

HEALTHCARE PROFESSIONALS' KNOWLEDGE OF APHASIA:
CONVEYING PROGNOSIS FOR LANGUAGE RECOVERY AND LIFE
PARTICIPATION TO PATIENTS

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Abstract

KAITLYN THERESA MORTIMER: Healthcare professionals' knowledge of aphasia:
Conveying prognosis for language recovery and life participation to patients
(Under the direction of Katarina Haley, Ph.D.)

Aphasia is an acquired disorder that affects all language modalities, but does not affect intelligence. Recovery from aphasia is variable and may continue for years after onset. Life participation is possible for people with aphasia and effective strategies can be used to facilitate communication. The purpose of this study was to understand respondents' knowledge of aphasia, of prognosis for recovery and life participation, and of strategies used for communicating. Respondents reported level of comfort felt when answering patients' questions about aphasia. Information was obtained through a questionnaire administered to resident physicians in neurology, occupational therapy students, and physical therapy students. Results indicated respondents feel somewhat comfortable answering patients' questions about aphasia. Respondents had decreased understanding of language modalities affected by aphasia, language recovery time, and life participation outcomes; but had adequate knowledge of strategies used to facilitate communication. Education is recommended to increase respondents' overall knowledge of aphasia in order to improve interactions with patients with aphasia.

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Table of Contents

List of Tables.....	vi
List of Figures.....	vii
Chapter I – Introduction.....	1
Chapter II – Review of the Literature.....	4
Aphasia.....	4
Cortical Aphasia Subtypes.....	5
Fluent Aphasia Types.....	5
Nonfluent Aphasia Types.....	6
Recovery from Aphasia Following Stroke.....	7
The Spontaneous Recovery Period.....	8
Factors Predicting Recovery from Aphasia.....	9
Chronic Recovery from Aphasia.....	11
Life Participation with Aphasia.....	12
Lack of Knowledge of Aphasia.....	15
General Public.....	15
Medical Field.....	16
Facilitated Communication for People with Aphasia.....	18
Healthcare Professionals and Aphasia.....	20
Medical Residents and Aphasia.....	21
Rehabilitation Students and Aphasia.....	22
Purpose.....	23

Chapter III – Methodology.....	25
Questionnaire.....	25
Questionnaire Administration.....	27
Coding and Reliability.....	27
Chapter IV – Results.....	29
Respondents.....	29
Data Analysis.....	30
Questionnaire Questions.....	30
Background and Demographic Information.....	39
Chapter V – Discussion.....	42
Research Questions.....	42
Background and Demographic Information.....	55
Limitations.....	56
Implications for Practice and Future Research.....	59
Conclusion.....	60
Appendix A – Tables.....	62
Appendix B – Figures.....	66
Appendix C – Questionnaires.....	73
References.....	77

List of Tables

Table 1.1 Classification of Cortical Aphasia Subtypes.....62

Table 5.1 Demographic and Background Information of Respondents.....63

Table 5.2 Respondents' Rationale for Life Participation.....64

Table 5.3 Respondent Comparisons by Time Spent Collecting a History.....64

Table 5.4 Respondent Comparisons by Frequency of Seeing Patients
with Chronic Aphasia.....64

Table 5.5 Respondent Comparisons by Personal Experience with Aphasia65

List of Figures

Figure 5.1 Respondents who Refer Directly to the PWA to Gather
Medical and Social History.....66

Figure 5.2 Communication Strategies Suggested for Facilitating
Communication with PWA.....67

Figure 5.3 Respondents’ Definition of Aphasia.....68

Figure 5.4 Respondents’ Responses to Life Participation with Aphasia69

Figure 5.5 Respondents’ Suggested Time for Language Recovery.....69

Figure 5.6 Respondents’ Level of Comfort Answering Questions about Aphasia.....70

Figure 5.7 Respondents’ Explanations for Being Not at All Comfortable
Explaining Aphasia to Patients and Families.....70

Figure 5.8 Respondents’ Explanations for Being Somewhat Comfortable
Explaining Aphasia to Patients and Families.....71

Figure 5.9 Respondents’ Explanations for Being Very Comfortable
Explaining Aphasia to Patients and Families72

Chapter I

Introduction

Aphasia is a language disorder resulting from damage to the language dominant hemisphere of the brain. Subtypes of aphasia are characterized by speech fluency, repetition ability, and auditory comprehension (Damasio, 2008; Helm-Estabrooks & Albert, 2004). Recovery of aphasia is variable with factors such as initial aphasia severity believed to be predictive of outcome (Bakheit, Shaw, Carrington, & Griffiths, 2007; Enderby, Wood, Wade, & Hewer, 1987; Kertesz & McCabe, 1977; Laska, Hellblom, Murray, Kahan, & Von Arbin, 2001; Lazar et al., 2010; Pederson, Jorgensen, Nakayama, Raaschou, & Olsen, 1995; Pederson, Vinter, & Olsen, 2003). Regardless of the factors influencing prognosis for language recovery, the process itself is ongoing and may continue for years after the initial stroke (Naesar et al., 1998; Smania et al., 2010).

The initial recovery period, referred to as the spontaneous recovery period, is characterized by neural reorganization, decreased edema, and restoration of blood flow within the brain (Hillis & Heidler, 2002; Keefe, 1995; Olsen, Larsen, Herning, Skriver, & Lassen, 1983). The spontaneous recovery period is reported to last anywhere from one month to one year post-stroke (Bakheit et al., 2007; Kertesz & McCabe, 1977; Laska et al., 2001; Lazar et al., 2010; Pederson et al., 1995). Therapeutic interventions can help support natural restoration of function and eventually promote compensation strategies for when spontaneous recovery has ceased (Code, 2001). After this period, recovery slows but does not end.

Longitudinal studies on aphasia recovery show that gains are made many years after stroke (Naesar et al., 1998; Smania et al., 2010).

Neurologists and other healthcare professionals may only be exposed to the initial, negative impact aphasia has upon patients and their families. They often do not work with the patient long enough to see that people living with chronic aphasia are able to go on to lead functional, productive lives and are fully capable of life participation. There may also be lack of training about aphasia for many medical professionals, which may lead to incorrect information being given to patients. Misinformation about aphasia can lead to an incorrect prognosis for language recovery, which in turn can have negative repercussions. These negative repercussions include a decreased sense of hope as well as potentially increased feelings of depression (Cross, 2010; Gainotti, Antonucci, Marra, & Paolucci, 2001).

In addition to having a decreased knowledge of aphasia and prognosis for recovery, healthcare professionals may have a lack of understanding of appropriate and helpful strategies to use when communicating with patients with aphasia (Legg, Young, & Bryer, 2005). Without effective strategies to facilitate communication, misunderstandings may occur causing the person with aphasia (PWA) to have decreased access to medical information and decreased understanding of their diagnosis (Knight, Worrall, & Rose, 2006; Welsh, Abbanat, & Szabo, 2009).

The purpose of this study was to understand the current knowledge of aphasia and use of communication strategies among neurology residents, physical therapy (PT) students, and occupational therapy (OT) students. In addition, this study also sought to elicit the level of comfort these healthcare professionals feel answering patients' questions about aphasia. By having a comprehensive understanding of this knowledge, recommendations for education

can be made. This education can help to ensure that complete and accurate information is given to patients and their families.

Chapter II

Review of the Literature

Aphasia

The left cerebral hemisphere of the brain is considered to be language dominant in the majority of people. Evidence shows that more than 95% of people who are right-handed and approximately 70% of people who are left-handed have left hemispheric dominance for language (Helm-Estabrooks & Albert, 2004). Within the left hemisphere is the 'zone of language,' which is primarily vascularized by the middle cerebral artery. This language zone includes the Sylvian fissure and surrounding areas in the frontal, parietal, and temporal lobes. Some of the specific areas included within this zone are Broca's and Wernicke's area, which are connected by an underlying white matter tract known as the superior longitudinal fasciculus. Additional areas within the zone of language include the angular and supramarginal gyri. All of these areas work together by way of neural networks and each contribute to language function.

Focal lesions to the zone of language are most often caused by stroke and result in a disorder known as aphasia. Aphasia is defined as an acquired communication disorder characterized by an impairment of language modalities including speaking, comprehending, reading, and writing. Aphasia is not the result of a sensory or motor deficit, a general intellectual deficit, confusion, or a psychiatric disorder (Hallowell & Chapey, 2008). Difficulty with speech and auditory comprehension may be more salient than impairments

with reading and writing; however most individuals with aphasia will have some impairment of comprehension and production of written words (Beeson & Henry, 2008). Deficits associated with reading and writing are referred to as alexia and agraphia, respectively (Hallowell & Chapey, 2008).

Aphasia can be cortical or subcortical in nature. Since less is known about subcortical aphasia (Helm-Estabrooks & Albert, 2004), this review will focus on the cortical aphasia subtypes.

Cortical Aphasia Subtypes

Aphasia classification is not based on lesion localization, but by the specific language functions impacted by that lesion. Differential diagnosis of the aphasia subtypes can be achieved via formal testing batteries and by examining three defining domains: spoken language fluency, auditory comprehension, and repetition ability (Damasio, 2008; Helm-Estabrooks & Albert, 2004). The terms ‘receptive’ and ‘expressive’ aphasia are not accurate categorizations of aphasia subtypes, because it is rare that a patient will present with exclusively expressive or receptive deficits. Aphasia is more appropriately separated into fluent and nonfluent types, which characterize the type of verbal output. The aphasia subtypes are identified below with their comprehension, repetition, and speech characteristics explained. See table 1.1 in appendix A for categorization of subtypes based on their defining characteristics.

Fluent Aphasia Types

Wernicke’s aphasia is a fluent type of aphasia resulting from damage to the posterior portion of the superior temporal gyrus. It is characterized by poor auditory comprehension and poor repetition ability. Secondary to poor auditory comprehension there is a lack of self-

awareness with the errors made in spoken language. Speech is prosodic and fluid, but filled with paraphasias, jargon, empty words and phrases, as well as perseverations. Press of speech may be seen as well, where a patient speaks rapidly and with unnecessary words or sounds when conveying a point.

Conduction aphasia is a fluent aphasia type resulting from damage to the underlying white matter pathway between Broca's and Wernicke's areas and/or the supramarginal gyrus. Auditory comprehension is essentially normal, but repetition ability is poor. The speech output includes abnormal pauses, paraphasias, and circumlocution. Individuals with conduction aphasia recognize errors in their speech and attempt to self-correct.

Anomic aphasia is a fluent aphasia often occurring from lesions to the angular gyrus or middle temporal gyrus. Characteristics include good auditory comprehension and spared repetition ability. The hallmark of speech is word-finding difficulties as well as some circumlocutions and semantic paraphasias.

Transcortical sensory aphasia is a fluent type of aphasia caused by damage within the parietal and temporal lobes but sparing Wernicke's area. Auditory comprehension is poor, however ability to repeat is surprisingly intact. Characteristically, the speech output includes filler words such as 'things,' semantic paraphasias, and perseverations. Speech may appear empty secondary to anomia and to lack of meaningful content.

Nonfluent Aphasia Types

Broca's aphasia is a nonfluent aphasia resulting from damage to areas surrounding and including Broca's area within the inferior gyrus of the frontal lobe. Auditory comprehension remains intact, but there is poor repetition ability. Speech is characterized by

short phrase length, agrammatisms, anomia, phonemic paraphasia, and articulation difficulties. Speech production is slow with prolongations and attempts to self-correct.

Transcortical motor aphasia is a nonfluent aphasia caused by a lesion within the superior and middle frontal gyri interrupting the pathway between the supplementary motor cortex and Broca's area. Auditory comprehension and the ability to repeat are both relatively spared. Speech characteristics include impaired initiation of verbal output, short phrase length, and anomia.

Global aphasia is a nonfluent aphasia resulting from extensive damage to all parts of the zone of language resulting in severe language deficits across all modalities. Auditory comprehension and repetition ability are severely compromised. Speech output is limited and may be restricted to a few stereotyped utterances of words, syllables, or phonemes often spoken in a prosodic tone.

Mixed transcortical aphasia is nonfluent. Auditory comprehension is poor, but repetition ability is spared. Limited meaningful speech output is characterized by severe anomia, stereotypical utterances, phonemic paraphasias, and perseverations.

Recovery from Aphasia Following Stroke

Research has only recently begun to investigate specific language outcomes following stroke; studies researching motor recovery or quality of life are far more common. Factors characterizing aphasia recovery are restoration and compensation, which each have underlying mechanisms of reorganization at the neural, cognitive, and behavioral levels (Code, 2001). Neural reorganization relates to the principles identified with spontaneous recovery, cognitive reorganization includes processes and pathways that underlie language

functions, and behavioral processes relate closely to the psychosocial impacts of aphasia (Code, 2001).

The Spontaneous Recovery Period

Oxygen and glucose are brought to the various regions of the brain by way of the bloodstream. During a stroke blood flow within the brain is interrupted, subsequently causing changes in brain tissue and cell death (Keefe, 1995). Primary damage resulting from a stroke can occur anywhere from hours to days post onset before becoming static. Secondary processes, as a consequence of primary damage, continue to evolve over the course of recovery. These secondary processes include transneuronal degeneration, a deterioration of areas resulting from loss of neuronal input or output from the damaged area; denervation supersensitivity, a hypersensitivity of neurons resulting from a loss of input from the affected area; and diaschisis, a loss of function in areas related to but far from the infarct (Keefe, 1995).

As the brain begins to heal, cortical plasticity can be seen by the reorganization of structural and functional relationships (Hillis & Heidler, 2002; Keefe, 1995). Other factors involved in the healing process include reduction or resolution of edema, resolution of diaschisis (Hillis & Heidler, 2002), as well as collateral sprouting, where axons create new connections on neurons that have lost their input from the damaged area (Keefe, 1995). A final factor in the healing process includes restoration of blood flow to the ischemic penumbra. The ischemic penumbra is the area around the infarct that is viable but not functioning properly because of decreased or inadequate perfusion (Olsen et al., 1983). The evolution of secondary processes as well as the reorganization of structural and functional relationships occurs over a longer period of time than the initial damage does (Keefe, 1995).

Because of the ongoing evolution of these processes, the spontaneous recovery period has been noted to last anywhere from one month to one year post stroke and the greatest gains in language recovery are observed during this time (Bakheit et al., 2007; Kertesz & McCabe, 1977; Laska et al., 2001; Lazar et al., 2010; Pederson et al., 1995).

Language recovery does not cease after a year, but instead slows and smaller gains are seen. During this ongoing phase of recovery, the language gains related to neural healing have occurred and the ongoing improvements reflect of function (Cloutman, Newhart, Davis, Heidler-Gary, & Hillis, 2009). Early speech and language treatment concentrates on the restoration of function, whereas treatment during the chronic stages is often focused on compensation (Code, 2001).

Factors Predicting Recovery from Aphasia

Many research studies have examined factors to help explain and predict prognosis for aphasia recovery following stroke. Researchers agree that initial severity of aphasia during the acute stages of stroke is a predictor of recovery in the chronic stages. Those with mild aphasia at onset will recover more fully than those with more severe aphasia (Bakheit et al., 2007; Enderby, et al., 1987; Kertesz & McCabe, 1977; Laska et al., 2001; Lazar et al., 2010; Pederson et al., 1995; Pederson et al., 2003).

Research on age predicting outcomes has demonstrated great variability. Some researchers concluded that a younger age would predict better outcomes (Bakheit et al., 2007; Kertesz & McCabe, 1977; Laska et al., 2001), whereas others found that age cannot significantly predict outcomes (Cloutman et al., 2009; Pederson et al., 1995; Pederson et al., 2003). Research has also shown that gender does not predict prognosis (Cloutman et al., 2009; Kertesk & McCabe, 1977; Pederson et al., 1995; Pederson et al., 2003). Other factors

that may influence recovery in aphasia, but are not conclusive predictors of outcome, include insight and awareness of deficits, as well as size and site of lesion (Bakheit et al., 2007).

Prediction of outcomes based upon initial aphasia type also varies amongst researchers. Kertesz and McCabe (1977) found that people with Broca's or conduction aphasia show the highest recovery rates and people with global aphasia have a poor prognosis. These researchers also concluded that more than half of study participants with anomic, conduction, or transcortical aphasias made complete recovery (Kertesz & McCabe, 1977). A study completed by Bakheit et al. (2007) showed that people with Broca's aphasia displayed greater improvement on standardized aphasia tests, as compared to people with Wernicke's and global aphasia. In contrast, Laska and colleagues (2001) reported that it was people with Wernicke's or global aphasia that made the most improvement, although these participants never improved to the same level those with milder types of aphasia did.

One factor of recovery that is agreed upon is that aphasia type evolves during recovery (Bakheit et al., 2007; Kertesz & McCabe, 1977; Laska et al., 2001, Lazar et al., 2010; Pederson et al., 2003). Aphasia type usually changes from severe to mild and becomes more fluent (Bakheit et al., 2007; Kertesz & McCabe, 1977; Pederson et al., 2003). If the change is ever seen in reverse it is typically indicative of a new stroke or other brain damage (Kertesz & McCabe, 1977). Wernicke's aphasia is the most likely type to evolve during recovery (Laska et al., 2001) and most aphasia types evolve into anomic aphasia (Bakheit et al., 2007; Kertesz & McCabe, 1977). Based on the above findings, researchers claim that it is necessary to exercise caution when giving prognosis in the acute stages based on initial aphasia type alone, due to the variability of recovery patterns and evolution of aphasia types (Kertesz & McCabe, 1977; Pederson et al., 2003).

Chronic Recovery from Aphasia

Longitudinal studies are important to understand chronic aphasia and language outcomes past the first few years following stroke. Formal speech and language therapy typically does not continue for years post stroke. PWA can continue to utilize informal resources for therapeutic purposes such as aphasia groups or community outreach and awareness projects for ongoing language stimulation (Chapey et al., 2008).

Naeser and colleagues followed a group of 12 people with various aphasia types from 7-16 months (time one) post stroke and again at 5-12 years (time two) post stroke. At both time one and time two the PWA participated in language testing and a CT scan. At time two there was significant improvement in naming scores as well as significant increase in phrase length for those with initial non-fluent speech. Also discovered was a slight increase in lesion size in nine of the participants with no indication of a second stroke or new neurological insult. The increase in language scores, despite the expanding borders of the initial lesion, indicate that brain reorganization is present in long-term aphasia recovery (Naeser et al., 1998).

To this author's knowledge, no group studies have examined long-term recovery with aphasia longitudinally. A study conducted by Smania and colleagues (2010) followed a man with severe global aphasia for 25 years post stroke. This man attended speech therapy for the first two years of his recovery period, initially for five times per week and eventually decreasing to three times per week. In the first year after stroke he made gains in the areas of verbal comprehension and word repetition. In the first 1-3 years post stroke, naming and reading skills emerged. From year three through year 25 he was found to have improvement in spontaneous speech and in previously emerging language functions. This PWA's long-

term progress, in the years after formal speech therapy, was attributed to motivation, community aphasia groups, and family support (Smania et al., 2010).

More studies are needed on long-term outcomes in aphasia, but individuals with aphasia as well as their clinicians report that such recovery does occur. Personal accounts from people with aphasia, such as the ones examined by Hinckley (2006) attest to the ongoing recovery process. These personal accounts also speak to living successfully with aphasia and are discussed further in the next section.

Life Participation with Aphasia

Research utilizing formal testing to measure improvements in language functions rely on changes in overall score, percentile, or aphasia quotient on a test battery to describe recovery, which is not sensitive to what recovery may actually mean to an individual (Code, 2001). In addition to defining aphasia recovery in terms of language gains it is important to view recovery in terms of life participation.

PWA must readjust to new circumstances and find ways to reintegrate into family, social, and vocational situations, which is not an easy task. A review of the literature on life participation for PWA details both positive and negative aspects of vocational opportunities, social participation, and self-image. Many PWA face a loss of identity characterized by their decreased physical, cognitive, and emotional abilities (Fraas & Calvert, 2009). However, despite the many difficulties faced it is possible for PWA to go on to live meaningful lives (Hinckley, 2002).

Hinckley (2006) sought to answer the question “what does it take to live successfully with aphasia?” as defined by PWA. She searched the literature for personal narratives that had already been published, were nationally available, and were authored or co-authored by a

PWA. The accounts were then described by their content and purpose and evaluated for implicit or explicit descriptions or suggestions about living successfully. The stories that addressed living successfully were further coded to determine common themes. The four main themes that Hinckley identified were: social support, renegotiating self-identity, setting new future goals, and taking responsibility for one's own continued improvement (Hinckley, 2006). These themes are explained further in the next paragraph.

Social support was identified as being primarily from family members, but also coming from friends or rehabilitation professionals. Perception of a new self was described as the acceptance of living with aphasia. Setting future goals included going back to school or work and also educating others about aphasia and life after stroke. Taking responsibility for one's ongoing improvement came in the form of seeking out ways to improve communication ability even after formal rehabilitation stopped. Some PWA would meet with friends or colleagues to practice speaking and others would take writing classes (Hinckley, 2006).

Because personal feelings about language deficits may influence aspects of life participation for PWA, it is beneficial to understand how PWA view their own language abilities. Fromm and colleagues (2011) analyzed 71 interviews with PWA from the AphasiaBank Project. Researchers posed the question, "how do you think your speech is these days?" Responses from the interviewees, who were between 6 months and 39 years post stroke, were coded as positive, negative, or neutral based upon both verbal and nonverbal cues from the PWA. For example, a response such as "good, I'm great" with a 'thumbs-up' gesture was coded as a positive response. The results indicated that 59% of patients gave a positive response, 18% gave a negative response, and 17% gave a neutral

response. Severity of aphasia correlated with these findings, as people with severe aphasia indicated more negative responses and those with mild aphasia indicated more positive responses (Fromm et al., 2011).

Returning to work is often a goal for PWA as it brings a sense of independence and is financially beneficial (Hinckley, 2002). Factors that influence returning to a previous job include work place flexibility, social support, motivation, as well as motor and cognitive abilities (Hinckley, 2002). One study with 20 participants with aphasia discovered that after participating in an intensive speech therapy program 62% of the PWA who worked before their stroke returned to work within two years, although it was at a lower level position than the one they held previously (Hinckley, 2002). This rate is greater than what has been established in previous studies and is believed to be related to the intensive therapy these participants received. A previous study with 31 participants receiving less intensive therapy showed that only 26% of PWA returned back to work following stroke. Of these, none returned to their previous levels of employment (Hinckley, 1998).

There is great variation found across PWA in terms of their level of social participation (Dalemans, De Witte, Beurskens, Van Den Heuvel, & Wade, 2008). Factors influencing the variability of involvement in social participation include age, gender, functional ability to perform activities of daily living, and severity of aphasia (Dalemans et al., 2008). PWA report participating in fewer instrumental activities of daily living as compared to people without aphasia, feeling less engaged and being at a higher risk of social isolation (Hilari, 2011). Despite feeling less engaged, PWA felt supported by those around them in the few months post-stroke (Hilari, 2011). Activities that PWA report they did not participate in were primarily social or leisure activities (Hilari, 2011). It is difficult to specify

exactly which social activities have decreased participation, as many research articles report on social participation as a whole being reduced and do not highlight specific activities (Dalemans et al., 2008).

Lack of Knowledge of Aphasia

General Public

There is a lack of aphasia awareness within the general public. A study conducted by Simmons-Mackie, Code, Armstrong, Stiegler, & Elman (2002) surveyed 978 individuals in shopping malls or other public venues in various parts of the world. Only 13.6% of the individuals surveyed had ever heard of aphasia and only 5.4% met the criteria for having a basic knowledge of aphasia (Simmons-Mackie et al., 2002). This lack of awareness may be attributed to a number of factors including a reduced prevalence of aphasia on media circuits or a decreased amount of funding for aphasia research as compared to disorders with similar incidences (Elman, Ogar, & Elman, 2000). Decreased awareness of aphasia will influence life participation for PWA by impacting reintegration into the community and workplace (Elman et al., 2000).

With a shortage of public knowledge about aphasia there is a lack of empathy and understanding for individuals with aphasia. PWA may not initially understand how prevalent this diagnosis is, leading them to feel isolated and in turn exacerbating the psychosocial implications already associated with aphasia. In addition, family members and friends of PWA may not be aware of resources available to help support them as they cope with the changes they are encountering (Elman et al., 2000). All of these factors will negatively impact a PWA's reintegration into society.

Medical Field

Similar to the lack of awareness in the general public, there is a lack of awareness of aphasia within healthcare facilities. Participants in the survey developed by Simmons-Mackie et al. (2002) were asked to provide their occupation. Some of those who had identified themselves as healthcare workers were unable to define aphasia accurately (Simmons-Mackie et al., 2002). McCauslin, Florance, & Rabidoux (1980) surveyed 17 family-practice residents about speech pathology and the speech pathologist's role in a hospital. Some of the questions on the survey targeted knowledge of aphasia. When given an open-ended question to define aphasia, 18% wrote it was an inability to speak, 24% wrote it was an inability to verbalize thoughts, and other responses included Broca's or Wernicke's, difficulty understanding, and nonsense (McCauslin et al., 1980). The majority of these responses were correct in saying that aphasia is an inability to speak, difficulty with understanding, and has various subtypes, however these responses are not a complete definition of aphasia.

A component of aphasia that may be underestimated is a patient's ability to comprehend spoken language. Lack of knowledge regarding auditory comprehension abilities of PWA has been discovered amongst healthcare professionals. McClenahan, Johnston, & Densham (1990) asked doctors and nurses in an inpatient hospital setting, as well as relatives, to predict test results for auditory discrimination tasks from the Western Aphasia Battery for 30 of their patients. Results indicated that the estimates given by the medical staff and family members were inaccurate and consistently greater than the patients' actual score (McClenahan et al., 1990). The authors interpreted these data to indicate that healthcare professionals are likely to communicate with patients at higher levels than the

patients are able to understand, which in turn causes a greater disconnect between healthcare professional and patient (McClenahan et al., 1990).

PWA aphasia may not receive the same access to medical professionals as people without language disorders (Welsh et al., 2009). Stroke survivors and their families often report leaving the hospital without an understanding of aphasia (Knight et al., 2006; Welsh et al., 2009). Welsh and colleagues (2009) list anecdotal reports from PWA that: their doctors never discussed their medical condition with them; they were never told about resources, services, or outcomes; and that doctors had said they had reached a plateau in their recovery and should not look forward to future improvements. This lack of communication and accurate information could relate directly to doctors' knowledge of aphasia and the education they receive regarding aphasia in medical school.

For medical students, training often involves instruction on the pathophysiology of aphasia and assessment at the bedside, but does not include any strategies to help facilitate communication (Legg et al., 2005). When relaying a diagnosis of stroke to a patient with aphasia it is important to use strategies to ensure the patient has a complete understanding of his or her diagnosis. Aphasia-training seminars are becoming popular all over the country to help educate medical students and other healthcare professionals on the importance of being sensitive to supporting communication for their patients with aphasia (Legg et al., 2005; Welsh et al., 2009). These training seminars have shown significant improvements for medical students in terms of improved ability to gather information and build rapport with their patients with aphasia (Legg et al., 2005). By learning techniques to facilitate conversation and support life participation, physicians and other healthcare professionals

may be able to improve the quality of care patients with aphasia receive and help ensure full access to medical information.

Facilitated Communication for PWA

As a way to help others learn how to best facilitate communication with PWA, Kagan (1998) created Supported Conversation for Adults with Aphasia (SCA). SCA was designed to reduce the psychosocial impact of aphasia by increasing confidence in communication and training communication partners in effective adult communication (Kagan, 1998). It is based on the idea that PWA have the right to communication access by way of ‘communication ramps’ with partner-supported conversational techniques (Kagan, 1998). It is important for conversational partners to learn a variety of techniques for facilitating communication because effective SCA is based upon the use of multiple strategies, as different individuals will require different adaptations. Facilitating communication can be done through the acknowledging or revealing of competence (Kagan, 1998).

SCA starts with the acknowledgement of competence. It is important to avoid treating the PWA in a condescending or patronizing manner. This can be avoided by letting the PWA know that you understand their intelligence remains intact, despite their difficulties with communication. Acknowledgement of competence can be done by using humor or appropriate tone of voice, as well as by acknowledging understanding of what the PWA is trying to say or letting them know when you as a clinician do not understand what they are trying to convey (Kagan, 1998). Sometimes healthcare professionals will speak with family members or consult a chart for information as opposed to addressing the PWA directly. This could be related to the difficulties faced when trying to communicate with an individual who

has aphasia or could be due to a misperception of a loss of intelligence with aphasia. Regardless, it eliminates the acknowledgement of competence for PWA.

The second part of SCA includes revealing competence, which includes ensuring comprehension, providing the PWA with a means of responding, and verifying responses to summarize or expand upon what has been communicated (Kagan, 1998). This can be accomplished by using gestures, writing down key words, or drawing to keep the topic of conversation clear. To ensure the PWA has a means of responding, it is helpful to ask yes/no or fixed choice questions, give extra time to respond, and use visuals to point to or select. It is important to keep in mind the simultaneous use of techniques and talking in a way that enhances natural conversation (Kagan, 1998).

The manner of communication and the information being conveyed are both essential parts of rebuilding poststroke identity (Anderson & Marlett, 2004). It is critical that medical doctors and other healthcare professionals not only give patients accurate information about aphasia, but that they also use appropriate conversational adaptations. If healthcare professionals do not use facilitated communication, PWA may not understand important medical information that is being conveyed to them about such things as their diagnosis or prognosis for recovery. A number of straightforward techniques can be used to facilitate communication to ensure a patient's access to medical information. By applying these techniques, healthcare professionals will be able to ensure that individuals with aphasia understand the information being given to them and have the opportunity to respond and ask questions.

Healthcare Professionals and Aphasia

When healthcare professionals understand long-term prognosis for language recovery they can avoid giving short windows of time for recovery. By better understanding prognosis for language recovery, healthcare professionals can encourage their patients that recovery is an ongoing process with no finite time limit. The patients and their families may then feel hopeful for making gains in their language for many years. In addition, by receiving a correct prognosis for life participation and return to meaningful activities, patients with aphasia may feel less depressed about their situation.

Doctors and rehabilitation professionals may have the ability to influence the recovery process by giving a positive prognosis. They can support a sense of hope for recovery, which does not mean promising recovery back to previous self but that some amount of recovery is possible and may continue for many months or years after the stroke. Hope relates to self-healing, self-esteem, well-being, and quality of life (Cross & Schneider, 2010). Hope can influence the later stages of stroke recovery and it remains a constant factor in the healing process even years after a stroke (Cross & Schneider, 2010). Conversely, doctors can diminish the sense of hope a patient feels by giving incorrect information about prognosis for life participation or language recovery.

For a patient population that is already at a high risk for depression, giving a poor prognosis or short window of recovery time could lead to an even higher risk of depression. Following stroke, at least 30% of survivors experience depression (Gainotti et al., 2001). Poor outlook and negative views of rehabilitation might cause the PWA to have feelings of frustration, failure, and suffering (Shapiro, 2011), therefore increasing their risk of depression.

Medical Residents and Aphasia

Medical residents are taught to solve clinical puzzles using “preset algorithms” and “decision trees” (Groopman, 2007, p.4-5). Current practice emphasizes evidence based medicine (Groopman, 2007) and, although important, this practice may steer residents away from taking into account the psychological effect a diagnosis has upon the patient and the potential long-term consequences on life activities. With the progress modern medicine has made in the area of acute stroke management there is a greater focus on early medical intervention, which further detracts from the psychosocial considerations in acute stroke management. Newly trained physicians may not be aware of the effect a diagnosis of aphasia can have on life participation and the possibility of adapting and learning to live with this disorder for many years to come.

Neurology residents may see patients when they initially arrive into the emergency room. Time is of the essence and often care is focused on medical management in that acute stage. Residents may consult the chart of family members to collect the medical and social history that is pertinent at that time, neglecting to refer to the patient who may be too medically compromised to answer such questions. In addition, the residents who work with patients acutely may have a decreased understanding of long-term recovery. The residents who do work with PWA into the chronic stages of recovery may have a grasp on language recovery but have a decreased understanding of life participation. These residents focus more on medical management than on life participation, which is an area that occupational therapists (OTs) and physical therapists (PTs) target more closely.

Rehabilitation Students and Aphasia

Rehabilitation professionals such as OTs and PTs work with patients on a variety of skills necessary for the patient to return to performing meaningful life activities. OTs and PTs often work with stroke survivors, addressing the patients' physical needs and the emotional implications related to those physical needs. Although their therapy does not directly target language recovery, the work they do will depend heavily on a patients' comprehension of the instructions being given and the strategies used to communicate those instructions. In addition, effective communication is key when interacting with patients to determine what their personal goals are and what meaningful recovery is to them. This focus on the patient's personal goals is at the core of a client-centered approach to treatment. In this approach to treatment, clinicians enhance and acknowledge the patient's autonomy and decision-making throughout their recovery process.

The Life Participation Approach to Aphasia (LPAA) is a client-centered intervention perspective that is specifically focused on aphasia. According to LPAA, the purpose of intervention is to improve quality of life and engagement in valued life activities (Chapey et al., 2008). The philosophy is focused on supporting PWA and those around them in achieving their immediate and long-term life goals. These goals may be different depending on the stage of recovery the individual is in. For instance, while in the hospital a goal may be to develop effective communication strategies such the use of a communication board to express wants and needs, whereas a year after stroke that goal may be to reintegrate into the workplace (Chapey et al., 2008).

LPAA shifts the principles of treatment and intervention from working primarily on disabilities to focusing on residual ability and natural supports in the individual's

environment (Chapey et al., 2008). Examples of this shift include: assessments based upon relevant life participation needs and client competencies, intervention targets that are environmental factors outside of the individual, and outcomes documenting specific quality of life and life participation changes instead of just changes in language and communication (Chapey et al., 2008). By adopting the LPAA philosophy, healthcare professionals promote and support life participation goals for PWA instead of focusing solely on the remediation of disabilities.

Education that residents, OTs, and PTs receive on aphasia, prognosis and recovery, as well as communication strategies may be variable. Often training may include a short lecture or single textbook chapter, instead of an in-depth aphasia seminar or hands-on experience with PWA. Current research shows that healthcare professionals have variable knowledge of what aphasia is and what its recovery process entails (McCauslin et al., 1980; McClenahan et al., 1990; Simmons-Mackie et al., 2002). By gaining a better understanding of healthcare professionals' overall knowledge of aphasia, including life participation, prognosis, and communication strategies, recommendations can be provided regarding education necessary to improve their interactions with patients with aphasia.

Purpose

The purpose of this study was to understand what resident physicians in neurology, OT students, and PT students know about aphasia and to determine how they are likely to convey this information to patients. This study also sought to understand residents' and students' knowledge about aphasia recovery and the effects aphasia has upon life participation. Finally, this study estimated the level of comfort these new clinicians feel when answering a patient's questions about aphasia.

We asked the following research questions:

- 1) How do resident physicians in neurology and students in OT and PT explain aphasia to their patients?
- 2) What do resident physicians in neurology and students in OT and PT communicate to patients and families about the long-term prognosis for PWA in terms of (a) language recovery and (b) life participation?
- 3) What strategies and compensations do resident physicians in neurology and students in OT and PT use to help facilitate communication with patients with aphasia?
- 4) Do resident physicians in neurology and students in OT and PT address the patient with aphasia directly to obtain a history?
- 5) How comfortable do resident physicians in neurology and students in OT and PT feel answering patients' questions about aphasia?

Chapter III

Methodology

Questionnaire

A questionnaire was used to address neurology residents', OT students', and PT students' current knowledge of aphasia, including prognosis for language recovery and life participation, as well as strategies used to facilitate communication and the level of comfort these healthcare professionals feel when communicating with patients with aphasia. The questionnaire was two pages, single-sided, and stapled together. Adequate space was given after each question for responses. Neurology residents, OT students, and PT students were chosen as respondent groups as they work very closely with patients with aphasia during the recovery process. In addition, the researcher was able to administer the questionnaire in person to these groups, adding an element of convenience as well as assurance that each respondent answered independently. See appendix C for a copy of the questionnaire.

The questionnaire began with a section eliciting demographic and background information from participants while maintaining their anonymity. Information about age and gender was elicited. In addition, neurologists-in-training were asked to identify themselves as medical students, residents, or fellows and identify which area of neurology they planned to specialize in. Rehabilitation students were asked what year of their allied health education they were in as well as which area they planned to specialize in upon graduation. This was the only question that varied among the three groups in order to accommodate for the

differences in the training programs. Additional questions in the background section were in multiple-choice format. They included a question about time spent taking a history from a new patient with stroke, a question about how often the respondent sees patients who are six or more months post stroke, and a question about personal experience with aphasia.

Following the background section was a short, written scenario depicting a hypothetical patient with aphasia and five open-ended questions addressing that scenario. Open-ended questions were used as opposed to multiple-choice questions in order to reduce responder bias. By using open-ended questions respondents are able to answer based on what they actually know or do in such a situation, instead of choosing what they believe is the ‘right’ or ‘best’ answer from a list of choices.

In addition, open-ended questions 3-5 were written as if the patient or his wife were asking the question. It was believed that a PWA or a family member would be likely to ask about returning to a ‘normal life’ or how long ‘speech’ will improve instead of using more precise, but technical terms, such as prognosis, life participation, and language recovery. This way of phrasing the question was used to emulate a clinical scenario, encouraging the respondents to answer each question as if they were speaking directly to the patient or family member.

A sixth question, unrelated to the clinical scenario, was added at the end of the questionnaire to address level of comfort felt when answering patient and family questions about aphasia. This question used both a multiple-choice and an open-ended format. Each respondent rated his or her level of comfort from multiple choices and was then prompted to explain the choice.

Each question on the questionnaire addressed a separate research question; however the order in which the research questions were addressed in the questionnaire was different than the way they are listed in the purpose section of this paper. The reason for the different order of questions is to eliminate any responder bias that may have occurred in answering one question before another. For example, has the respondent addressed strategies to communicate with the PWA prior to answering the question about sources used when collecting a case history, the respondent may have been implicitly prompted to give the PWA as a source for the information.

Questionnaire Administration

Respondents were recruited from scheduled academic meetings for their respective training programs, including a lunch lecture series for neurology residents, a physical therapy comprehensive exam review series, and a weekly course in occupational therapy. Prior to disseminating the questionnaire all groups were instructed that it was completely optional, anonymous, and would in no way impact their educational or vocational standing. Each participant was encouraged to answer each question to the best of his or her ability. The questionnaire took approximately 20 minutes to complete.

Coding and Reliability

The researcher was the primary coder for the responses to this questionnaire. Each questionnaire question was coded individually to gather answers to the proposed research questions. The coding procedure is explained in detail for each question in the results section of this paper.

The second coder was a first-year master's student in speech-language pathology. He was trained to code each response based on operational definitions provided by the primary

coder. The instructions were given both verbally and in writing, with examples provided when clarifications were necessary. Instructions included criteria for what was to be coded as correct for each response based upon research from the literature review. The second coder coded 50% of the first five open-ended questions on the questionnaire. The primary and secondary coded responses were then compared to obtain inter-observer reliability. Reliability is reported separately for each question in the results section of this paper.

Chapter IV

Results

Respondents

The Institutional Review Board approved this study for exemption. Table 5.1 in appendix A reports the demographic and background information of the respondents of the study. There was a 100% response rate for this questionnaire. There were a total of 46 respondents including 11 neurology residents, 19 second-year masters students in OT, and 16 third-year doctoral students in physical therapy. The mean age of all respondents was 25.8 years, and the range was 23 years to 41 years. One participant chose not to list his age and was therefore excluded from the average. In total, 11 males and 35 females participated in this survey.

Of the residents, 10 were specializing in various areas of neurology including stroke. The OT and PT students listed areas of concentration such as acute care, inpatient and outpatient rehabilitation, and gerontology, amongst others, as areas they may specialize in after graduation. Of the total respondents six (13.0%) had personal experience with aphasia, listing a parent, grandparent, friend, or other family member as having aphasia.

When asked about how much time is spent collecting information from new patients who have had stroke, no one responded less than 5 minutes, 8.7% responded with 5-10 minutes, 50.0% of total respondents said 11-20 minutes, and 41.3% said greater than 21 minutes. The majority of PT students (75.0%) chose the 11-20 minute category and the

majority of OT students (68.4%) chose the greater than 21 minute category. Residents were more evenly spread across response options, with 27.3% choosing 5-10 minutes, 27.3% choosing greater than 21 minutes, and 45.5% choosing 11-20 minutes.

When asked about how often they anticipated seeing patients who are more than 6 months post stroke the answers were much more variable. Overall, a total of 45.7% of respondents chose weekly, 32.6% monthly, and 10.9% for both 3 to 6 times per year and less than twice per year. Residents answered fairly equally with weekly (36.4%), monthly (27.3%), or less than twice per year (36.4%), with no one selecting 3 to 6 times per year. The majority of OT students responded with either weekly (36.8%) or monthly (42.1%) with less choosing 3 to 6 times per year (15.8%) or less than twice per year (5.3%). The PT students responded that they anticipated seeing such patients weekly (62.5%), with less response for monthly (25.0%), 3 to 6 times per year (12.5%), and no one choosing less than twice per year.

Data Analysis

Each open-ended question for this questionnaire was coded and analyzed individually. Below are the questions as well as the coding system and results for that question. Following the open-ended question analysis are the results from the demographic and background information analysis. The corresponding table or figure is listed with each open-ended or demographic question.

Questionnaire Questions

Questionnaire Question #1: What sources will you consult to learn about Jim's medical and social history?

Coding: Responses were coded based on whether or not the respondent stated that he or she would direct questions about social and medical history to the patient. Answers where the respondent did not mention the patient directly but did mention using various communication strategies appropriate for someone with aphasia were coded as addressing the patient. All responses were mutually exclusive, so either the respondent included the person with aphasia or he/she did not. Inter-rater reliability was 95.7% for this question.

Results: Of the total respondents, 71.7% said they would communicate with the patient to learn about medical and social history, despite his moderate to severe aphasia. Figure 5.1 shows 45.5% of residents, 72.7% of OT students, and 87.5% of PT students mentioned they would communicate directly with the patient to obtain the history. For those who did not refer to Jim, some listed specific information they would want to gather and other common answers included referring to the chart, calling family, and speaking with other medical professionals to learn about the patient's history.

Questionnaire Question #2: What strategies will you use to make it easier for Jim to talk with you during the evaluation?

Coding: Responses were coded as correct if they were a part of the SCA guidelines (Kagan, 1998; Kagan, Black, Duchan, Simmons-Mackie, & Square 2001). Responses that were not on the SCA list of effective communication strategies were examined qualitatively to determine whether they were similar to these recommendations. As individuals with aphasia often require various communication strategies to help improve communication, the communication partner should always be ready with multiple strategies. Therefore, strategies provided by each respondent were totaled to determine how many different techniques for

facilitating communication were suggested. Inter-rater reliability was 87.3% for this question.

Results: See figure 5.2 for a graph of the strategies used by each group. Across the disciplines a variety of strategies were suggested to aid in the facilitation of communication for PWA. The most common responses from all respondents were asking yes and no questions (58.6%), using visuals or a communication board (46.8%), writing (35.9%), and gesturing (34.1%). The majority of responses are consistent with SCA guidelines. Two strategies that were not a part of the SCA guidelines were deemed appropriate strategies to use: assessing a patient's verbal communication ability and eliminating environmental distractions. Approximately 11.2% of all respondents listed consulting family members or other medical professionals as a strategy to use when speaking with the patient during the evaluation. This strategy was considered unconstructive for supporting communication, as it removes the acknowledgement of preserved intelligence PWA have. A category of 'other' was included for answers such as wearing a nametag, researching aphasia strategies, maintaining eye contact, and using music.

The most popular strategies suggested by residents were using writing (45.5%) or yes/no questions (54.6%). This group did not list strategies they could personally use to help facilitate communication such as acknowledge understanding, clarify miscommunications, speak slowly and clearly using simple language, and acknowledging the patient's preserved intelligence. OT students most frequently suggested asking yes/no questions (52.6%) and using visuals (63.2%) such as a communication board, picture cards, or objects to aid in communication. In addition, they listed strategies they could use to personally facilitate conversation such as speaking slowly, acknowledging competence, acknowledging

understanding, and clarifying communication breakdowns. The majority of PT students (68.8%) suggested using yes/no questions when communicating with the PWA. They listed some strategies that they could use to personally modify the environment, such as listening and giving time for expression as well as speaking slowly and clearly while using simple language.

The majority of respondents reported at least one or more strategies to use when facilitating communication. Of the total respondents, 15.2% listed one appropriate strategy, 28.2% listed two appropriate strategies, and 54.3% listed three or more appropriate strategies to be used to facilitate conversation. A small percentage (2.2%) was considered to not provide any correct strategies as the only strategies listed included having a family member present to help with communication. On average, residents gave two strategies while OT and PT students suggested three strategies used to help with communication.

Questionnaire Question 3: “You say he has aphasia, what is that?”

Coding: The responses to this question were coded based upon the following definition: “aphasia is an acquired communication disorder caused by brain damage, characterized by an impairment of language modalities: speaking, listening, reading, and writing; it is not the result of a sensory or motor deficit, a general intellectual deficit, confusion, or a psychiatric disorder” (Hallowell & Chapey, 2008). Responses to this question were analyzed for 7 key points: 1) language impairment, 2) not a loss of intellect, 3) not a motor or sensory deficit, can affect all modalities of language including 4) speaking, 5) comprehension, 6) reading, and 7) writing. Ideally, healthcare professionals would not give this definition verbatim, but the key points are important for the patient and his or her family to understand. These categories were not mutually exclusive of one another, as a respondent

could give multiple characteristics of aphasia in his or her definition. Answers were also coded for incorrect information. Inter-rater reliability was 86.9% for this question.

Results: Figure 5.3 shows the percentage of respondents from the three groups that mentioned each specific feature of aphasia. Looking at the groups individually, 54.5% of residents, 57.9% of OT students, and 31.3% of PT students identified aphasia as being some type of language disorder, which is correct. Respondents, however, did not appreciate that this meant difficulties across all modalities of language and that language is different than speech.

Ninety percent of residents, 89.5% of OT students, and 93.8% of PT students said aphasia is a problem with speech. In terms of auditory comprehension ability, 54.5% of residents, 52.6% of OT students, and 37.5% of PT students mentioned that aphasia affects comprehension. For writing, 18.2% of residents, 10.5% of OT students, and no PT students reported that this was a modality of language. None of the respondents reported that reading was a language modality affected by aphasia. Preserved intelligence is an important characteristic to explain to patients. Only 18.2% of residents, 21.1% of OT students, and 12.5% of PT students defined aphasia with preserved intelligence as a characteristic.

There were a few incorrect answers given about what aphasia is. The most common incorrect explanation was that speech and comprehension difficulties were mutually exclusive of one another. Patients often present with both expressive and receptive deficits, which is why there is a trend to refer to aphasia types as fluent versus non-fluent to alleviate the misperception that there is a mutual exclusivity of deficits. Another incorrect explanation included that PWA always have intact comprehension, which could again relate to the misperception of deficits being mutually exclusive or a lack of understanding that aphasia

affects all modalities of language. Lastly, two respondents explained aphasia as a motor impairment, which is incorrect as aphasia is not a problem with oral musculature.

Questionnaire Question #4: “Will he be able to live a normal life again? What kinds of things will he be able to do?”

Coding: When analyzing this question, it was noted that only two of the respondents addressed both parts of this question. Both of these respondents ported that work was an activity that the PWA could return to with adaptations to his environment. Due to the lack of responses for the second part of this question, only the answers to the first part of the question were coded and analyzed. There was some written feedback from respondents about the variability of ‘normal life,’ which the researcher agrees with. As mentioned earlier, this question was phrased from the perspective of the PWA and their family. It was believed that they would ask about a ‘normal life’ as opposed to asking specific information about ‘life participation.’

Answers were coded based on whether the respondent affirmed that life activities would definitely be possible or whether they gave some other answer to this question, making the two categories mutually exclusive of one another. Affirmative answers included responses that mentioned the patient returning back to doing the things he enjoys. Answers that were coded as belonging to the other category included responses that were variable in their response to returning to life participation or responses that did not specifically mention any return back to participating in life. Responses were then analyzed to identify explanations that were given to support the affirmative or other response. Inter-rater reliability was 95.8% for placing respondents in the affirmative or other category and 92.9% for placing respondents in the categories corresponding with their explanations.

Results: Figure 5.4 shows how many respondents affirmed that PWA will participate in life following stroke, table 5.2 gives the rationale for the responses. Of the total respondents, 64.9% responded with an affirmation that PWA will participate in life following stroke, while all other respondents were a part of the other category. For the residents, 36.4% responded affirmatively and 63.6% gave a different response. Some explanations for a definitive, positive response included the patients' ability to participate in life with the help of rehabilitation or having adaptations and adjustments to the environment. Those in the other category included explanations such as it is too early or hard to tell about recovery, that it will depend on how the patient does in rehabilitation, that further assessment of deficits is needed, and that recovery is too variable to know.

OT students answered with 89.5% responding affirmatively and 10.5% giving other answers. Explanations provided with affirmative responses included that despite challenges the PWA will be able to participate in life, that compensations and adaptations can be made in the environment, that rehabilitation will help the PWA with life participation, and that although the PWA is in the acute stage after stroke and recovery is variable there is hope for life participation. Explanations falling into the other category included that it is too early to say, that it depends on rehabilitation, and that recovery is variable.

The majority of PT students (69.9%) also answered affirmatively, with 31.3% responding with a different response. The common explanations for an affirmative response included that life participation is possible with adaptations to the environment, that it is possible to return to participating in life despite challenges, and that rehabilitation can help. Answers in the other category claimed that it was too early to give prognosis, that it depends

on how the patient does in rehabilitation, that recovery is a slow process, and that the patient may be limited to returning to life participation because of communication impairments.

Questionnaire Question #5: “How long will his speech continue to improve?”

Coding: The answers to this question were coded in six categories, mutually exclusive of one another: 1) less than 6 months, 2) up to 12 months, 3) up to two years, 4) uncommitted, 5) many years, and 6) did not answer. Sometimes respondents justified their responses - for example, “most improvements will occur in the first month but can continue through the first year.” These responses were coded according to the time mentioned (e.g. as less than six months), with a justification noted of possibly being longer. Inter-rater reliability was 83.3% for this question.

Results: Figure 5.5 displays the results. The majority of respondents were uncommitted with their responses. The majority of OT students (63.6%) and PT students (56.3%) as well as a number of residents (27.3%) were coded within this uncommitted group. Responses coded as being uncommitted included that recovery depends on the stroke, that it depends on rehabilitation, that they are unsure because research reports great variability, or that they would ultimately refer this question to the speech language pathologist.

Aphasia recovery is an ongoing process; however only 9.1% of residents, 9.1% of OT students, and 12.5% of PT students responded that there is no time limit for recovery. The frequency of responses for recovery lasting six months or less was equal to or greater than the responses for ongoing recovery. Eighteen percent of residents, 9.1% of OT students, and 12.5% of PT students said that recovery lasts for six months or less, with some qualifying their responses. Qualification included responses that defined six months as typical, but making mention of some recovery being possible after that point.

Questionnaire Question #6: How comfortable do you feel answering patients' and caregivers' questions about aphasia? Please explain your choice.

Coding: This question used both a multiple-choice and an open-ended format. Each respondent rated his or her level of comfort based on four choices: a) not at all comfortable, b) somewhat comfortable, c) very comfortable, and d) completely comfortable. The number of respondents for each choice was summed and divided by the total number of respondents to find the percentage of each response. Explanations for the level of comfort selected were then analyzed and grouped into categories. Explanations falling into the categories “experience with aphasia” or “lack of experience with aphasia” included both educational and clinical experience with aphasia, as well as respondents indicating that aphasia is not their area of clinical interest. Responses in the “other” category included answers such as being an empathetic person or needing more specific patient information when answering questions about aphasia. Inter-rater reliability was not available for this question in the interest of time and because the anticipated levels of reliability were expected to approximate those in previous questions.

Results: Figure 5.6 shows the reported level of comfort for answering questions about aphasia. The majority of respondents, 54.5% of residents, 73.7% of OT students, and 81.3% of PT students, selected they were somewhat comfortable answering their patients' questions about aphasia. A smaller percentage of OT students (26.3%) and of PT students (6.3%) chose not at all comfortable for their response. Of the residents, 45.5% felt very comfortable answering the questions and 12.5% of PT students also responded feeling very comfortable answering questions about aphasia. No respondent chose that they felt completely comfortable answering questions about aphasia.

Reasons given for feeling the various levels of comfort were coded when provided. Figure 5.7 shows the various reasons given by each group as to why they do not feel comfortable answering patients' questions about aphasia. The reasons given included lack of experience and that these questions are typically deferred to the speech-language pathologist.

Figure 5.8 shows the reasons given as to why respondents chose they felt somewhat comfortable answering questions about aphasia. These reasons were both positive and negative in nature. Positive reasons included feeling they had adequate knowledge about aphasia. Negative reasons included a lack of experience, lack of knowledge about aphasia recovery, and the general variability to stroke recovery. Other respondents also responded that these questions are usually deferred to the speech-language pathologist.

Figure 5.9 shows the reasons given within each group for feeling very comfortable answering questions about aphasia. The two main reasons respondents gave for feeling comfortable answering these questions included their knowledge of aphasia and their experience with patients with aphasia.

Background and Demographic Information

Time spent collecting a case history

Respondents who reported that they spent 21 minutes or more collecting a care history from a new patient who has had a stroke were compared to those who said they spent less time collecting the history, to determine if the respondents who took longer referred to the patient more often or used a greater number of strategies on average when facilitating communication. Those who spent less than 21 minutes collecting a history referred to the patient directly an average of 74.1% of the time and identified approximately two strategies to use to facilitate communication. Those who spent longer than 21 minutes collecting a

history referred to the patient directly 68.4% of the time and identified approximately three strategies to use when facilitating communication. See table 5.3 in appendix B for results.

Frequency of encountering patients who are more than six months post stroke

Respondents who reported that they anticipate seeing patients who are more than six months post stroke weekly were compared to those who said they would see patients who are more than six months post stroke less frequently to see if the former had a better understanding of language recovery or life participation. Respondents who anticipated seeing these patients weekly gave an affirmative response to life participation 71.4% of the time and similarly the group of respondents who anticipated seeing patients less frequently gave an affirmative response 68% of the time. The most popular response for both respondents who saw these patients on a weekly basis (57.1%) and less frequently (40%) was uncommitted in terms of language recovery in aphasia. Nineteen percent of respondents who anticipate seeing patients weekly reported that language recovery was ongoing and 12% who anticipate seeing these patients with less frequency reported that recovery was ongoing. See table 5.4 in appendix B for results.

Influence of having a personal connection with aphasia

To determine if personal experience with aphasia affected response patterns, respondents who reported that they had a friend or family member with aphasia were compared to those who did not. A total of six participants, two from each respondent group, reported having a personal experience with aphasia. Answers were fairly consistent between the two groups for responses to all questions. Two thirds of both groups reported they would refer to the patient directly when obtaining information about medical and social history. On average, each group reported two strategies to help facilitate communication. In terms of

definition of aphasia, 83.3% of people who reported knowing someone with aphasia and 92.5% of the other respondents highlighted speech deficits. Approximately 17% of respondents from both groups identified preserved intelligence as a characteristic of aphasia. Approximately two thirds of each group gave an affirmative response for life participation and the results for language recovery time were fairly variable within each group. Finally, the majority people who reported knowing someone with aphasia (66.7%) and the other respondents (72.5%) reported feeling somewhat comfortable discussing aphasia with patients and their families. See table 5.5 for results.

Chapter V

Discussion

The purpose of this study was to better understand what resident physicians in neurology, PT students, and OT students know about aphasia and how they would express that knowledge in a given clinical scenario. Their knowledge of aphasia included knowledge of prognosis for both language recovery and life participation. This questionnaire also elicited which strategies respondents would use to facilitate communication with their patients with aphasia. In addition, this study sought to find the level of comfort these resident physicians and students in rehabilitation professions feel when answering patients' questions about aphasia. The results of the questionnaire provide information to answer each of the proposed research questions and suggest a number of clinical implications for improving interactions between healthcare professionals and patients with aphasia. The research questions will be addressed, followed by the questions from the background section of the questionnaire. Limitations of and conclusions drawn from this study will be discussed at the end of this section.

Research Questions

How do resident physicians in neurology and students in OT and PT explain aphasia to their patients?

Previous studies have shown that the general public as well as medical professionals frequently misunderstand aphasia (Simmons-Mackie et al., 2002; McCauslin et al., 1980).

Past research has shown that aphasia definitions may be accurate but inadequate or incorrect information may be provided. In the survey given by Simmons-Mackie and colleagues (2002), it was determined that 13.6% of their 978 participants from the general public had heard of aphasia and of that percentage only 5.4% had a basic knowledge of aphasia. In the current study, none of the respondents indicated that they were unfamiliar with the term, which is most likely because of their specific career or course of study. The Simmons-Mackie study did not provide a definition of what was meant by ‘a basic knowledge’ of aphasia, therefore making it difficult to compare the results of this study to the results of that study. In addition, this study provided context that allowed respondents to have a general idea of what aphasia is, whereas the Simmons-Mackie study did not provide context.

McCauslin and colleagues (1980) used an open-ended question in a survey given to 17 residents to gather a definition of aphasia. The only context the respondents were provided with was that aphasia related to speech-language pathology. Results reported 18% mentioned an inability to speak, 24% an inability to verbalize thoughts, with other responses such as defining types of aphasia or difficulty understanding. In the current study a larger percentage of our residents (90.1%) reported aphasia as an inability to speak. An inability to verbalize thoughts could be interpreted as either preserved intelligence or difficulty with speech, so it is difficult to compare this study to the McCauslin study in that respect.

Overall the results of this study do show that there is a correct definition of aphasia provided to patients, however it often omits important features of aphasia. Residents and students were correct in mentioning that aphasia is a language disorder, however they did not mention that this means difficulties across all modalities of language – speech, auditory comprehension, reading, and writing. The lack of the mention of various modalities could

partially be due to a misconception that the terms speech and language are interchangeable, as a large majority of respondents defined aphasia as being difficulty with speaking. Some of the respondents did go on to mention auditory comprehension deficits and a small portion mentioned writing deficits. None of the respondents reported that reading deficits were characteristic of aphasia.

Complete and accurate definitions of aphasia, which include all language modalities, are important. Speech is a characteristic most often attributed with aphasia because it is arguably the most salient feature. Deficits in auditory comprehension, writing, and reading are often neglected in the definition of aphasia, as they are less obvious features of aphasia. Misunderstandings related to auditory comprehension abilities could lead to a breakdown in communication. In a study conducted by McClenahan, Johnston, & Densham (1990) healthcare professionals and relatives of PWA rated the PWA's auditory comprehension abilities to be consistently greater than they actually were. Without an understanding of auditory comprehension deficits, the healthcare professional may speak to the PWA in a manner that they are not able to follow. There may also be a breakdown in communication between the PWA and their family members if auditory comprehension deficits are not accurately explained.

Reading and writing are important aspects of language to keep in mind because some of the more prominent strategies identified in this questionnaire for facilitating communication involve reading and writing. Limited understanding of reading and writing deficits associated with aphasia may be attributed to the prominence of spoken communication within our society (Beeson & Henry, 2008). The healthcare professional may have the best of intentions by using writing to communicate important information to the

PWA, but he or she may not be able to read that information. Without proper understanding of reading and writing deficits there can be a breakdown in communication between the PWA and healthcare professional, as well as the PWA and their family members.

Another important feature within the definition of aphasia is that PWA have preserved intelligence. Anecdotal reports from PWA often describe that he or she is ignored because doctors will refer only to the family members. This could be because there is a misunderstanding that a person's inability to speak is a direct reflection of their intelligence. It is important to address the PWA directly, in turn acknowledging their competence and giving them a sense of autonomy in medical decision-making or goal setting. In addition, there may often be a misunderstanding of the difference between intelligence and auditory comprehension. If a PWA has impaired auditory comprehension, the misunderstanding of the message they received may appear to be a lack of knowledge of the topic. It is important for conversational partners to have an understanding that the deficit is at the level of auditory comprehension and not intelligence so that this misunderstanding does not occur.

A few incorrect answers were seen with the definitions the residents or students provided. The first incorrect explanation of aphasia included that deficits in speech and comprehension are mutually exclusive of each other. Many people see aphasia as being either receptive or expressive in nature, when in fact the majority of people with aphasia have both types of deficits in varying degrees. Aphasia is more appropriately categorized by fluent versus non-fluent in nature, as to alleviate the misunderstanding that speech and comprehension deficits are separate.

Also noted as an incorrect response was that people with aphasia always understand what is being said to them and that deficits are only with speech. As mentioned previously,

this is incorrect because people with aphasia almost always have deficits in both speech and comprehension. This could relate to using language and speech as interchangeable terms or the lack of understanding surrounding the various language modalities affected by aphasia. Lastly, incorrect responses were seen with explaining aphasia as a motor deficit. Aphasia is neither a motor deficit nor a motor planning deficit. The muscles necessary for speech are intact, the breakdown in language with aphasia occurs within the brain.

By giving an incomplete or incorrect definition of aphasia to PWA and their families, a misunderstanding of deficits will occur leading to confusion and frustration. If a PWA is told that aphasia is difficulty with speech, he may become concerned when he cannot read. Communication breakdowns may occur between patients and their loved ones because of a misunderstanding about aphasia's impact upon comprehension. People with aphasia may feel degraded when they are spoken down to and treated condescendingly because no one explained that intelligence remains intact. All of these misunderstandings can be detrimental to the person with aphasia and relate back to the lack of knowledge surrounding aphasia and how that negatively impacts life participation. By educating healthcare professionals further on a definition of aphasia, the misunderstandings that result from incorrect and incomplete definitions can be avoided.

What do resident physicians in neurology and students in OT and PT communicate to patients and families about the long-term prognosis for PWA in terms of (a) language recovery and (b) life participation?

Aphasia recovery is variable as there are personal factors that may influence prognosis and also because aphasia type is evolving throughout the course of recovery (Laska et al., 2001; Pederson, Vinter, & Olsen, 2003; Kertesz & McCabe, 1977; Bakheit et

al., 2007). The greatest amount of language recovery is seen during the spontaneous recovery period, which can last anywhere from one month to one year post stroke (Laska et al., 2001; Bakheit et al., 2007; Pederson et al., 1995; Kertesz & McCabe, 1977). After this period, language recovery does not cease but just slows. Although there are only a few longitudinal studies on aphasia in comparison to studies in the acute stage, there is still evidence that shows recovery can continue throughout the lifespan (Naeser et al., 1998; Smania et al., 2010).

Responses from this questionnaire demonstrated that there is a lack of concrete knowledge on language recovery in aphasia, as a large percentage of respondents were uncommitted in their response. Answers to this question instead included that it depends on the stroke, that it depends on rehabilitation or that they are unsure because research reports great variability. In addition, some reported they would ultimately defer this question to the speech-language pathologist. It is important to recognize the variability of language recovery in aphasia especially in the acute stage, as research does warn against giving prognosis based upon the initial presentation of aphasia (Pederson, Vinter, & Olsen, 2003; Kertesz & McCabe, 1977).

Although it is better to give an uncommitted answer as opposed to giving the incorrect information, responses with such uncertainty or variability could be disconcerting for PWA and their family members. There is a great deal of anxiety surrounding the future after a person has a stroke. When the physician or rehabilitation professional cannot directly answer questions about recovery this may increase feelings of anxiety. It may be helpful for medical professionals to explain why there is such variability in language recovery to PWA and their families to help alleviate those feelings of uncertainty.

There is some longitudinal research available on language recovery in aphasia demonstrating that recovery can last years and decades post stroke (Naeser et al., 1998; Smania et al., 2010). In the current study, only a small percentage from each group of respondents definitively reported that language recovery was ongoing. Of those who reported language recovery being ongoing, some justified this response by saying that although recovery is ongoing the greatest recovery is seen in the first year or that therapy is going to enhance this recovery. These justifications complement the current research that shows the greatest recovery is seen during the spontaneous recovery period (Laska et al., 2001; Bakheit et al., 2007; Pederson et al., 1995; Kertesz & McCabe, 1977) and that treatment for aphasia is effective (Robey et al., 1998).

Some respondents answered that recovery is possible for up to six months. Of these respondents, half justified their response with saying that recovery may be possible after this point but still gave a six-month window of recovery time. One of the respondents in this group responded with recovery actually ceases after six months, as the patient will reach a plateau. Some respondents also chose the one-year or two-year mark as the amount of time for language recovery. Justifications for these responses included that it was too early to tell, recovery is variable from person to person, or as long as the patient is still in therapy then recovery is possible.

It is important to convey an accurate knowledge of language recovery in aphasia. If the healthcare professional gives a finite period of time for recovery, the person with aphasia may be less motivated to participate in therapy or may become frustrated when he or she has not made a great deal of progress by that certain time mark. By telling patients it is too early to tell, implying that recovery is uncertain, patients may also become discouraged and

worried about what the future will bring. In addition, when patients are told that their recovery will depend on how they do in rehabilitation they may feel as though they have failed if they are not recovering as they thought they would.

Education can be provided to healthcare professionals to remediate uncertainty about language recovery for patients with aphasia. In addition, healthcare professionals can be educated on referring to the speech-language pathologist for patient's questions surrounding recovery times instead of giving an incorrect or variable answer. A greater number of longitudinal studies for aphasia recovery would be helpful to characterize long-term recovery patterns and magnitude.

As healthcare professionals it is important to keep the element of hope alive while being realistic about prognosis. Aphasia is a life changing diagnosis and people need to learn to adapt to their life in a new way. Life participation for PWA can be influenced by a variety of factors including age, gender, functional ability to perform ADLs, and severity of aphasia (Dalemans et al., 2010). Overall, PWA report a decreased level of participation in social or leisure activities (Hilari, 2011). Life participation is possible for all PWA, although it may be in a different form than it once was. Rehabilitation, adaptations to the environment, and compensatory techniques may all be factors that help promote life participation for individuals with aphasia.

A greater percentage of OT and PT students than residents responded affirmatively that PWA will be able to live a normal life again. The majority of affirmative responses for all three groups were justified by various responses including the need for adjustments and adaptations and rehabilitation to support life participation. In addition, some respondents stated that return to a normal life is possible despite language deficits. It is believed that a

higher percentage of PT and OT students answered that life participation is possible because they most often work on life participation skills with their patients as well as see patients more frequently in the chronic stages of recovery.

It was hypothesized that residents may have responded with less of a definite positive response to this question because they may only see patients early on in their diagnoses, however responses from the questionnaire show that these residents see patients who are six months or more post stroke on a weekly basis. A more likely reason may be that residents do not see the life participation gains made, as they do not directly target the skills necessary for life participation in the treatment they provide patients. Residents explanations for not giving a definite positive response included it is too early to say, recovery is too variable, it depends on the stroke severity and progression, and some mentioned it depends on early intervention and progress in rehabilitation.

Regardless of the role of the healthcare professional – whether it is to enhance rehabilitation or to treat medically – it is important to not diminish hope for life participation and language recovery. Hope is related to self-healing, self-esteem, well-being, and overall quality of life and influences later stages of stroke recovery (Cross & Schneider, 2010). By educating healthcare professionals about the ongoing language recovery and ability for participation in life, these professionals can answer patient’s questions more accurately and support the PWA’s hope for the future.

What strategies and compensations do resident physicians in neurology and students in OT and PT use to help facilitate communication with patients with aphasia?

PWA and their family members have reported leaving the hospital without an explanation of aphasia and anecdotal reports have shown that healthcare professionals may

neglect to discuss patient's medical conditions with them (Knight et al., 2006; Welsh et al., 2009). These reports may be related to a decreased understanding of preserved intelligence in PWA or it could also be due to a decreased understanding of strategies to use when communicating with PWA. Some research has shown the benefits of providing aphasia-training seminars to medical students to improve information collection from and development of rapport with PWA (Legg et al., 2005).

There were a wide variety of strategies suggested by respondents, with the majority of strategies following the SCA guidelines (Kagan, 2008). Suggestions included writing, using a communication board, gesturing, acknowledging competence, clarifying misunderstandings, and acknowledging understanding of the message being expressed. OT and PT students reported a wider variety of strategies than residents did. Overall it appeared residents most often elected to utilize tools in the environment, such as communication boards or writing, to facilitate communication as opposed to suggesting skills they could demonstrate such as listening, having patience, and using clear speech and simple language.

The types of strategies suggested by each group may relate to their perceived role in the relationship with the PWA. Residents may view their role as giving information to the patient as opposed to communicating with to the patient. The residents' perception of his or her role may explain the suggestion of tools in the environment to use for facilitating communication as opposed to the more psychosocial strategies of listening or clarifying misunderstandings that were suggested by the rehabilitation students. The OT and PT students may view themselves as communication partners to the PWA, trying to reach a common goal of successful life participation, which relates back to a client-centered

treatment approach. This would explain why they suggested strategies such as taking the time to listen, having patience, and acknowledging understanding of what is being communicated.

The current study reports that a little over half of all respondents knew of three or more appropriate strategies to use to facilitate communication with their patients. It is important to have an understanding of more than one or two strategies to help facilitate communication, as you need various means of communication to verify that there is accurate comprehension for both communication partners (Kagan, 2008). In addition, each PWA responds differently to various means of communication so it is helpful to have knowledge of more than just one or two strategies to try. It is also important to consider that PWA may want to initiate or elaborate on topics instead of just answer direct questions, so having something available to help support elaboration of a topic may be helpful. By having more than a couple of strategies to try, hopefully there will be less of a chance of a communication breakdown between patient and clinician.

Only a small percentage of respondents suggested assessing to see if the patient was able to communicate verbally as a strategy. The hypothetical patient presented in the vignette was described as having a moderate to severe aphasia, with no mention of type or salient features. It appears the majority of respondents assumed that the moderate-severe aphasia impacted verbal communication severely, but not reading, writing, or comprehension, as such a high percentage suggested asking yes/no questions or using writing.

As previously stated, few respondents defined aphasia as including reading and writing deficits. On the other hand, a large percentage of respondents answered that they would use writing as a means of communication. With a lack of understanding of deficits in

all language modalities there may be a decreased understanding of which strategies are helpful to use and which exacerbate the communication breakdown.

Do resident physicians in neurology and students in OT and PT address the patient with aphasia directly to obtain a history?

Sometimes healthcare professionals will speak with family members or consult a medical chart for information instead of addressing the PWA. This may be attributed to a number of reasons, including lack of awareness of preserved intelligence in PWA, as was demonstrated previously in this questionnaire when respondents were asked to provide a definition of aphasia.

In this study, a greater percentage of OT and PT students than resident physicians reported that they would address the patient with moderate to severe aphasia directly when trying to elicit information about medical and social history. The respondents who did not address the patient directly reported they would talk with family members present or by phone, review the patient's medical chart, and/or contact other healthcare professionals who are familiar with the patient in order to obtain the information. By directing questions to friends or family members the healthcare professional is acknowledging that this onset of disability affects the entire family, however it is still very important to address the PWA to give them a sense of autonomy in their care.

Some respondents who neglected to list the PWA as a source of information listed the specific information they would like to elicit, as opposed to how they would gather it, in response to this question. This specific information is important as it will lead to decisions about treatment, although that was not the information this question was eliciting in the questionnaire.

When gathering medical and social history it is important to review the medical chart and talk to other professionals familiar with the patient, but it is nearly impossible to understand exactly what the patient wants or needs without consulting them directly. Medical professionals see a variety of patients with all different types of conditions and diseases and will mostly likely refer to the patient directly to gather information. When the patient presents with a communication disorder, however, it appears that it is somewhat more likely that the professional will refer to other sources to gather information. By addressing a patient directly you give that patient a sense of competence in making his or her own medical decisions.

Healthcare professionals need to be educated on strategies they can use to better facilitate communication with their patients with aphasia. Although a number of respondents for this questionnaire gave three or more strategies to use when communicating with a PWA, there is still a percentage that only gave one or two strategies to use. This lack of understanding of strategies could influence the healthcare professionals' ability or level of comfort in addressing the patient directly. By giving the doctors and students specific ways of communicating with the patient they may in turn feel more comfortable addressing the patient directly. This can only work to enhance the communication and interactions between patients and their healthcare providers.

How comfortable do resident physicians in neurology and students in OT and PT feel answering a patient's questions about aphasia?

No research was found on personal feelings residents or rehabilitation students have when speaking with patients with aphasia. These feelings could have an impact on the encounters with the patient and their family and may be a factor contributing to the decreased

communicative interactions and quality of those interactions, as mentioned previously. This question aimed to elicit the level of comfort felt answering questions about aphasia. The questionnaire also inquired about explanations for the level of comfort felt to have a better grasp on what recommendations can be made to ensure that healthcare professionals feel comfortable and competent interacting with their patients with aphasia.

No one responded with feeling completely comfortable answering a patient's questions about aphasia. A majority of respondents in each group selected that they were somewhat comfortable answering questions about aphasia. Some of the reasons provided for feeling only somewhat comfortable included a lack of experience with aphasia and being unsure about recovery, prognosis, or communication strategies. By providing education about aphasia recovery, prognosis, and communication strategies to these professionals we can enable them to feel more comfortable answering patients questions about aphasia.

Background and Demographic Information

The background information from each participant was elicited to determine how time spent collecting a patient's history, chronic exposure to aphasia, and/or personal experience with aphasia may influence the responses to the questionnaire. It was hypothesized that greater time spent with a patient with aphasia may lead to the respondent more often referring to the patient directly or influencing the respondent's knowledge of strategies to use in facilitating communication. No difference was discovered between groups with referring to the patient directly. Respondents who spent a longer time collected a case history from a patient listed one more strategy on average than did respondents who spent less time collecting a case history.

It was also hypothesized that frequent exposure to people with aphasia who are in the chronic stages of recovery may have a greater understanding of life participation outcomes or language recovery times. No difference was seen with the knowledge of life participation outcomes. It was discovered that those who have less experience with patients in the chronic stages of recovery more often reported that language recovery was only possible for up to six months.

Finally, it was hypothesized that personal experience with aphasia may influence how the respondent answered all questions on the questionnaire, as they would presumably have had more experience with aphasia. No differences were noted with respondents who had personal experience with aphasia as opposed to those without personal experience with aphasia.

Limitations

This study had a small sample size with 46 respondents. This study was meant to be a pilot study to determine if future research in this area is warranted. This study was also completed on a fairly homogeneous population. The students were all from the same university and were in the same year of study, which limits generalization of the findings of the knowledge of aphasia for OT and PT students. The residents also came from the same department of the hospital and were at similar points within their residency. This again limits the external validity.

There are limitations as well to studying students, as they presumably have a different understanding of aphasia than an experienced, practicing clinician does. The OT and PT students in this study were graduating students, but still had a lack of clinical experience. The students' clinical experiences relate to the various clinical rotations they have had, which

could lead to a lack of exposure to PWA and could ultimately affect responses on the questionnaire. Experienced clinicians may have a better understanding of how to answer these questions as they have a greater exposure to PWA and more experience interacting with them. A few of the students cited a lack of educational and clinical experience as a reason they only feel somewhat comfortable discussing aphasia with patients. In addition, another limitation to studying students is that their clinical interest is varied. A student who plans to work with pediatrics may have less knowledge of aphasia in general, as they may have taken different classes than those with an adult focus or may have not studied the information as intently because it is not of interest to them.

Another limitation of the study could be the use of a questionnaire, as the questions are up to the interpretation of the reader. A different way to collect this information is to observe the residents or students interacting with PWA to see firsthand how these questions are answered. This method of data collection was not feasible for this pilot study due to time constraints, financial limitations, and overall complexity of such a study. One suggestion would be to use professional actors in place of PWA, as that may decrease some of the constraints of such a complex study. In the future, it may be beneficial to observe the respondents in a clinical setting to obtain more accurate information and decrease the variability of interpretation of questionnaire questions.

Steps were taken to try and account for any misinterpretations of questions on the questionnaire that may occur, but it is difficult to completely control for this. There were a few misinterpretations within the background section of the questionnaire that were addressed during the administration of the survey. The question eliciting which sources are consulted to obtain medical and social history appeared to be misinterpreted. Some

respondents listed the specific medical information they wanted, where as others listed the actual source (i.e. patient, family member, doctor, chart, etc) they would consult.

All groups had difficulty interpreting questions that were aimed at a “typical medical setting” as the responses to the question would vary depending on the medical setting they were in. The phrase “typical medical setting’ was chosen because this questionnaire was given to a variety of healthcare professionals who all may work or plan to work in different medical settings. In the future it may be helpful to allow the respondent to write in the medical setting or be able to give responses for a variety of typical medical settings for their profession.

Some respondents claimed there was not enough information provided about the hypothetical patient in the vignette. They wrote that it was difficult to comment on the possibility of returning to a normal life without knowing other concomitant conditions or deficits from the stroke. The vignette was meant to be broad to control for any bias towards responding to the questions. For example, by stating that the patient had difficulty with moderate to severe aphasia presenting with difficulties in speaking and writing, the respondent may have answered the question of defining aphasia differently. In addition, if the vignette stated the patient had paresis or paralysis following the stroke, the respondent may have been more likely to comment on life participation in terms of motor deficits and not language deficits. Another way of decreasing responder bias was to have the open-ended questions on the questionnaire.

One limitation of using open-ended questions is that answers are not always straightforward which can make responses difficult to code. The coding for this questionnaire was very detailed and individualized for each question. Due to the detailed coding system,

inter-rater reliability for each question on this questionnaire was strong despite the open-ended nature of the questions. Efforts should be made to use an equally detailed coding system for future administrations of this questionnaire.

Implications for practice and future research

There is a lack of information in the literature about specific knowledge of aphasia and how that information is conveyed to patients, as well as how comfortable residents and students in OT and PT are with responding to patient questions about prognosis for language recovery and life participation. Despite the limitations of this study, results of this questionnaire do show that there is a need for greater education for healthcare professionals planning to work with patients with aphasia.

This education should focus on clinically relevant aspects of aphasia such as what the recovery process is like, how a person with aphasia can lead a meaningful life, and what strategies can be used to maximize communication with PWA. Education can be provided through demonstrations, case studies, interviews with PWA, or anything that would really allow the professionals to practice these skills and answering these questions.

This study should be replicated in the future with a larger, more diverse respondent group to gather a better understanding of overall knowledge of aphasia among healthcare professionals. The feedback on the questionnaire from current respondents, such as the misunderstanding of some of the background questions as outlined in the limitations section of this paper, should be taken into account to alleviate future misinterpretations. More specifically, clarification about what is meant by a ‘typical medical setting’ and by ‘sources’ used to gather background information is suggested.

Another adjustment to make on future administrations of this questionnaire is accounting for the variability in how each discipline interacts with the PWA based on their clinical role. It is important to note differences in these roles and account for them in the questionnaire. For example, each discipline may collect a case history differently, which would affect how they answer the questions about time spent collecting a history and the sources consulted in taking the history. Accounting for the differences between disciplines may give a more accurate representation of the respondents' interactions with PWA.

Conclusion

The current study reflects the knowledge neurology residents, OT students, and PT students have about aphasia, language recovery, and life participation, as well as level of comfort answering questions about aphasia and strategies used to make communication more functional. The results revealed 5 major points:

1) Neurology residents, OT students, and PT students have an accurate understanding of some of the salient features of aphasia, but do not give a complete definition of the disorder

2) Neurology residents, OT students, and PT students do not anticipate giving specific feedback about language recovery and often give an uncommitted response

3) Neurology residents are less likely to affirmatively address life participation with individuals with aphasia and their families than OT students and PT students

4) Neurology residents, OT students, and PT students are knowledgeable of some strategies to facilitate communication with PWA, but do not demonstrate awareness of the need to use a comprehensive set of strategies for various patients

5) Neurology residents, OT students, and PT students feel somewhat comfortable answering patients' questions about aphasia, and they attribute this level to a lack of experience and/or limited understanding of recovery and prognosis for PWA.

Appendix A – Tables

Table 1.1 Classification of Cortical Aphasia Subtypes

Cortical Aphasia Subtypes							
Fluent				Nonfluent			
Wernickes Conduction Anomic Transcortical Sensory				Brocas Transcortical Motor Global Transcortical Mixed			
Good Aud Comp		Poor Aud Comp		Good Aud Comp		Poor Aud Comp	
Conduction Anomic		Wernickes Transcortical Sensory		Brocas Transcortical Motor		Global Transcortical Mixed	
Good Rep	Poor Rep	Good Rep	Poor Rep	Good Rep	Poor Rep	Good Rep	Poor Rep
Anomic	Conduction	Transcortical Sensory	Wernickes	Transcortical Motor	Brocas	Transcortical Mixed	Global

Table 5.1 Demographic and Background Information of Respondents

<u>Respondents</u>	Total	Residents	OT Students	PT Students
	46	11	19	16
<u>Age</u>	Total*	Residents*	OT Students	PT Students
Mean	25.8	29.4	25.6	27.1
Range	23-41	26-32	23-38	24-41
<u>Gender</u>	Total	Residents	OT Students	PT Students
Male	11	6	2	3
Female	35	5	17	13
<u>Areas of Planned Specialization</u>		Residents	OT Students	PT Students
		Epilepsy	Gerontology	Outpatient Rehab
		Neurophysiology	Inpatient Rehab	Orthopedics
		Sleep	Pediatrics	Geriatrics
		Neuromuscular	Veterans	Athletes
		Stroke	Mental Health	Neurology
		Undecided	Cognitive Deficits	Sports Medicine
			Dementia	Pediatrics
			Outpatient Rehab	Acute Care
			Undecided	Stroke Rehab
<u>Time spent collecting a history from a new patient who has had a stroke:</u>				
	Total	Residents	OT Students	PT Students
Less than 5 min	0 (0%)	0 (0%)	0 (0%)	0 (0%)
5-10 min	4 (8.7%)	3 (27.3%)	0 (0%)	1 (6.3%)
11-20 min	23 (50.0%)	5 (45.5%)	6 (31.6%)	12 (75.0%)
21+ min	19 (41.3%)	3 (27.3%)	13 (68.4%)	3 (18.8%)
<u>Frequency of seeing patients who are 6 or more months post stroke:</u>				
	Total	Residents	OT Students	PT Students
Weekly	21 (45.7%)	4 (36.4%)	7 (36.8%)	10 (62.5%)
Monthly	15 (32.6%)	3 (27.3%)	8 (42.1%)	4 (25.0%)
3-6x per year	5 (10.9%)	0 (0%)	3 (15.8%)	2 (12.5%)
Less than 2x per year	5 (10.9%)	4 (36.4%)	1 (5.3%)	0 (0%)
<u>Has a friend or family member with aphasia:</u>				
	Total	Residents	OT Students	PT Students
Yes	6 (13.0%)	2 (18.2%)	2 (10.5%)	2 (12.5%)
No	40 (86.9%)	9 (81.8%)	17 (89.5%)	14 (87.5%)
Who?		Parent, grandparent	Great aunt, grandparent	Friend, grandparent

*One respondent left this blank

Table 5.2 Respondents' Rationale for Life Participation

Explanations for affirmative responses	Resident physicians	OT students	PT students
Despite it being too early to tell	0%	5.3%	0%
Despite recovery variability	0%	15.8%	0%
With rehabilitation	27.3%	10.5%	12.5%
Adaptations needed	9.1%	68.4%	5.6%
Despite deficits	9.1%	15.8%	18.8%
No reason given	0%	0%	6.3%
Explanations for other responses	Resident physicians	OT students	PT students
May be limited by communication impairments	0%	0%	6.3%
Recovery is a slow process, variable outcomes	18.2%	5.3%	6.3%
Need further assessment of deficits	9.1%	0%	0%
Depends on stroke severity and progression	9.1%	0%	0%
Depends on how patient does in rehabilitation	27.3%	5.3%	25.0%
Too early or difficult to say	36.4%	5.3%	18.8%

Table 5.3 Respondent Comparisons by Time Spent Collecting a History

Question 1	21+ min	<21 min
Refer to patient	68.4%	74.1%
Refer to other	31.6%	25.9%
Question 2	21+ min	<21 min
Average # of strategies	3.2	2.2

Table 5.4 Respondent Comparisons by Frequency of Seeing Patients with Chronic Aphasia

Question 4	Weekly	Less frequently
Affirmative response to life participation	71.4%	68.0%
Other	28.6%	32.0%
Question 5	Weekly	Less frequently
Up to 6 months	4.8%	20.0%
Up to 12 months	14.3%	12.0%
Up to 2 years	4.8%	8.0%
Ongoing	19.0%	12.0%
Uncommitted	57.1%	40.0%
Did not answer	0%	8.0%

Table 5.5 Respondent Comparisons by Personal Experience with Aphasia

Question 1	Know PWA	Other
Refer to patient	66.7%	72.5%
Refer to other	33.3%	27.5%
Question 2	Know PWA	Other
Average # of strategies	2.5	2.65
Question 3	Know PWA	Other
Language Impairment	16.7%	52.5%
Not a loss of intelligence	16.7%	17.5%
Speech deficit	83.3%	92.5%
Auditory comprehension deficit	0%	55.0%
Writing deficit	0%	0%
Reading deficit	0%	10.0%
Not a motor or sensory impairment	16.7%	0%
Question 4	Know PWA	Other
Affirmative response to life participation	66.7%	70.0%
Other	33.3%	30.0%
Question 5	Know PWA	Other
Up to 6 months	16.7%	12.5%
Up to 12 months	16.7%	12.5%
Up to 2 years	0%	7.5%
Ongoing	33.3%	12.5%
Uncommitted	33.3%	50.0%
Did not answer	0%	5.0%
Question 6	Know PWA	Other
Not at all comfortable	0%	15.0%
Somewhat comfortable	66.7%	72.5%
Very comfortable	33.3%	12.5%
Completely comfortable	0%	0%

Appendix B – Figures

Figure 5.1 Respondents who Refer Directly to the PWA to Gather Medical and Social History

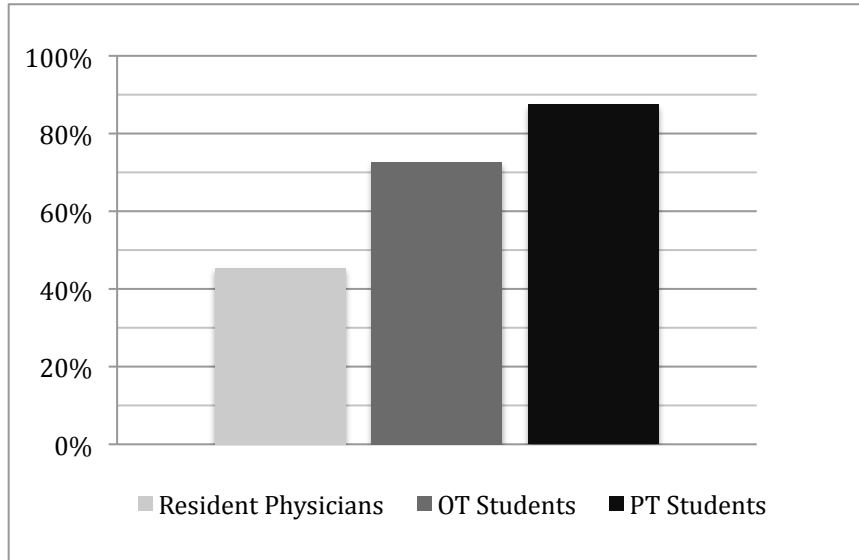


Figure 5.2 Communication Strategies Suggested for Facilitating Communication with PWA

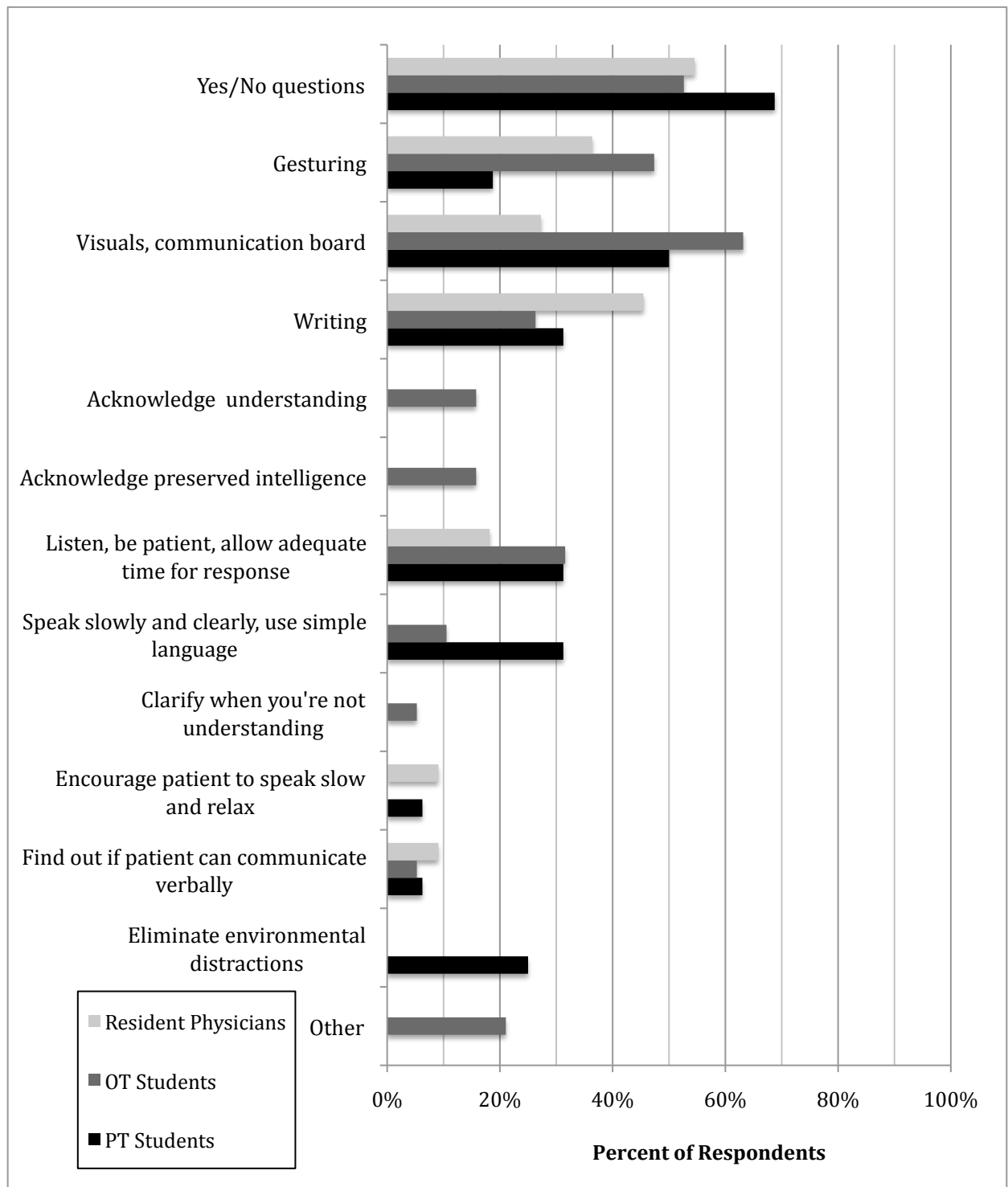


Figure 5.3 Respondents' Definitions of Aphasia

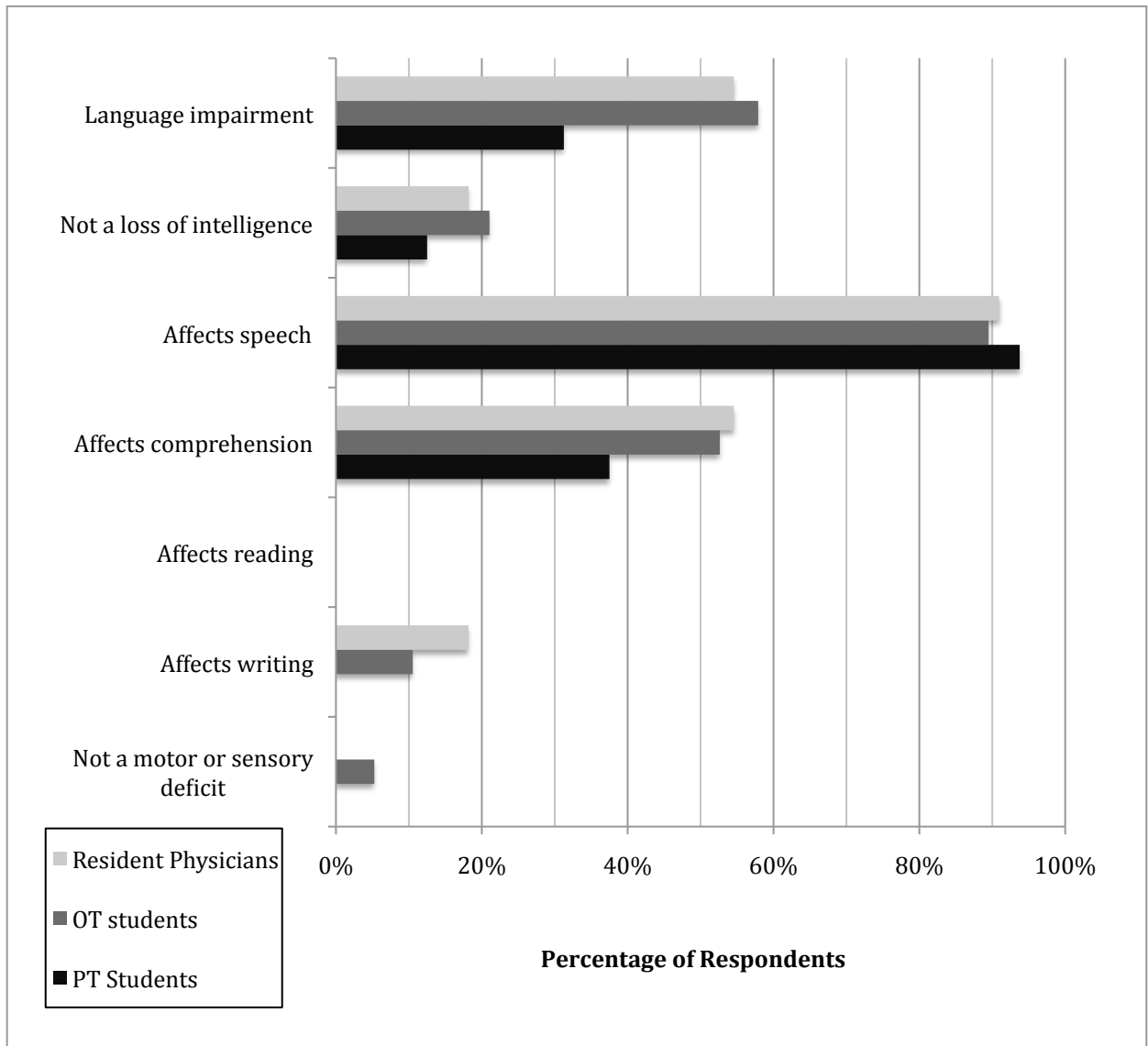


Figure 5.4 Respondents' Responses to Life Participation with Aphasia

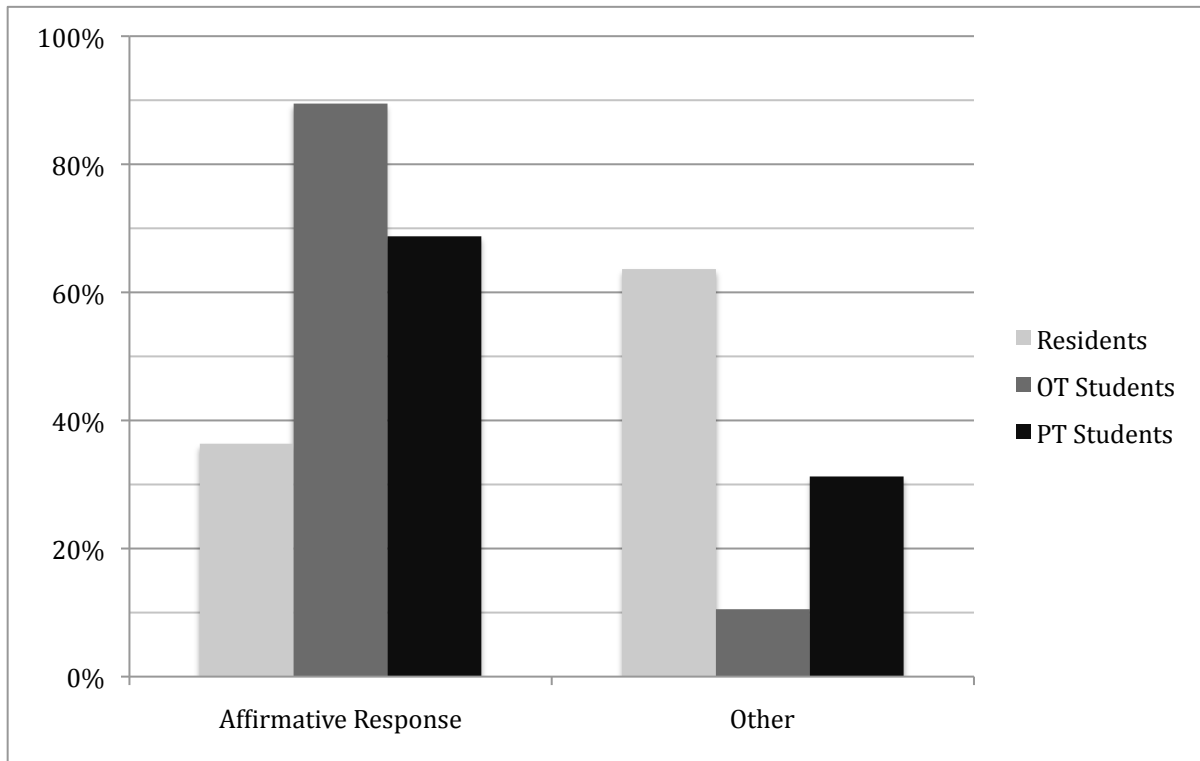


Figure 5.5 Respondents' Suggested Time for Language Recovery

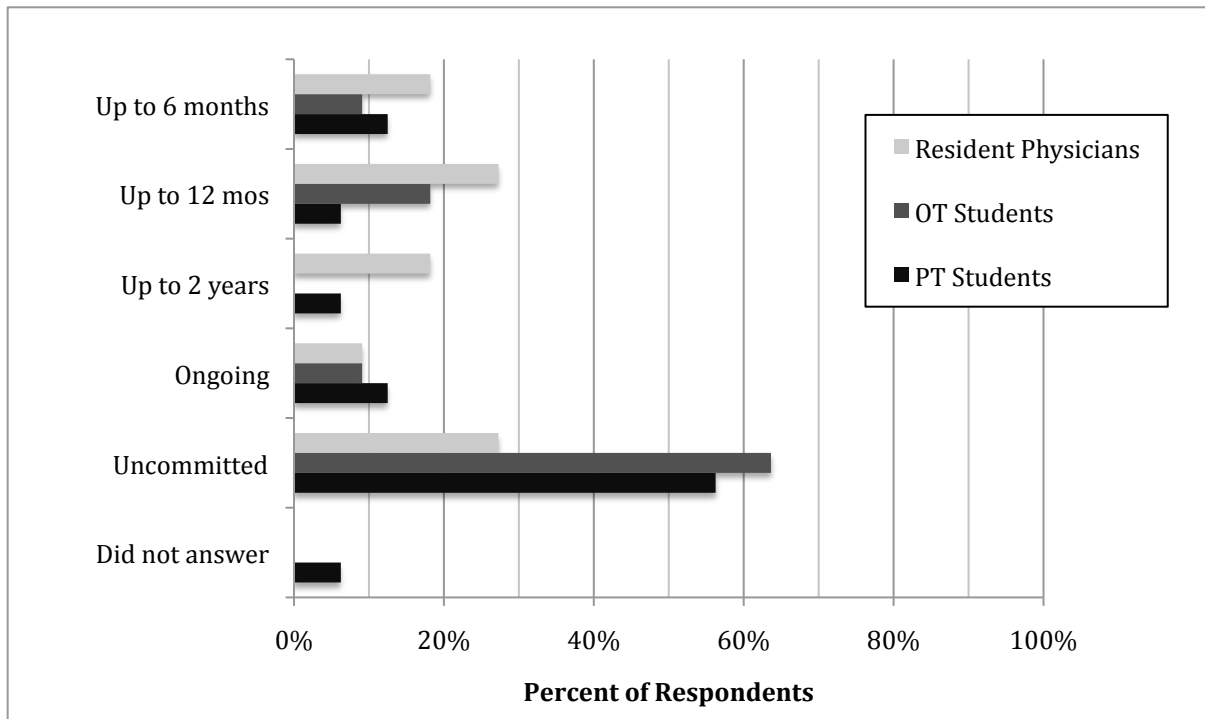


Figure 5.6 Respondents' Level of Comfort Answering Questions about Aphasia

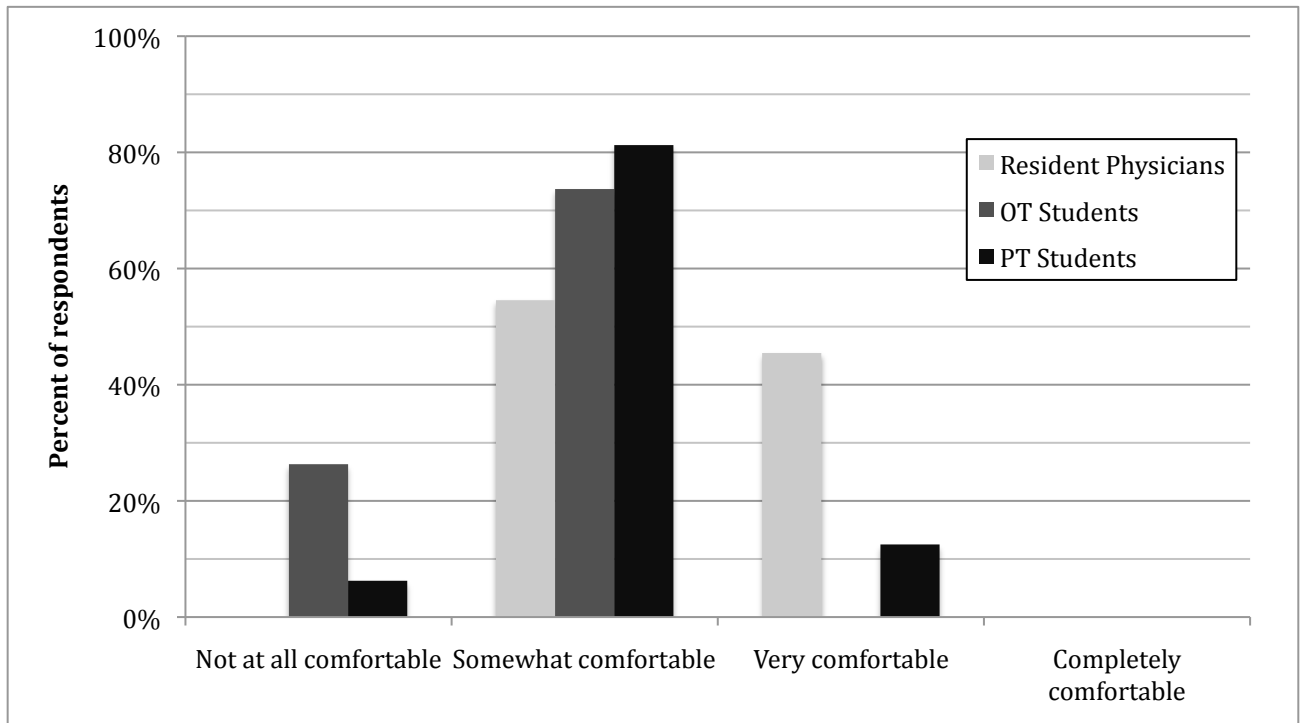


Figure 5.7 Respondents' Explanations for Being Not at All Comfortable Explaining Aphasia to Patients and Families

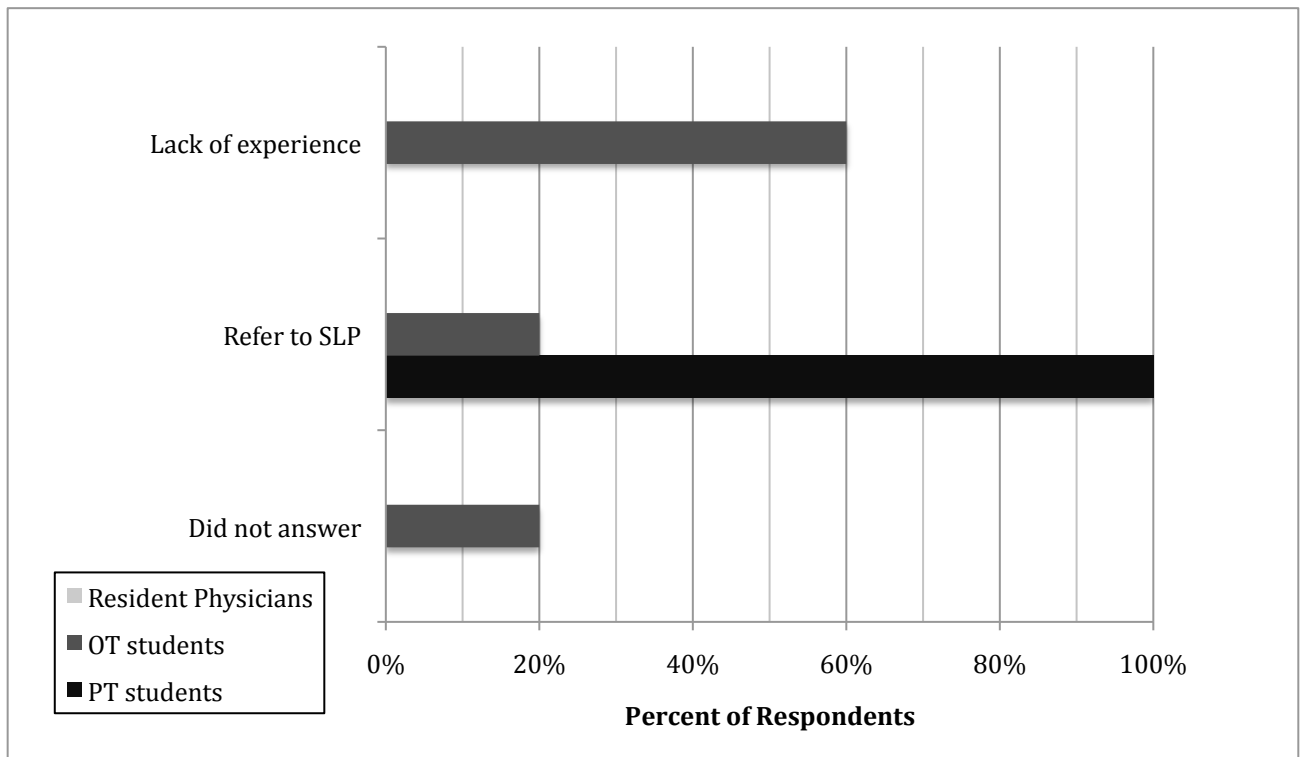


Figure 5.8 Respondents' Explanations for Being Somewhat Comfortable Explaining Aphasia to Patients and Families

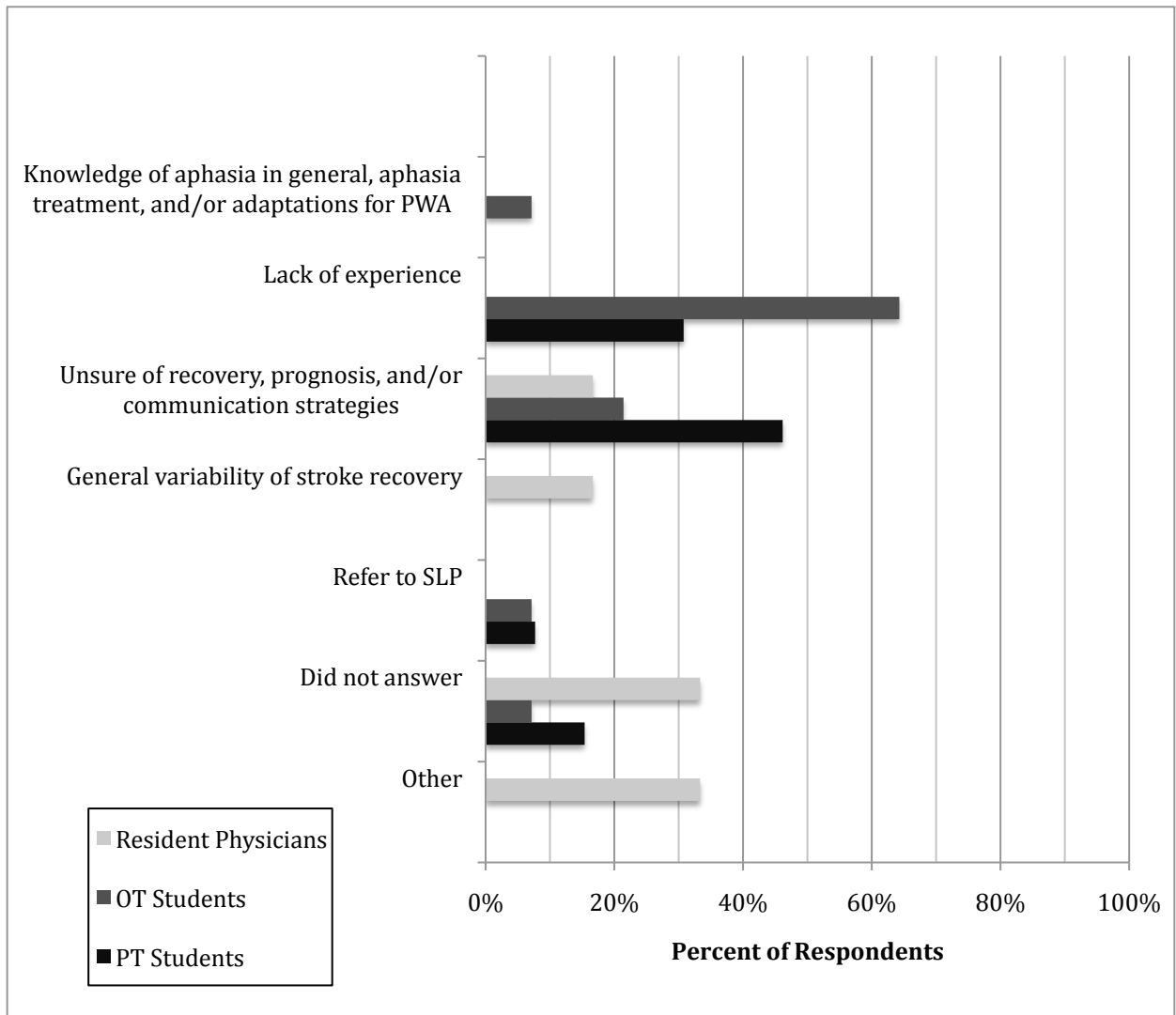
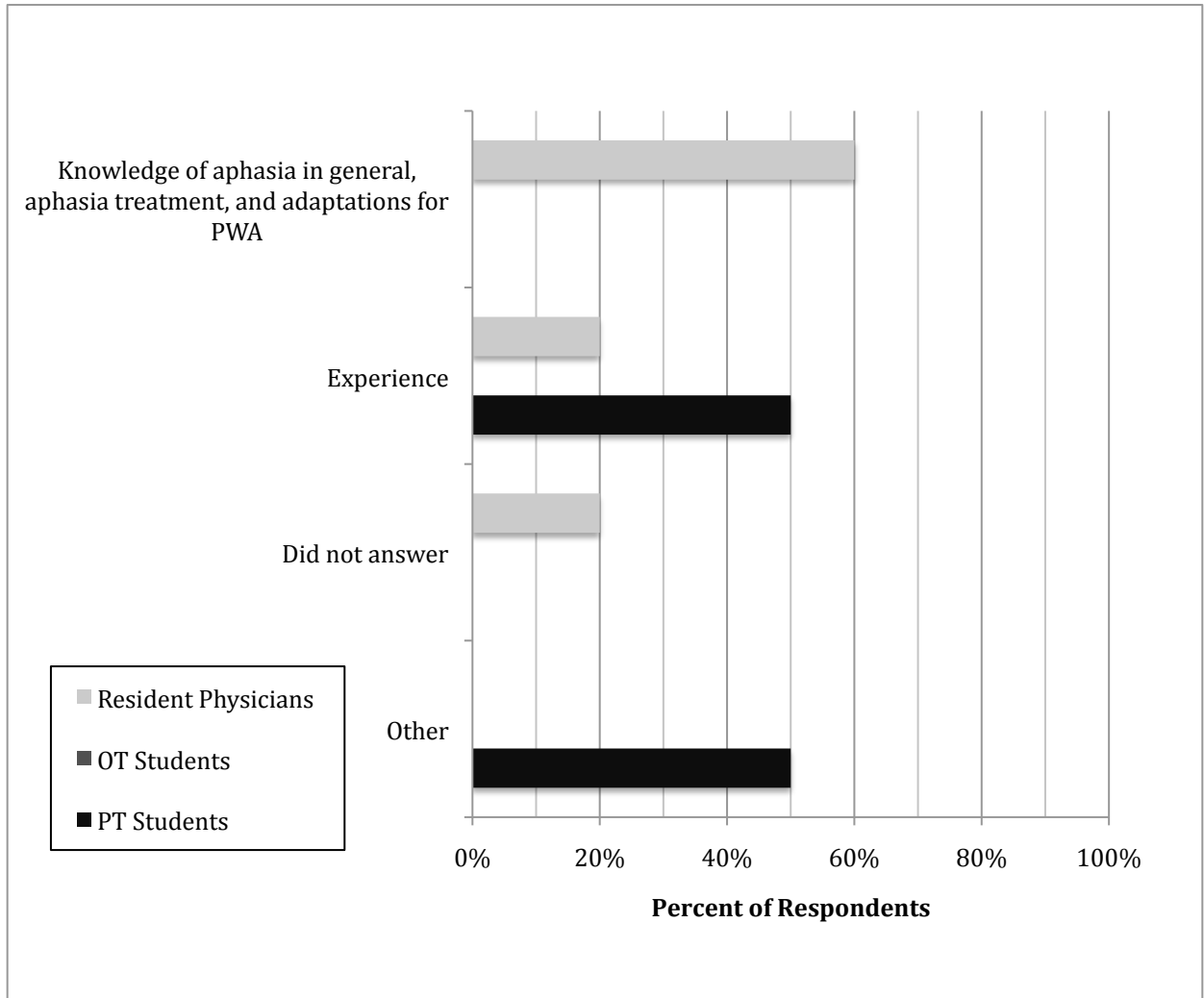


Figure 5.9 Respondents' Explanations for Being Very Comfortable Explaining Aphasia to Patients and Families



Appendix C: Questionnaires

Questionnaire for Residents

1. Age: _____
2. Gender: _____
3. Are you a medical student, resident, or fellow? _____
4. Do you plan to specialize in a particular area of neurology? Yes / No (circle one)
If yes, which area?

5. In a typical medical setting for your profession, how much time does it take to collect a history from a new patient who has had a stroke?
 - a. Less than 5 minutes
 - b. 5-10 minutes
 - c. 11-20 minutes
 - d. 21+ minutes
6. In a typical medical setting for your profession, how often would you anticipate seeing patients who are more than 6 months post stroke?
 - a. Weekly
 - b. Monthly
 - c. 3-6 times per year
 - d. Less than twice per year
7. Do you have, or have you had, a friend or family member with aphasia? Yes /No (circle one)
If yes, please select your relationship to that person:
 - a. My parent
 - b. My sibling
 - c. My friend or acquaintance
 - d. My grandparent
 - e. Other (please specify): _____

Please refer to the following scenario when answering the next five questions:

Jim is a 55-year old man who has worked as a bank manager for the past 30 years. He is married and has two children who are both in college. Jim enjoys working out at the gym, reading, playing cards with his friends, and traveling with his family. Last week, Jim had a left middle cerebral artery stroke leaving him with moderate to severe aphasia. You are about to see Jim for the first time in the acute care setting.

- 1) What would you do to learn about Jim's medical and social history?

2) What might you do to make it easier for Jim to talk with you during the evaluation?

Jim and his wife are extremely concerned and want as much information as you can give them regarding Jim's prognosis. His wife asks the following three questions. How do you respond?

3) "You say he has aphasia, what is that?"

4) "Will he be able to live a normal life again? What kinds of things will he be able to do?"

5) "How long will his speech continue to improve?"

6) In general, how comfortable do you feel answering patients' and caregivers' questions about aphasia?

- a) Not at all comfortable
- b) Somewhat comfortable
- c) Very comfortable
- d) Completely comfortable

Please explain your choice.

Questionnaire for OT/PT Students

1. Age: _____
2. Gender: _____
3. What year of your graduate (allied health) education are you currently in? _____
4. What patient/client population do you hope to work with once you graduate? _____
5. In a typical medical setting for your profession, how much time does it take to collect a history from a new patient who has had a stroke?
 - a. Less than 5 minutes
 - b. 5-10 minutes
 - c. 11-20 minutes
 - d. 21+ minutes
6. In a typical medical setting for your profession, how often would you anticipate seeing patients who are more than 6 months post stroke?
 - a. Weekly
 - b. Monthly
 - c. 3-6 times per year
 - d. Less than twice per year
7. Do you have, or have you had, a friend or family member with aphasia? Yes/No (circle one)
If yes, please select your relationship to that person:
 - a. My parent
 - b. My sibling
 - c. My friend or acquaintance
 - d. My grandparent
 - e. Other (please specify): _____

Please refer to the following scenario when answering the next five questions:

Jim is a 55-year old man who has worked as a bank manager for the past 30 years. He is married and has two children who are both in college. He enjoys working out at the gym, reading, playing cards with his friends, and traveling with his family. Last week, Jim had a left middle cerebral artery stroke leaving him with moderate to severe aphasia. You are about to see Jim for the first time in the acute care setting.

- 1) What would you do to learn about Jim's medical and social history?

2) What might you do to make it easier for Jim to talk with you during the evaluation?

Jim and his wife are extremely concerned and want as much information as you can give them regarding Jim's prognosis. The wife asks the following three questions. How do you respond?

3) "You say he has aphasia, what is that?"

4) "Will he be able to live a normal life again? What kinds of things will he be able to do?"

5) "How long will his speech continue to improve?"

6) In general, how comfortable do you feel answering patients' and caregivers' questions about aphasia?

- a) Not at all comfortable
- b) Somewhat comfortable
- c) Very comfortable
- d) Completely comfortable

Please explain your choice.

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