will not be deceived in the course of this study. Risks due to the limits in the ability to guarantee privacy of participants drawn from a small population is addressed in the next section.

Your Privacy:

This interview will be recorded. Only Dr. Paslawski, the principal investigator in this study, and the interviewer will have access to the tape. Once the words from the interview tape have been written out into a transcript (a paper copy of your words) the tape will be destroyed. I cannot absolutely ensure that no one will know that you participated in this study. However, I will do many things to protect your privacy. Your name will never be used in the report or in the paper copy of your words. I will make up a name to go along with what you have said for the report to protect your privacy. Any information that would identify you, such as dates, addresses and names of people who may be mentioned in the interview, will be changed.

All of the forms for this study and the transcripts will be kept in a private, secure place. It will all be in locked file cabinets, in a locked office (for paper files such as consent forms and interview transcripts). Any information you give me will only be available to research staff. Any information that I will keep on the computer will be accessed by password only; computers are kept in locked offices. None of the electronic information will have your name recorded. Backup copies of the information will be kept by the researchers and contained in a locked file drawer in a locked office. When the study is **finished the paper copy of your words, which will not contain your name, will be kept at the University of Alberta at the offices of Dr. Teresa Paslawski for 5 years and then destroyed.**

Right to Withdraw:

As a person who is agreeing to be part of this study, you can change your mind at any time. If there are some questions you don’t want to answer you do not have to. You can stop participating in this study at any time for any reason, and you don’t have to give a reason. Choosing to leave the study will not affect your access to, or continuation of, services provided by public agencies such as Universities, hospitals, social services, schools, and therapists. If you choose to withdraw, your information will be deleted from the study and destroyed.

Although the information that you share will be published and presented publicly, the information will be reported in a way that protects your identity, so that it will not be possible to figure out who you are. The consent forms will be stored separately from the materials used, so that it will not be possible to associate a name with any given set of responses. Please do not put your name or other identifying information on the materials used.

Questions:

If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researcher, Dr. Teresa Paslawski at (780) 248-1218, if you have questions at a later time.

Consent to Participate:

I have read this form and I understand what it means to be part of this study. Any questions that I had have been answered. I give my consent to be a participant in this study described above, with the understanding that I may change my mind to be part of the study at any time, without any consequence to me. **A copy of this consent form has been given to me for my records.**

____

(initial please)

Feedback on Results

We are happy to share the results with you. When the report is finished we will send you a summary that explains what we learned from this study.

Ethics Approval

This study has been approved by the Heath Research Ethics Board at the University of Alberta on ________________. Any questions can be directed to the researcher, Dr Teresa Paslawski, or to the Health Research Ethics Board (780) 492-0302. You may call the Ethics Review Board office collect if you need to make a long distance call.

Researcher:

Dr. Teresa Paslawski
Department of Speech Pathology and Audiology
University of Alberta
Phone: (780) 248-1218

I agree to participate in the study as outlined above. I understand that I can withdraw from the study at any time without giving reasons and without any consequences.

______________________________	______________
(Signature of Participant)	**(Date)**
______________________________	______________
(Signature of Researcher or Interviewer)	**(Date)**

____
(Name of Interviewer)

Appendix D: Consent Form B

You are being asked to be a part of a research study called: "Resilience in Aphasia- Perspectives of Stroke Survivors and their Families." **Please read this form carefully, and feel free to ask any questions you might have.**

What is this study about?

I am asking to interview you because someone related to you has had a stroke resulting in communication difficulties. I would like to find out about your experiences related to your communication difficulties after your stroke and your thoughts about what has helped you be successful.

There are no right or wrong answers to any of the questions. The researcher wants to know what you think and what you experienced. The interview will last from 1 to 1 1/2 hours.

Potential Benefits:

I believe what you have to say about your experiences is important; however, there are no direct benefits to you in participating in this study. What you have to say could help others learn about what is helpful for people with similar experiences as you. The information that comes out of the interview will be put together with the information from others who also take part in this study and a report will be written that discusses this information. This report may help other people learn about what you have experienced.

Parts of this report will be written up by students who are in a Master's program in Speech Language Pathology at the University of Alberta. The information may also be presented at conferences and may be published in journals.

Risk or Deception:

Participants will not be deceived in the course of this study. Risks due to the limits in the ability to guarantee privacy of participants drawn from a small population is addressed in the next section.

Your Privacy

This interview will be recorded. Only Dr. Paslawski, the principal investigator in this study and the interviewer will have access to the tape. Once the words from the interview tape have been written out into a transcript (a paper copy of your words) the tape will be destroyed. I cannot absolutely ensure that no one will know that you participated in this study, however, I will do many things to protect your privacy. Your name will never be used in the report or in the paper copy of your words. I will make up a name to go along with what you have said for the report to protect your privacy. Any information that would identify you, such as dates, addresses and names of people who may be mentioned in the interview, will be changed.

All of the forms for this study and the transcripts will be kept in a private, secure place. It will all be in locked file cabinets, in a locked office (for paper files such as consent forms and interview transcripts). Any information you give me will only be available to research staff. Any information that I will keep on the computer will be accessed by password only; computers are kept in locked offices. None of the electronic information will have your name recorded. Backup copies of the information will be kept by the researchers and contained in a locked file drawer in a locked office. When the study is finished **the paper copy of your words, which will not contain your name, will be kept at the University of Alberta at the offices of Dr. Teresa Paslawski.**

Right to Withdraw:

As a person who is agreeing to be part of this study, you can change your mind at any time. If there are some questions you don't want to answer you do not have to. You can stop participating in this study at any time for any reason, and you don't have to give a reason. Choosing to leave the study will not affect your access to, or continuation of, services provided by public agencies such as Universities, hospitals, social services, schools, and therapists. If you choose to withdraw, your information will be deleted from the study and destroyed.

Although the information that you share will be published and presented publicly, the information will be reported in a way that protects your identity, so that it will not be possible to figure out who you are. The consent forms will be stored separately from the materials used, so that it will not be possible to associate a name with any given set of responses. Please do not put your name or other identifying information on the materials used.

Questions:

If you have any questions concerning the study, please feel free to ask at any point; you are also free to contact the researcher, Dr. Teresa Paslawski at (780) 248-1218 if you have questions at a later time.

Consent to Participate:

I have read this form and I understand what it means to be part of this study. Any questions that I had have been answered. I give my consent to be a participant in this study described above, with the understanding that I may change my mind to be part of the study at any time, without any consequence to me. **A copy of this consent form has been given to me for my records.**

____

(initial please)

Feedback on Results

We are happy to share the results with you. When the report is finished we will send you a summary that explains what we learned from this study.

Ethics Approval

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Researcher:

Dr. Teresa Paslawski
Department of Speech Pathology and Audiology
University of Alberta
Phone: (780) 248-1218

I agree to participate in the study as outlined above. I understand that I can withdraw from the study at any time without giving reasons and without any consequences.

________________________________	________________
(Signature of Participant)	**(Date)**
________________________________	________________
(Signature of Researcher or Interviewer)	**(Date)**

____

(Name of Interviewer)