Quality of Life and Aphasia

Are proxy responses from spouses/caregivers reliable to use in research with persons with aphasia?

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ABSTRACT
Persons with aphasia (PWA) have language difficulties and their Quality of Life (QoL) has most likely been affected. Because of their loss of language abilities, it is difficult to use PWA in QoL studies. This can lead to the use of proxy responses (a person who answers for the PWA). The aim of this study was to compare the rankings from QoL questionnaires for PWA with the rankings from their spouses/caregivers (i.e., proxy response). We also wanted to find out which of the 11 aspects of life PWA and spouses/caregivers ranked as the most respectively the least impacted ones. A total number of 57 persons participated in the study. The participants consisted of two groups, one group with PWA and one group of their spouses/caregivers. A questionnaire-based cross-sectional survey completed via a face-to-face interview was used to collect data from both groups. The results showed that there was poor internal consistency and a weak correlation between the two groups. The two groups ranked different aspects of life as “most impacted” and “least impacted”. The PWA ranked Vocation/Occupation as the “most impacted” and Family life as the “least impacted” aspects of life. The spouses/caregivers ranked Overall ability to communicate as the “most impacted” and Ability to self-care as the “least impacted” aspects of life. The results indicate that proxy responses may not be appropriate and should be interpreted with caution in QoL studies with PWA.

Keywords: Persons with aphasia, spouse/caregiver, Quality of Life, aspects of life, proxy responses.

SAMMANFATTNING

Nyckelord: Personer med afasi, anhöriga, livskvalitet, livsaspekter, proxysvar.
1. Introduction

Early in the process of writing our master’s thesis we knew that we wanted to write about aphasia. We were both interested to go abroad and work with another university. Since we wanted to avoid language difficulties we decided to go to the USA. We got in touch with Paul Evitts, Ph.D., CCC-SLP, at Towson University, Maryland, USA who had an ongoing study on Quality of Life (QoL) and persons with aphasia (PWA). Since we both think that this is a very interesting and important field in speech and language pathology we took the opportunity to do something different with our master’s thesis and to learn more about speech and language pathology from another country’s point of view. We spent four weeks at Towson University in the beginning of fall 2013. During this time we collected data at Snyder Center for Aphasia Life Enhancement (SCALE), wrote on our master’s thesis and went on study visits. This collaboration with Evitts was a learning experience where we got to see different ways on how to work as a speech and language pathologist with PWA.

With this master’s thesis we present our collaboration with Evitts.
2. Background

2.1. Stroke

2.1.1. Definition, etiology and natural Course

Cerebrovascular accident or stroke are terms for disturbance of brain function. These disturbances are due to loss of blood supply or bleeding (Alexandrov, 2010; Brookshire, 2003). Symptoms of stroke are rapidly noticed and include weakness on one body side, impairment of vision, difficulties speaking or understanding speech, dizziness or episodes of falls, and severe headache, particularly in conjunction with other symptoms (Brookshire, 2003).

Strokes can look different from one person to another depending on which part of the brain that is injured, but it is also the size of the stroke that determines the severity of the symptoms. A person who is having a small stroke may have less severe symptoms than a person who is having a larger stroke (National Stroke Association, 2013).

There are two different types of stroke, ischemic and hemorrhagic stroke (Alexandrov, 2010; Brookshire, 2003). An ischemic stroke is due to a blocked artery, which leads to losses in blood supply to parts of the central nervous system. This blockage occurs from a thrombotic or an embolic stroke. A thrombotic stroke is the result from a plug of material in the artery that gradually increases in size, while an embolic stroke is the result of a sudden blockage of the artery from material that has been moving through the vascular system (Alexandrov, 2010; Brookshire, 2003). A hemorrhagic stroke occurs when a cerebral blood vessel is ruptured. These ruptures can be due to weakness of a vessel wall, traumatic injury, or extreme changes in blood pressure (the latter one is more rare). A hemorrhage can occur outside the brain, called extracerebral hemorrhage, or within the brain or brain stem, called intracerebral hemorrhage. The extracerebral hemorrhage is then divided into subclasses, subarachnoid, subdural and epidural hemorrhages. The different subclasses got their names depending on location of accumulation of the bleeding (Brookshire, 2003). Ischemic strokes are far more frequent than hemorrhagic stroke. About 85% of the people who suffers from a stroke suffer from an ischemic stroke compared to 15% who suffers from a hemorrhagic stroke (Riks-Stroke, 2013).

In Sweden there are about 30,000 people each year that experience a stroke (Riks-Stroke, 2013). This represents approximately 0.3% of the Swedish population, estimated on a population of 9,606,522 people (Statistiska centralbyråen, 2013). In America there are about 795,000 people each year that experience a stroke (Go et al., 2013). Estimated on a population of 316,618,210 people (United States Census Bureau, 2013) about 0.25% of the population suffers from a stroke each year.

Neurological recovery starts a few days post-onset the stroke. Then the brain starts to react to the damage that the stroke has caused and starts to restructure itself (Stein, 2004). Several sources implicates that stroke recovery mostly happens within three to six months, and then the recovery slowly starts to decrease (Intercollegiate Stroke Working Party, 2008; Medscape, 2013; Skilbeck et al., 1983). For example Skilbeck et al. (1983) found that when looking at differences in speech, arm function, Activities of Daily Living (ADL) ability and walking less than one month, three months, six months...
and 12 months after onset they could see the largest improvement between less than one month and three month post onset.

2.1.2. Risk factors
A risk factor is a characteristic or an exposure that leads to a higher risk of becoming sick (Nationalencyklopedin, 2013). There are several risk factors for stroke, e.g., high blood pressure, which is a common risk factor for both ischemic and hemorrhagic stroke. Out of those who have their first stroke, approximately 77% have high blood pressure. Arterial fibrillation (i.e., disturbance in heart rhythm; Nationalencyklopedin, 2013) is a risk factor which increases the risk of stroke five times independent of age (Go et al., 2013). Current smokers have, in comparison to nonsmokers or for people who have stopped smoking more than 10 years ago, a two to four times higher risk of stroke (Alexandrov, 2010; Go et al., 2013). Heredity is also a risk factor. If one parent had a stroke by the age of 65 years the risk of ischemic stroke increases three times, even when adjustments for other risk factors are made (Go et al., 2013).

2.2. Aphasia
2.2.1. Definition, etiology and natural Course
One of the most common symptoms following stroke is aphasia (Code, 2012). According to the American Speech-Language-Hearing Association (ASHA), aphasia is “a disorder that results from damage to the parts of the brain that contain language [most often located to the left hemisphere]. Aphasia causes problems with any or all of the following: speaking [expression], listening [comprehension], reading, and writing” (ASHA, 2013). The loss of these language abilities can be totally or partly. Stroke is the most common cause of aphasia (traditionally estimated to 85%) (LaPointe, 2005), but any disease or damage to the language parts of the brain can cause aphasia (ASHA, 2013; Code, 2012). Head trauma, brain tumor, and neurodegenerative diseases are other possible causes of aphasia (LaPointe, 2005). Aphasia alone does not affect the person’s intelligence (National Aphasia Association, 2013).

The incidence of aphasia after stroke is about 30% in the acute phase after onset (Laska et al., 2001). The incidence of aphasia following stroke is higher in the acute phase than in the chronic phase (Code, 2012; Code & Petheram, 2011), which indicates a recovery of the aphasia post-onset (Code, 2012). In Sweden, about 12,000 persons suffer from aphasia following any brain disease or damage each year as estimated by the Swedish Aphasia Association (Afasiförbundet i Sverige, 2013). Based on the figures presented by Code and Petheram (2011) and the fact that Sweden’s population is about 9,500,000 persons, approximately 5,000 acquire aphasia following stroke each year (incidence) and 33,000 persons in Sweden have aphasia following stroke (prevalence). Based on estimates from Klein in 1995, the National Aphasia Association suggests that the incidence of aphasia, regardless of course, is about 80,000 in the US and that the prevalence is about one million people (Code, 2012).

Research has shown that recovery from acute stages is made by most of the person with aphasia (PWA) (Code, 2012). Recovery can be divided into “losses”, i.e., abilities that cannot be recovered, and “behavioral deficits”, i.e., attempts to shift control to undamaged neural systems. The behavioral deficits are compensatory, which means that recovery for a PWA can be a combination of restitution of lost cognitive functions and compensation for lost functions (Code, 2012). Different studies on recovery of aphasia
show some variation in results, depending on assessment time and measures. However, the majority of these studies suggest that about one third of those who survive stroke with following aphasia have recovered from aphasia 12 to 18 months after the stroke and about 60% still suffer from aphasia (Pedersen et al., 2004). Lazar et al. (2010) suggests that the initial aphasia severity and the extent of recovery during the first weeks post-onset can have prognostic value with the extent of long-term disability. Spontaneous recovery from aphasia decreases after three months post-onset and reaches a plateau at about six months after the stroke. This period of three months when the language abilities improves the most and then stops is called “spontaneous recovery period” (Lazar & Antoniello, 2008; Lendrem & Lincoln, 1985).

Aphasia might improve with treatment, although it is not clear how much recovery that can be expected and for how long the process will be. Because of the fact that the severity of aphasia can range from mild to severe, the improvement differs from patient to patient (David, 1989). The language therapy should start early in the recovery process, because patients that receive therapy early on show more progress than those who does not receive therapy in the early stages (David, 1989). This finding is related to the spontaneous recovery period (David, 1989). The impaired language and communication skills in PWA can improve years after onset as an effect of language therapy (Basso & Macis, 2011; David, 1989). Long term therapy in combination with intense therapy show more progress than less therapy (Basso & Macis, 2011; David, 1989). It is suggested that intensive language therapy for PWA should be available for those who are motivated and have the energy to work with the reduced abilities to improve these (Mackenzie, 1991). Today, there are different therapeutic approaches to aphasia in the field. The approaches have evolved from linguistics, psychology and other branches of clinical speech pathology (Code & Müller, 1989). For a review of aphasia therapy, see Code (2012).

2.2.2. Symptoms

As mentioned earlier, aphasia is a consequence of a disease or damage to the language parts of the brain, which most often are located to the left cerebral hemisphere (ASHA, 2013). This language/communication disorder can affect all linguistic levels, such as the phonological (sound), morphological and syntactical (grammar), lexical (word) level, and pragmatics (Ahlsén, 2006; Code, 2012). There are typical symptoms associated with aphasia like literal paraphasias, i.e., addition, deletion or substitutions of phonemes, and verbal paraphasias, i.e., word substitutions (Ahlsén, 2006). PWA can use new, made-up words that often are incomprehensible for people surrounding the person, these words are called neologisms. They can use perseverations, i.e., constantly repeating a word or syllable. Their language can be agrammatical, which means that the language has reduced grammatical accuracy (Ahlsén, 2006). Then the language often involves short or incomplete sentences and omission or substitution of function words and grammatical morphemes. It is hard for these people to interpret utterances with help from the grammar. If PWA have word-finding problems it is called anomia. Another symptom associated with aphasia is reduced comprehension of language, both auditory and orthographic (Ahlsén, 2006).

2.2.3. Categorization

The loss of language abilities can be total or partial and the aphasia can affect any or all of the language abilities (LaPointe, 2005). The aphasia outcome can differ from person to person, and this means that aphasia can be categorized into different subtypes. There
are two main “schools” in aphasia research and therapy today (Ahlsén, 2006). The Boston (neo-classical) classification, which is based on the reintroduction of the Wernicke-Lichtheim model (Tesak & Code, 2008) inspired by the neurologist Geschwind and others, and the classification of Luria and his theory on functional systems (Ahlsén, 2006). Luria was a physician and neuropsychologist (Ahlsén, 2006). Both of these classifications classify aphasia into different subtypes depending on symptoms and localization of the injury in the language parts of the brain (Ahlsén, 2008). Both classifications are used in Sweden (see Ahlsén, 2006 for more information).

Aphasia can also be categorized more simply as fluent or non-fluent (Code, 2012). Due to how the brain is organized, non-fluent forms of aphasia typically result from a lesion in the anterior part of the language area (in front of the central sulcus) in the left hemisphere and fluent forms of aphasia typically result from a lesion in the posterior part (behind the central sulcus) (Ahlsén, 2006; Code, 2012). This distinction with fluent or non-fluent aphasia speech is widely used and classic aphasia types are generally grouped together based on whether they are fluent or non-fluent (Code, 2012). Non-fluent aphasia is characterized by speech that is slow and hesitant with utterances that have many pauses and a lack of articulatory precision and prosody (Ahlsén, 2006; Code, 2012). Anomia for verbs is common with non-fluent aphasia and the grammar is usually incorrect (agrammatism), especially for function words (Ahlsén, 2006; Code, 2012). In addition, word inflections are missing or being misused with non-fluent aphasia. For most people, the writing is affected in the same way as their speech. Language comprehension can also be affected, but usually not to the same extent as speech and writing abilities (i.e., expressive abilities) (Kearns, 2005). One of the most common types of non-fluent or anterior aphasia is Broca’s aphasia (Ahlsén, 2006; Code, 2012). Broca’s aphasia can range from mild, with mild articulatory problems and agrammatism, and word-finding problems, to severe, with prominent apraxia of speech and severe agrammatism. Comprehension is often preserved when mild Broca’s aphasia, but subtle deficits in language comprehension can be seen with any severity of Broca’s aphasia (Code, 2012).

Aside from an injury in the anterior portion of the brain causing non-fluent aphasia, an injury in the posterior part of the brain can be categorized as fluent aphasia (Ahlsén, 2006; Code, 2012). When this type of aphasia, the speech is often tangled which is shown by self-interruptions, restarts, paraphrases and unsystematic substitutions or omissions of grammatical morphemes (Caspari, 2005). Both literal and verbal paraphasias as well as neologisms are present as well as anomia. In addition to expressive deficits, language comprehension may also be affected (Caspari, 2005). The most common form of fluent or posterior aphasia is Wernicke’s aphasia (Ahlsén, 2006; Code, 2012). The hallmark symptoms of Wernicke’s aphasia are fluent speech, frequent paraphasias and comprehension problems. Similar to other types of aphasia, these symptoms range from mild to severe (Code, 2012).

Although, it is important to keep in mind that aphasia is not just one thing or another, the degree of aphasia varies widely among PWA - from those where the reduction is not noticeable in conversations to those who can’t use any of their language modalities (Code, 2012).
2.3. Communication

2.3.1. Importance of communication
Communication is an important part of behavior, but when the word communication is used colloquially, it is often used with a different meaning than the true meaning of the word (Rai & Rai, 2009). Communication is not only talking, writing or sending messages to another person. It also involves making sure that the message was received by the person it was meant for, that the receiver understands the message, and that the receiver respond to the message, and then that we, ourselves, have the ability to understand, respond and answer to someone else’s message (Rai & Rai, 2009). Communication is an ability that humans possess and is difficult to hold back (Rayudu, 2010). Without communication with one another there will be no mutual understanding, which is the most important part of a human relationship. Humans have several ways to communicate. For instance we use sight, touch, sound, smell, and more to communicate with one another (Rayudu, 2010). Communication in all its forms is essential when establishing and maintaining relationships (Holmes, 2001).

2.3.2. Difficulties in communication following aphasia
The ability to communicate is affected in several ways when suffering from aphasia. As written above your speech could be fluent or non-fluent, you may have anomia, agrammatism, use different kinds of paraphasias, have difficulties with reading and writing, etc. Most of the PWA do not only have aphasia, many people do also have cognitive impairments (Code, 2012). According to Tatemichi et al. (1994) and their study on cognitive impairment after stroke 35.2% of stroke survivors suffer from cognitive impairment. Cognitive ability in form of attention, memory, sensitivity to and production of emotional expressions and the capacity to oversee the situation as a whole are important elements that affect the use of language in communication. Cognitive issues could lead to difficulties with socialization and communication. Other aspects that could raise a problem with communication for PWA are trouble understanding longer utterances, metaphors, inference, abstractness, and more (Ahlsén, 2006). Research has also shown that PWA do often not get the chance to take a speaker role, because relatives often speak for them (Code, 2012). Davidson et al. (2008) found that older PWA more often take a passive role in interaction, talks less in telephone, and have smaller social networks than the people without aphasia. Having impaired communicative ability, such as aphasia could lead to decreased social participation (Davidson et al., 2008).

2.4. Related disorders – persons with aphasia and cognitive deficits
Stroke may affect all cognitive functions, but there are some more frequent cognitive impairments seen after stroke, e.g., aphasia (which is the most common one), memory impairment, disorders of executive functions, impairment of attention, visuo-spatial disorders (Knapp, 2010; Lincoln et al., 2011).

A cognitive impairment seen after stroke is difficulties with memory (Knapp, 2010; Lincoln et al., 2011). The prevalence of memory impairments one to two weeks after stroke onset varied from 13% to 50 %. This number declined to 11% to 31% one year after stroke onset (Snaphaan, 2007). Different types of memory can get affected, e.g., episodic memory which is the memory of personal events, or working memory, which is the memory that makes it possible to retain and manipulate information for a short amount of time (Lincoln et al., 2011). Executive functions involve several cognitive
domains, e.g., cognitive flexibility, planning and problem solving (Lincoln et al., 2011). Vataja et al. (2003) found that approximately 34% of the participants in their study suffered from executive dysfunction. Difficulties focusing and maintaining attention are difficulties adults with brain-injury may experience (Brookshire, 2003; Knapp, 2010). These difficulties can lead to poorer performance the further you get into a task. Attention and focusing difficulties may vary over time, with intervals of better or worse performance in tasks that seemingly independent to changes in tasks, etc. (Brookshire, 2003). Neglect and agnosia are types of visuo-spatial disorders that most often occur after a lesion in the right parietal lobe. These types of disorders can be noticeably disabling, and might lead to difficulties living and functioning on their own (Knapp, 2010).

2.5. Quality of Life

Quality of Life (QoL) is a concept that is both subjective and multidimensional (Cella, 1994). It is preferred to be measured from the patient’s perspective (subjective) and it involves different areas of the patient’s life (multidimensional), such as physical well-being, functional ability, emotional well-being and social well-being (Cella, 1994). The term Health related Quality of Life (HRQoL) is also subjective and it consists of multiple dimensions of a person’s health, such as the concepts of physical, social and emotional health (WHOQOL Group, 1998). HRQoL is more directly linked to health than QoL and it gives information about the impact of a health state on a person’s ability to live a meaningful life (Bullinger et al., 1993; Guyatt et al., 1993). The term QoL is wider than HRQoL, which means that it includes more conditions that are related to a person’s daily functioning (e.g., family, social contacts). QoL also includes, but is not limited, to health (Bullinger et al., 1993).

2.5.1. Impact of stroke on Quality of Life

Stroke results in a major change in life for those who survive and can affect different aspects in a person’s life. Many of the stroke outcome assessments that are available today are often limited to the extent of neurologic impairment and extent of functional disability. Such assessments often overlook the stroke survivors’ well-being. Measurements of HRQoL are probably more or at least as relevant to stroke patients than measurements of the impairments or disabilities that the stroke resulted in (Abubakar & Isezuo, 2012). To use HRQoL assessments in health care evaluations, the stroke survivors can give their perspective of the impact of the disease (Intercollegiate Stroke Working Party, 2008). That is, HRQoL measurements can give insight on how the stroke has affected the patient, which is important information for professionals and the other people surrounding the patient (e.g., family members, caregivers). It can also result in a broader description of the disease and the outcomes that it brings (Abubakar & Isezuo, 2012).

One of the more common HRQoL measurements is the Stroke Impact Scale (SIS; University of Kansas Medical Center, 2013), which was launched in 1999 as a tool to measure the multidimensional consequences of stroke. SIS is diagnostic specific and the measure considers the perspective of the stroke patient in multiple domains, ranging from ADL and memory to communication and social participation (Duncan et al., 1999). For example, Nichols-Larsen et al. (2005) used the SIS in an investigation on factors that influence QoL in stroke survivors. Results showed that age, gender, education level, stroke type, concordance (paretic arm = dominant hand), upper
extremity motor function and comorbidity were significantly associated across all the different SIS domains. Nichols-Larsen et al. (2005) used SIS but stated that their results may not generalize to lower functioning stroke patients. The authors noted that it is important to consider individual characteristics of stroke survivors with mild to moderate stroke when developing comprehensive, targeted interventions that are used to maximize recovery after the stroke and at the same time improve HRQoL in stroke survivors. Individual interventions also provide social support (Kriuthof et al., 2013). A review by Kriuthof et al. (2013) shows that social support has a positive relation to stroke survivors’ HRQoL.

2.5.2. Impact of aphasia on Quality of Life

Humans use language to communicate; it is our key for interplay with each other (Polkinghorne, 1988). Language allows us to give and receive messages, i.e., social participation. Because of language, people are a part of a larger social group (Polkinghorne, 1988). Aphasia following stroke can be a huge disruption of one’s previous life and may affect all dimensions of QoL (Code & Herrmann, 2003). This may be especially true when it comes to communication ability and language use. PWA following stroke are victims of losing an ability they had and used regularly (Duncan et al., 2002). This disruption in life is often sudden and dramatic (Code & Herrmann, 2003). According to Hilari (2011), PWA report significantly poorer HRQoL than a control group of stroke survivors without aphasia. Furthermore, Ross and Wertz (2003) reported that PWA report poorer QoL than healthy controls, especially when in independence, regarding social relationships and access to aspects of their environment domains. All of this provides support for the notion that the presence of aphasia can have a significant impact on a person’s life.

Most of the emotions in people are related to the interactions we have with others (Code & Herrmann, 2003). It is these interactions that give us different feelings in different contexts, such as happiness, sadness, anxiety and so on (Code & Herrmann, 2003). When discussing the impact of aphasia, it is important to recognize that aphasia not only has an impact on the PWA, but also has a significant impact on their social environment, in particular the family and loved ones (Code & Herrmann, 2003). The acquired communicative disability forces the PWA to adjust to a new communicative environment and research shows that PWA and their families experience stressful changes (Code, 2012). These stressful changes can arise from professional, social and/or familial role changes, including reductions in social contacts, being depressed or frustrated and increased aggression (Code, 2012). Each of these not only translates into immense changes in QoL for the PWA but also their families (Code & Herrmann, 2003).

Clearly, PWA may have reduced QoL for all the reasons outlined above and part of the therapy is to improve the quality of the persons’ communicative experience. To do this, the communicative and social environment of the PWA needs to be adjusted (Code, 2012). This is important because research shows that recovery and response to therapy in PWA are significantly influenced by both emotional and psychosocial factors (Ahlsén, 2006; Code & Herrmann, 2003). When it comes to both stroke and aphasia, the goals of rehabilitation programs and therapy include attempting to improve the person’s sense of health, well-being and QoL (Intercollegiate Stroke Working Party, 2008). One of the more daunting tasks of both research and therapy is to identify which factors are more strongly associated with a person’s HRQoL. Without this information, it is hard to
formulate intervention and rehabilitation programs that are adapted to PWA (Carod-Artal & Egido, 2009). HRQoL assessments are therefore an important part in health evaluations (Abubakar & Isezuo, 2012).

2.5.2.1 Difficulties associated with obtaining Quality of Life data from persons with aphasia
Since HRQoL is subjective (Cella, 1994) and dynamic, and because of the fact that PWA have communication problems, PWA are often excluded from QoL studies because of their communication impairments. It is therefore difficult to generalize the results from these studies and apply them to PWA. Furthermore, studies that do include PWA often use proxy responses (i.e., a person who answers for the PWA). Sometimes when the PWA are included, the data collection is unfinished because of the communicative difficulties and results are therefore incomplete (Duncan et al., 2002). If PWA are included in studies, it is very common that the studies don’t mention how the PWA could handle the complex questionnaires that are used (King, 1996). Despite the difficulties, it is desired that studies in QoL and aphasia should be based on self-reports from PWA because of the fact that QoL is highly subjective and self-reports are therefore more valid than any proxy report (WHOQOL Group, 1998).

2.5.2.2 Lack of appropriate survey instrument
One of the major difficulties in delineating QoL for PWA is that many of these people do have concomitant cognitive and language impairments and are thus unable to complete the questionnaires. Most QoL or HRQoL questionnaires are not designed to be used with people that have language and communication difficulties and this could lead to missing and incomplete data. As a result, this can lead to overall biased estimates of QoL and HRQoL in PWA (Pickard & Knight, 2005). However, there are assessments developed for PWA, such as the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39), that has been proved valid and reliable (Hilari et al., 2003).

The Aphasia Institute in Toronto, Canada, developed an assessment tool that is designed to be suitable for PWA and to access aspects that affects QoL (Aphasia Institute, 2013). The Assessment for Living with Aphasia (ALA; Aphasia Institute, 2013) is a measurement that has been shown to be valid and reliable and is used with stroke patients to measure their own view on aphasia and life participation (Aphasia Institute, 2013). The ALA provides quantitative and qualitative data based on self-report. It is designed with a pictographic approach thus allowing for participation across a full range of aphasia severity. The ALA was developed to capture real-life issues that are connected to aphasia (Kagan et al., 2008). In addition, the ALA was based on Living with Aphasia: Framework for Outcome Measurement (A-FROM; Kagan et al., 2008), which is in line with World Health Organization’s International Classification of Functioning, Disability Health (ICF) (Kagan et al., 2008).

2.5.2.3 Summary of previous research
As stated above, there are difficulties in obtaining data from PWA primarily due to the potential presence of language and cognitive deficits. However, there are some existing research in the field of living with aphasia and QoL. As a summary of the ongoing research: Hilari et al. (2012) found in their review on quantitative studies on HRQoL for PWA that emotional distress/depressions, aphasia severity and communication disability, comorbidity, activity level and social factors were predictors of HRQoL. Hilari et al. (2012) summarized results from qualitative studies and found a similar trend: high degrees of looking forward to the future/having a positive attitude, verbal
communication, body functioning and social support were associated with a higher HRQoL.

Hilari et al. (2012) also summarized results from several long-term outcome stroke studies. The summary shows that depression is a more frequent problem among stroke survivors with aphasia than in stroke survivors without aphasia. Aphasia severity is related to HRQoL, where more severe aphasia is associated with lower HRQoL. Limited social support is also shown to be associated with lower HRQoL. According to this study, PWA showed the largest negative relationship to HRQoL than the other disease groups (cancer and Alzheimer’s).

2.5.3. **Proxy vs. non proxy responses**

There are some difficulties associated with using a spouse or a caregiver as a proxy since they might overestimate impairments. Because of this proxy responses may not be reliable (Cruice et al., 2011). However, one study done by Carod-Artal et al. (2009) with the SIS showed that patient-proxy agreement had no statistically significant difference in 6 out of 8 domains. The parts that proxies significantly scored lower were ‘strength’ and ‘ADL’. According to this study the subjective domains should be evaluated with caution since the agreement strength was low. In another study done by Hilari et al. (2007) they found, by using SAQOL-39, that there were only small differences between the PWA and their proxy’s answers. They also looked at agreement based on the Intra-class Correlation Coefficient (ICC), and found that for the overall scale and the physical domain it was excellent, good for the communication domain and the psychosocial domain, and moderate for the energy domain. The authors therefore propose that proxy respondents can provide reliable information using the SAQOL-39. According to both Carod-Artal et al. (2009) and Hilari et al. (2007) the characteristics, such as sex and age, for the PWA and their proxy did not affect the agreement level in the assessments used in the studies. According to the review made by Oczkowski and O’Donnell (2010) of nine different studies, they found that rating physical function and self-care had greater compliance than when rating pain, emotion and social function. They found that the reliability of proxy respondents for QoL was moderate to substantial, and the most consistent predictor was the severity of the stroke. In summary, there are studies that show that it is possible to use proxy-responses, whereas some studies show that for some aspects it is not reliable to use proxy responses. If proxy response is used it is important to evaluate the responses carefully especially when using it to gather information about subjective domains.

2.6. **Rational for the study**

PWA have language difficulties (Code, 2012) and their QoL has most likely been affected (Code & Herrmann, 2003). Because of their loss of language abilities, it is difficult to use PWA in QoL studies, which can lead to the use of proxy responses (Duncan et al., 2002). This way of collecting information may not be reliable since it is difficult to know how other persons feel (WHOQOL Group, 1998), especially when that person has difficulty conveying their thoughts/emotions. This thesis is done in collaboration with Paul Evitts’s, Ph.D., CCC-SLP, research on QoL and aphasia, investigating the issue of proxy answer reliability. The study uses pictures/icons to make the PWA understand the procedure and provide more accurate responses.
3. Aim

The aim of this study was to compare the rankings from QoL questionnaires for PWA with the rankings from their spouses/caregivers.

3.1. Specific research questions

1. How well do the ranking from persons with aphasia concerning QoL correspond to the rankings from their spouses/caregivers (i.e., proxy responses)?
2. What QoL aspects do PWA and their spouses/caregivers rank as the “most impacted” and the “least impacted”?
4. Method

The study was a questionnaire-based cross-sectional survey. The study involved two groups of participants (PWA and their spouses/caregivers) ranking 11 different aspects related to QoL. Spouses and/or caregivers were instructed to respond as proxies for their partners.

4.1. Participants

The participants consisted of two groups, PWA and spouses/caregivers. Both sets of participants were recruited from the Snyder Center for Aphasia Life Enhancement (SCALE) in Baltimore, MD, USA. SCALE is a non-profit aphasia support and community center for PWA and was founded in 2008 (SCALE, 2013). The overall mission of SCALE is to improve the QoL of those with aphasia and their families. SCALE is a place for people to connect, offering interactive group activities for members as they re-enter society following their stroke, providing educational materials to the community, and raising public awareness through outreach and advocacy (SCALE, 2013). Important to acknowledge is that the members at SCALE pays a membership.

4.1.1. Persons with aphasia

All members of SCALE diagnosed with aphasia 18 years and older \( (n = 50) \) were offered inclusion in the study. These persons had different types and severity of aphasia, with or without apraxia. Information about the type and severity of aphasia for each participating PWA was not included in the study. All members from SCALE were assessed by a speech and language pathologist (SLP) and diagnoses of aphasia were provided before the members entered SCALE. The participants had aphasia following stroke. Both men and women were included in the study.

4.1.2. Spouses/caregivers

The spouses/caregivers that were included were required to be 18 years or older. Both men and women were included in the study. For the purposes of this study, the term ‘caregiver’ was loosely defined and it was the responsibility of the PWA to identify whether or not the person was a caregiver. A caregiver could be a brother/sister, fiancé/fiancée, and son/daughter to the PWA. Information about what kind of caregivers and how long they had known their PWA were not included.

4.2. Data collection

This study was a part of a larger ongoing study by Evitts at Towson University. The data collection had been taking place for the last 20 months and was performed by several examiners. The questionnaire was developed for this study, and therefore it has not been proved valid or reliable. Except for the data used in this study, other data was collected for the larger ongoing study.

Please note that there are some deficiencies in Appendices A, E and F (see 6.2.), but since the instructions were given verbally these deficiencies were corrected by the examiner.
4.2.1. Questionnaire for persons with aphasia

The questionnaire (Appendix A) used in this study consisted of 11 aspects of QoL; the aspects were selected based on previous studies on stroke and QoL (Oczkowski & O'Donnell, 2010). The 11 aspects that were used were: (a) Leisure time; (b) Sex life; (c) Vocation/Occupation; (d) Social contacts; (e) Relationship with partner; (f) Family life; (g) Ability to self-care; (h) Finances; (i) Overall ability to communicate; (j) Physical problems associated with stroke; and (k) Life as a whole. Due to the presence of language deficits in all of the participants in this group, each aspect was accompanied by a picture/icon or a series of pictures/icons that visually depicted the concept of that aspect (Appendix B). For instance, the concept of leisure was accompanied by a series of pictures showing a person fishing, knitting, or reading. Evitts based these icons on similar icons used in the ALA. Each aspect was accompanied by a rating scale, also based on ALA (Appendix B). For the PWA that could not read or had comprehension difficulties, this scale could be used to clarify the meaning of the four cards used to show the examiner how impacted the 11 aspects were (see 4.2.2.).

4.2.2. Data collection procedure for persons with aphasia

The data collection was performed by approximately five examiners at SCALE. All of the examiners received training on administration of the testing procedure from Denise McCall, M.S., CCC-SLP who is a certified speech-language pathologist with 28 years of experience. Mrs. McCall also serves as the director of SCALE. The training session consisted of going through the questionnaire and the test procedure with presentations of how to ensure that the ranking of the aspects was understood by the PWA. The entire data collection lasted for approximately 20 months.

For the rating procedure, the participant and the examiner were alone in a room, sitting next to each other. The procedure started with the examiner going through the consent form (Appendix C), which explained the study and the participant’s rights. To better accommodate the PWA and in an attempt to overcome the language deficits, the consent form was designed with pictures and was consistent with the consent form included in the ALA. The examiner made sure that the participant did understand the consent form using pictures for “yes” and “no” (Appendix C). Once the participant acknowledged understanding, he/she and the examiner signed the consent form. A copy of the form was made for the participant. The examiner then started the testing with showing the icons of the 11 aspects of QoL. Then the examiner placed four text cards on the table. These cards showed a range from “severely impacted”, “somewhat impacted”, “mildly impacted” to “not impacted at all”. The participant’s task was to show the examiner, by using the four cards, how impacted the 11 aspects were these days. The aspects were shown one at a time and a question from the questionnaire (Appendix A) for each aspect was asked by the examiner. During this task the participant was told to keep all 11 aspects in mind, as he/she was answering each aspect. In some cases aspects were excluded since the PWA for instance may not have a partner. In such cases the examiner noted ‘n/a’ (not applicable) under the specific aspect. This was the first step towards the final ranking of the aspects. This step is not included in the results; it was only used to make it easier for the participant to rank the 11 aspects of life since the aspects were now grouped in four (i.e., “severely impacted”, “somewhat impacted”, “mildly impacted” and “not impacted at all”). After this, the participant was asked to rank the aspects from “most impacted” (number 1) to “least impacted” (number 11). The ranking started with the aspects in the “severely impacted” group and ended with the “not
impacted at all” group. From this ranking, the examiner entered the aspects onto a score sheet (Appendix D). The procedure described is the main procedure, but since aphasia can vary in severity, it was not possible for the examiner to follow the procedure fully all of the times. In such cases the procedure was adjusted, e.g., when a participant did not understand the task, two examiners could show the procedure by using role play or the participant could use the scale (see 4.2.1.). Such modifications were done to ensure that the participant fully understood the procedure.

4.2.3. Questionnaire for spouses/caregivers

The proxy questionnaire (Appendix F) consisted of the same 11 aspects of QoL as for the PWA. To make the test situations in both groups as similar as possible the same picture/icon or a series of pictures/icons (Appendix B) were used.

4.2.4. Data collection procedure for spouses/caregivers

The data collection was performed by approximately five examiners. All of the examiners received training from Mrs. McCall (see 4.2.2.). The entire data collection lasted for approximately 20 months.

The spouse/caregiver and the examiner were alone in a room, sitting next to each other. The procedure started with the spouse/caregiver reading the consent form (Appendix E), which explained the study and the participant’s rights. The examiner made sure that the participant did understand the consent form. Once the participant acknowledged understanding, he/she and the examiner signed the consent form. If the participant had any questions the examiner would answer these questions. After the participant agreed to participate the testing could start. The testing was carried out in the same way as for the PWA (see 4.2.2.). That is, the first task was to group the aspects into the four different groups using the four cards. The second task was to rank the 11 aspects of life from “most impacted” (number 1) to “least impacted” (number 11). All participants acting as a proxy were instructed verbally and in written form to complete the ranking based on how they thought their respected partner (their PWA) would complete the scale and not themselves. That is, the ranking was to be a reflection of their partners’ responses and not their own. When testing the spouses/caregivers other questionnaires (Appendix F) and score sheets (Appendix G) than in the PWA group were used.

4.3. Data analysis

Data from the score sheets were recorded in an Excel document and then the data were transferred to a statistical analysis software program (IBM SPSS Statistics Version 21) to process and analyze data. Measure of the internal consistency (covariance) of the two groups of rankings was tested by Cronbach’s Alpha. The alpha value runs from 0 to 1 and values >0,7 are considered to have increased reliability across rating groups (Esaiasson et al., 2010). It is a common belief that the Cronbach’s alpha ranges from 0 to 1, but the alpha can have a negative value if the internal consistency is extremely poor (Yu, 2001). Intraclass Correlation Coefficients (ICCs) were used to calculate proxy and self-report agreement. Both single and average measures were calculated. The single measure is a value for the reliability of rankings for one single rater (in this study a single rater is a pair, i.e., one PWA and their spouse/caregiver). The average measure is a value for the reliability of the average rankers together (Medcalc, 2013). ICCs are divided into groups indicating agreement: <0,40 indicates poor agreement; 0,40-0,75 indicates fair to good agreement; and 0,76-1,00 indicates excellent agreement (Rosner,
Finally, Spearman’s rho was calculated to determine the strength of the relationship between two variables (Laerd Statistics, 2013). Since our data was in ordinal scale and a normal distribution was not expected due to the existence of impairments, the non-parametric Spearman’s rho was used. The r value from Spearman’s rho runs from +1 to -1 with +1 indicating a perfect positive association, -1 indicating a perfect negative association and 0 showing no association (Laerd Statistics, 2013). These tests were used to gather information to answer the research question number one, regarding how well the ranking from PWA correspond to the rankings from the spouses/caregivers.

Mean values were calculated in IBM SPSS Statistics Version 21 to answer research question number two, regarding which of the 11 aspects the PWA and the spouses/caregivers had ranked as the “most impacted” and the “least impacted” ones. Mean values are sensitive to outliers (Esaiasson et al., 2010), which might make these results less reliable. Still, mean values could give interesting findings regarding the ranking of aspects of life, and they are therefore included in the results.

4.4. Ethical aspects

This study has been reviewed by the Institutional Review Board for the Protection of Human Participants at Towson University, MD, USA.

All the participants received a consent form with information about the study, confidentiality, gains and risks, that participation was voluntary and that the participant could withdraw at any time without explanation.
5. Results

5.1. Participants

In the group of PWA there were 24 men and seven women \((n = 31)\). The participants in this group had different types and degrees of severity of aphasia. The types and degrees of severity of aphasia were not documented at SCALE. Their mean age was 63.3 years (range = 44.4 – 86.3 years). Mean time since stroke-onset was 7.5 years (range = 0.8 – 19.3 years). In the spouse/caregivers group neither gender nor age were documented, since this was considered not important for answering our research questions. A total of 26 participants (five spouses/caregivers declined participation) in the spouse/caregiver group completed the ranking. In addition to spouses, this group consisted of brothers/sisters, fiancés/fiancées, and sons/daughters to the PWA (i.e., caregivers). In some cases the participants could not rank all of the aspects of life e.g., Relationship with partner, since they did not have a partner. This led to that the number of participants varies in different aspects. The total number of participants in the study was 57.

5.2. Statistics

5.2.1. Correlation between the ranking of the persons with aphasia and their spouses/caregivers

The results were based on the rankings of the 11 aspects ranged from “most impacted” (number one) to “least impacted” (number 11).

Results from Cronbach’s alpha, used to compare rankings of the 11 aspects of life from the two groups (PWA and spouses/caregivers), showed poor consistency. All of the values from the different aspects of life were low (<0.7) (Table 1). The aspect of life that showed the highest alpha value was Ability to self-care (0.608). This value showed the highest alpha value in this study, which means that this aspect has the highest internal consistency between the two variables (PWA and spouses/caregivers). However, the internal consistency for Ability to self-care was still low (<0.7). The aspect of life that showed the lowest alpha value was Vocation/Occupation (0.295). The results do also show a negative alpha value (Finances: -0.597), which means the internal consistency between the two variables (PWA and spouse/caregivers) in Finances was extremely poor.

ICC was used to calculate proxy and self-report agreement. The ICC reported both single and average measures (Table 1). Both measures are reported in Table 1, but the focus in the text will be on the single measures since the study was comparing single pairs of raters. The single measures were calculated from both the PWA and their spouse/caregiver. Single ICC values for Leisure, Sex, Vocation/Occupation, Life as a whole, Social contacts, Family life, Finances, Overall ability to communicate, Physical problems, and Relationship with partner were all <0.4, which indicated poor agreement. The single ICC value for Ability to self-care was >0.4, which indicated fair to good agreement.

Results from Spearman’s rho showed low association between the two variables (PWA and spouse/caregiver) on group level (Table 1). Two results have a \(p\) value below 0.05. These are Family life and Ability to self-care.
5.2.2. Most and least impacted aspects of life

Mean values for ranking the aspects were calculated to get information to answer question number two (Figure 1 and 2, and Table 2).

The mean values show which of the aspects that have been ranked as the “most impacted” (1) and the least impacted (11), for both PWA and spouses/caregivers. The PWA ranked Vocation/Occupation as the “most impacted” aspect of life ($M = 3,8$), and Family life as the “least impacted” one ($M = 8,0$). The spouses/caregivers ranked Overall ability to communicate as the “most impacted” aspect of life ($M = 3,4$), and Ability to self-care as the “least impacted” one ($M = 8,1$).
Table 2. Mean (M) ranking values and standard deviation (SD) of 11 aspects of life for persons with aphasia (PWA) and spouses/caregivers (s/c). It also shows the lowest and highest ranking value in both groups of participants for each aspect.

<table>
<thead>
<tr>
<th>Aspects of life</th>
<th>M</th>
<th>SD</th>
<th>Lowest single ranker</th>
<th>Higest single ranker</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>PWA</td>
<td>s/c</td>
<td>PWA</td>
<td>s/c</td>
</tr>
<tr>
<td>Leisure</td>
<td>5.3</td>
<td>6.7</td>
<td>2.6</td>
<td>2.6</td>
</tr>
<tr>
<td>Sex</td>
<td>4.9</td>
<td>6.0</td>
<td>3.3</td>
<td>2.9</td>
</tr>
<tr>
<td>Vocation/Occupation</td>
<td>3.8</td>
<td>3.7</td>
<td>2.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Life as a whole</td>
<td>4.9</td>
<td>3.8</td>
<td>2.5</td>
<td>2.5</td>
</tr>
<tr>
<td>Social contacts</td>
<td>6.5</td>
<td>7.0</td>
<td>3.2</td>
<td>2.7</td>
</tr>
<tr>
<td>Family life</td>
<td>8.0</td>
<td>7.6</td>
<td>2.8</td>
<td>2.5</td>
</tr>
<tr>
<td>Ability to self-care</td>
<td>7.3</td>
<td>8.1</td>
<td>3.1</td>
<td>2.7</td>
</tr>
<tr>
<td>Finances</td>
<td>6.7</td>
<td>5.3</td>
<td>3.2</td>
<td>2.9</td>
</tr>
<tr>
<td>Overall ability to communicate</td>
<td>4.9</td>
<td>3.4</td>
<td>2.9</td>
<td>2.9</td>
</tr>
<tr>
<td>Physical problems</td>
<td>5.0</td>
<td>5.3</td>
<td>2.6</td>
<td>3.2</td>
</tr>
<tr>
<td>Relationship with partner</td>
<td>7.7</td>
<td>7.4</td>
<td>2.8</td>
<td>2.9</td>
</tr>
</tbody>
</table>

*Figure 2.* Mean ranking values of 11 aspects of life for spouses/caregivers. Value 1 = “most impacted”, value 11 = “least impacted”.

*Table 2.* Mean (M) ranking values and standard deviation (SD) of 11 aspects of life for persons with aphasia (PWA) and spouses/caregivers (s/c). It also shows the lowest and highest ranking value in both groups of participants for each aspect.
6. Discussion

6.1. Result discussion

Overall results showed poor agreement and low internal consistency for proxy responses. Results also showed that PWA identified *Vocation/Occupation* as the “most impacted” aspect of life and *Family life* as the “least impacted” aspect, whereas, spouses/caregivers ranked *Overall ability to communicate* as the “most impacted” aspect of life and *Ability to self-care* as the “least impacted” aspect of life.

To answer our first research question Cronbach’s alpha, ICC and Spearman’s rho were used.

Results from Cronbach’s alpha reported low internal consistency. To be considered reliable the alpha value should be $>0.7$ (Esaiasson et al., 2010). All of the alpha values from the different aspects of life were $<0.7$. When the values are low ($<0.7$) the strength of the relationship between the two variables (PWA and spouses/caregivers) is considered not to be strong. This suggests that proxy rankings may not be reliable for use in studies on QoL for PWA. Since this is the first time this non-standardized questionnaire with a pictographic scale was used as a testing tool, it is important to keep in mind that this result may not be due to a weak relationship, but to a poor questionnaire. A large range between the alpha values in the different aspects of life (range $= 0.295 – 0.608$) can be seen.

ICC was used to calculate proxy and self-report agreement. The single measure gives a value for the reliability of rankings for one pair (PWA and spouse/caregiver) of raters. Ten of the aspects of life had a value that was lower than $<0.4$, which indicates poor agreement, and one aspect of life had a value $>0.4$, which indicates fair to good agreement. This result of low values shows that the reliability of rankings between PWA and spouse/caregiver is low. This, once again suggests that proxy rankings are not reliable for use in studies on QoL for PWA. Even though one value ($0.425$) is $>0.4$ it is nevertheless barely $>0.4$. This result may also be due to a poor questionnaire rather than that proxy rankings may not be reliable to use in studies on QoL for PWA. Previous research suggests that proxy respondents can provide reliable responses. In a study done by Hilari et al. (2007) like in this study, they looked at agreement based on ICC. Their results suggest that proxy responses may be reliable. There is one difference in the study done by Hilari et al. compared to this study. That is that they have used an assessment tool that has been shown to be valid and reliable (Hilari et al., 2003). This difference may be the cause of the opposite results.

To determine the strength of the relationship between two variables Spearman’s rho was used. The results from Spearman’s rho showed a low association between the two variables (PWA and spouse/caregiver) on group level. This result suggests that proxy responses may not be accurate to use in studies on QoL in PWA. Once again, these results can be due to a poor questionnaire since it has not been proved valid and reliable. When looking at the $p$ value there are two results from Spearman’s rho that have a value below 0.05. The $p$ value show if the result has been affected by randomness. The chosen significance level is 95%, which gives a $p$ value of 0.05. Since *Family life* and *Ability to self-care* are both below 0.05 these results can be considered not to be affected by
randomness and implies that PWA and their spouses/caregivers ranked the aspects the same.

To answer our second research question mean values were calculated in addition to the other statistics. When looking at the mean values of ranking for the two groups, it is noticeable that some aspects have a similar mean value. These results still do not give important information since just one person could have ranked high and another one could have ranked low (i.e., outliers). It is important to remember that mean values are sensitive to outliers (Esaiasson et al., 2010). The mean value does not say anything about the relationship between the two variables, and it is not a trustworthy way to determine whether or not proxy responses are reliable to use in QoL studies. However, there is still some value in looking at mean values since it can give interesting information.

The mean values show that the PWA and the spouses/caregivers rank different aspects of life as the “most impacted” respectively “least impacted”. It is interesting to see that the spouses/caregivers rank Overall ability to communicate as the “most impacted” aspect. Even though the PWA rank Overall ability to communicate as second “most impacted” aspect of life it can be considered to be a quite big difference between the mean values (spouses/caregivers M = 3,4 and PWA M = 4,9). This could indicate that the PWA feels that their communication difficulties do not affect them as much as the spouses/caregivers think that their PWA feels. Another interesting finding is that both groups ranked Family life and Relationship with partner high (≥7,4). This might indicate that aphasia does not affect relationships among relatives to the same extent as other aspects of QoL are affected.

6.2. Limitations

The participants in the PWA group were all attending SCALE, and all the spouses/caregivers had contact with SCALE. This might make it difficult to draw conclusions to other PWA and their spouses/caregivers that are not attending SCALE or another similar aphasia center. The same study done on other participants might give another result. However, it was an advantage to have all the participants gathered at the same place. This made it easier to be flexible with time and to be effective when collecting data. Another advantage to have the participants gathered is that they are familiar with the location. This might make it easier for them to feel comfortable enough to talk about QoL.

During the data collection, several disadvantages in the study were noticed. The entire data collection has been going on for approximately 20 months. In a few cases this has led to that the data collection for one pair of participants (i.e., PWA and spouse/caregiver) has been delayed. For some of these pairs the data collection of the PWA was done approximately one year before the testing of the spouse/caregiver. During this time it is possible that the PWA QoL has changed. This might lead to that the spouse/caregiver and the PWA answers differently since they are not answering the questionnaire in the same time spectrum. To increase reliability and validity the data collection should have been collected in a shorter time frame.

Even though the study had been going on for almost two years, deficiencies in the material were still discovered. The consent form (Appendix E) for the spouse/caregiver
with instructions for the testing was incorrectly directed. E.g., in the consent form it says “However, the current ways to determine changes in your life may not be the best way to look at these changes and the impact on your life. The purpose of this study is to investigate what areas have the most impact on you quality of life”. This quote from the consent form is directed to the PWA rather than to the spouse/caregiver. This might be a problem since the spouse/caregiver may feel that it is unclear whether they should respond based on how their life has been impacted or based on how their PWA life has been impacted. The questionnaires (Patient and Family, see Appendix A+F), used when collecting data are also incorrectly formulated. The first part in both questionnaires containing the purpose and instructions for the study is formulated to the PWA and the questions for each aspect are directed to the spouse/caregiver. This makes it confusing for the examiner, and might lead to unclear or incorrect instructions. If a pilot study had been done before the data collection began these deficiencies could have been avoided.

In this study there was only two inclusion criteria. These were that the participants in the PWA group had to have aphasia following stroke and that the participants in both groups (PWA and spouses/caregivers) had to be 18 years or older. To include more inclusion criteria in the study the results might have been different. For example if types and severity of aphasia were inclusion criteria the PWA group would have been more defined and results would be easier to generalize to a specific group. In this study the group of PWA was very broad and this might have affected the results. For example, if the PWA consisted of persons with mild aphasia, they might have higher QoL than persons with severe aphasia, or vice versa. Another inclusion criterion could be that the spouses/caregivers should have been more specifically and narrower defined. Since the “spouse/caregiver concept” was not defined the results could have been affected. For example, if the inclusion criterion was that the caregiver had to be a partner that have lived together with the PWA for at least five years before the stroke, they might be able to answer more accurate as a proxy. A more defined concept like this could have led to a more reliable result.

When testing a participant the examiner asks him/her to keep the 11 aspects of life in mind when answering how impacted each aspect is. To keep 11 aspects in mind may be difficult, both for the PWA and the spouse/caregiver. When keeping these 11 aspects in mind short-term memory is being used. According to Passer et al. (2009) the short-term memory capacity limit is seven digits, plus or minus two. This information is consistent with the thought that keeping 11 aspects in mind may be difficult.

Another possible disadvantage in the study is that we are not native English speakers. This fact may be a disadvantage since we do not have the same ability to vary our language to the same extent as a native speaker, for instance if a participant does not understand a word or sentence we may not have the ability to come up with another word or sentence to explain what we mean. It might also be difficult for us to understand the participant. In these cases when communication difficulties appeared we chose to get help from Mrs. McCall.

Even though there were some disadvantages with the material and written instructions, they were still easy to give and follow. Another advantage was that all the participants were available several times a week when they were attending SCALE. In this way we could continue the data collection another day if necessary.
6.3. Suggestions for further research

One suggestion for further research is to replicate an improved version of the study, where the disadvantages mentioned in the discussion have been controlled for, in another country. It is interesting to see if a replication in another country would give the same results as in this study, i.e., that proxy responses may not be reliable. Another suggestion is to do an improved version of the study on PWA and their spouse/caregiver that are not members of an aphasia center such as SCALE. In this way it would be possible to get information about how a membership, such as SCALE would affect QoL. A third suggestion for research is to look at how the spouse/caregiver’s QoL has been affected after the stroke.

6.4. Conclusions of the study

In this study there was poor internal consistency and a weak correlation between the two groups. These results indicate that proxy responses may not be appropriate and should be interpreted with caution in QoL studies with PWA. When looking at mean values for the ranking of the 11 aspects of life Vocation/Occupation was the “most impacted” aspect for PWA and Overall ability to communicate for the spouses/caregivers. The “least impacted” aspect of life for the PWA was Family life and Ability to self-care for spouses/caregivers. An interesting finding from the mean values is that the PWA may not feel that their communication difficulties affect them as much as the spouses/caregivers think that their PWA feels. Another interesting finding is that both groups ranked Family life and Relationship with partner high. The conclusion from this is that aphasia might not affect relationships among relatives.
7. Acknowledgement

At last, many people have contributed to make this master’s thesis possible. We would like to thank some of these in particular.

First we would like to thank Paul Evitts for letting us be a part of his research on QoL and aphasia. Thank you for all your help and support, and for being a great mentor.

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Thanks to Denise McCall and everyone at SCALE for sticking out with us. You are all great people and this experience will be something we will always remember.

Further thanks go to the Program Committee for Speech and Language Pathology, Institution of Neurology at Uppsala University and to the Swedish Aphasia Association (Afasiförbundet i Sverige) for the economical support.

We would also like to thank Paul Evitts and his wonderful family for taking very good care of us, showing us around in Towson and inviting us to your beautiful home.
8. References


Snyder Center for Aphasia Life Enhancement (2013). About SCALE. *Snyder Center for Aphasia Life Enhancement, Baltimore*. Downloaded 17th of September 2013 from http://www.scalebaltimore.org/Snyder_Center_for_Aphasia_Life_Enhancement/Who_Are_We.html


9. Appendices

Appendix A: Patient Questionnaire
Appendix B: Icons for the 11 aspects of life
Appendix C: Consent form for PWA
Appendix D: Patient questionnaire – Score sheet
Appendix E: Consent form for spouses/caregivers
Appendix F: Spouse/caregiver questionnaire
Appendix G: Spouse/caregiver questionnaire – Score sheet
Appendix A.

**Patient Questionnaire**

The purpose of this study is to investigate how the stroke has impacted you. Please rank the following categories according to how much of an impact you feel that the stroke has had on your life (where you are today).

1) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

**Leisure time**

- [ ] Severely Impacted
- [ ] Somewhat Impacted # ________
- [ ] Mildly Impacted
- [ ] Not impacted at all

2) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

**Sex Life**

- [ ] Severely Impacted # ________
- [ ] Somewhat Impacted
- [ ] Mildly Impacted
- [ ] Not impacted at all

3) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

**Vocation/Occupation**

- [ ] Severely Impacted # ________
- [ ] Somewhat Impacted
- [ ] Mildly Impacted
- [ ] Not impacted at all

4) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

**Social contacts**

- [ ] Severely Impacted # ________
- [ ] Somewhat Impacted
- [ ] Mildly Impacted
- [ ] Not impacted at all

5) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

1
Appendix A.

Relationship with his/her partner

- □ Severely Impacted  # ________
- □ Somewhat Impacted
- □ Mildly Impacted
- □ Not impacted at all

6) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Family Life

- □ Severely Impacted  # ________
- □ Somewhat Impacted
- □ Mildly Impacted
- □ Not impacted at all

7) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Ability to self-care

- □ Severely Impacted  # ________
- □ Somewhat Impacted
- □ Mildly Impacted
- □ Not impacted at all

8) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Finances

- □ Severely Impacted  # ________
- □ Somewhat Impacted
- □ Mildly Impacted
- □ Not impacted at all

9) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Overall ability to communicate

- □ Severely Impacted  # ________
- □ Somewhat Impacted
- □ Mildly Impacted
- □ Not impacted at all

10) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.


Appendix A.

Physical problems associated with stroke

☐ Severe Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

11) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her _____________________.

Life as a whole

☐ Severe Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

Are there any other comments that you would like to share about the quality of life for people who have had a stroke?
Leisure Activities

- bicycle
- drive
- make, build
- cooking
- gardening
- museum/gallery
- reading
- writing
- television
- painting
- sewing
- telephone
Appendix B.

Sex

[Image of two people kissing]

Sex
Appendix B.

Job

working
Life as a Whole
Friends
Partner
Appendix B.

Relationships / Family
Self-Care

dressing

bathing

toilet

laundry

Appendix B.
Appendix B.

Money
Communication

PROBLEMS UNDERSTANDING others:

- HARD to UNDERSTAND when OTHERS TALK
- HARD to UNDERSTAND when you READ

PROBLEMS getting others to UNDERSTAND YOU:

- HARD to TALK
- HARD to WRITE
- HARD to get your THOUGHTS OUT
Physical Problems

- Physical disability?
  - walking disability
  - arm paralysis

- Other physical problems?
  - hearing loss
  - vision
  - tired
  - medical condition
  - problems in the washroom

Appendix B.
Appendix C.

Consent to Participate in Research

BEFORE ➡️ STROKE ➡️ TODAY
1. Answer
Appendix C.

Will this help research? YES  

Will this help you to talk better? NO  

Right to Withdraw:

✅ You can stop at any time.

✅ It is your choice.

✅ It is ok to quit.
Potential Risks:

There is **NO** danger in participating in this study.

Everything is **confidential**.

Will this **harm** you?  **NO**
Do you UNDERSTAND?

YES

? NO
Appendix C.

Project Consent:
The information presented on the previous pages has been explained to me.

I agree to participate in this research project.

I have been given a copy of this form.

Signature of Participant                      Date

Signature of Witness                          Date

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Appendix D.

Patient Questionnaire

The purpose of this study is to investigate how the stroke has impacted you. Please rank the following categories according to how much of an impact you feel that the stroke has had on your life.

DIRECTIONS: Please rank the items below from 1-11 with 1 as having the most impact on you and 11 having the least impact.

<table>
<thead>
<tr>
<th>ITEMS</th>
<th>Rank 1-11</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Leisure time</td>
<td></td>
</tr>
<tr>
<td>b. Sex life</td>
<td></td>
</tr>
<tr>
<td>c. Vocation/occupation</td>
<td></td>
</tr>
<tr>
<td>d. Life as a whole</td>
<td></td>
</tr>
<tr>
<td>e. Social contacts</td>
<td></td>
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<tr>
<td>f. Relationship with partner</td>
<td></td>
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<tr>
<td>g. Family life</td>
<td></td>
</tr>
<tr>
<td>h. Ability to self-care</td>
<td></td>
</tr>
<tr>
<td>i. Finances</td>
<td></td>
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<tr>
<td>j. Overall ability to communicate</td>
<td></td>
</tr>
<tr>
<td>k. Physical problems associated with stroke</td>
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</tbody>
</table>

Are there any other comments that you would like to share about the quality of life for people who have had a stroke?
Informed Consent for Participants

**Purpose**
People who have had a stroke have significant changes in their life. However, the current ways to determine changes in your life may not be the best way to look at these changes and the impact on your life. The purpose of this study is to investigate what areas have the most impact on your quality of life. Results of the study will provide health care professionals and others important information about what factors people who have had a stroke think are important.

**Procedures**
If you decide to participate, you will be asked to do the following:
1. Complete a brief questionnaire.
2. Answer a list of questions about your quality of life.

**Risks**
There are no known risks associated with participation in this study.

**Benefits and/or Compensation**
There is no direct benefit to you as a result of your participation in this study. Ultimately, the information gained from this study may help researchers and clinicians develop a better understanding of quality of life issues following a stroke.

**Costs**
There will be no financial costs to you for participating in this study.

**Confidentiality**
All research related records from this study will be maintained in a secure area and shared only with those assisting with the project. The investigators will not reveal the identity of participants if they publish or present the results of the study.

**Voluntary Participation**
Participation in this study is voluntary. If you decide to participate, you are free to withdraw your consent and to discontinue participation at any time without penalty.
11.3. Questions
I have read the information in this form. The investigator has answered my questions to my satisfaction. I know if I have any more questions after signing this form, I may contact Paul Evitts, Ph.D., CCC-SLP, Asst Professor, Dept of ASLD, at (410) 704-3860. If I have any questions about my rights as a research subject, you may contact the Institutional Review Board Chairperson, Debi Gartland (dgartland@towson.edu, at Towson University, Phone: (410) 704-2236.

11.4. Consent
The investigators have given me information about what will be done in this research study. They also told me how it will be done, what I will have to do, and how long my participation will likely take. I agree to take part in this study as a research subject. I am aware that I may quit, refuse to answer questions, and/or refuse participation in any part of the research study at any time without repercussions. I have been informed that the investigator will give me a copy of this form to keep for my records.

_____ I have read and understood the information on this form.

_____ I have had the information on this form explained to me.

__________________________________  _______________________
Subject's Signature                Date

__________________________________  _______________________
Witness to Consent Procedures      Date

__________________________________  _______________________
Principal Investigator             Date

THIS PROJECT HAS BEEN REVIEWED BY THE INSTITUTIONAL REVIEW BOARD FOR THE PROTECTION OF HUMAN PARTICIPANTS AT TOWSON UNIVERSITY (410-704-2236).
Family Questionnaire

The purpose of this study is to investigate how the stroke has impacted you. Please rank the following categories according to how much of an impact you feel that the stroke has had on your life.

1) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Leisure time

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

2) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Sex Life

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

3) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Vocation/Occupation

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

4) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_____________________.

Social contacts

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all
5) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her _________________.

Relationship with his/her partner

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

6) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her _________________.

Family Life

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

7) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her _________________.

Ability to self-care

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

8) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her _________________.

Finances

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

9) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her _________________.

Overall ability to communicate

☐ Severely Impacted
☐ Somewhat Impacted
10) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_______________________.

Physical problems associated with stroke

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

11) In comparison to other aspects of your loved-one’s life, how has his/her stroke impacted his/her_______________________.

Life as a whole

☐ Severely Impacted
☐ Somewhat Impacted
☐ Mildly Impacted
☐ Not impacted at all

Are there any other comments that you would like to share about the quality of life for people who have had a stroke?
Appendix F.

Directions: Studies have shown that when people have a stroke, many aspects of their lives are affected. We are interested in knowing what aspects of your loved-one’s life have been most affected as compared to aspects of life that have not changed much even though they have had a stroke. The various aspects of life that we are most interested in discussing with you include:

1. Leisure time

m. Sex life
n. Vocation/occupation

o. Social contacts
p. Relationship with partner
q. Family life
r. Ability to self-care

s. Finances
t. Overall ability to communicate
u. Physical problems associated with stroke
v. Life as a whole

As you complete this questionnaire, we ask that you to keep all of the above aspects of life in mind as you respond about each one individually. We want to get a sense of which aspects have been most impacted by your loved-one’s stroke as compared to other aspects that have not been impacted at all.

After completing the questionnaire, your responses will be grouped by degree of impact (e.g., severely impacted, somewhat impacted, mildly impacted and not impacted at all). Then you will be asked to rank the aspects in each group from most impacted to least impacted.
List aspects that caregiver reported to be “severely impacted”. Then ask caregiver to rank from most impacted (1=most) to least impacted.

List aspects that caregiver reported to be “somewhat impacted” Then ask caregiver to rank from most impacted (1=most) to least impacted.

List aspects that caregiver reported to be “mildly impacted” Then ask caregiver to rank from most impacted (1=most) to least impacted.

List aspects that caregiver reported to be “not impacted at all” Then ask caregiver to rank from most impacted (1=most) to least impacted.
Appendix G.

**Questionnaire for Spouse/Caregiver**

The purpose of this study is to compare how the stroke has impacted your spouse or partner relative to how you think it has impacted him/her. Please note that this part of the survey is not about how the stroke has impacted you, but how you feel it has impacted the person who had the stroke.

Please rank the following categories according to how much of an impact you feel that the stroke has had on your **SPOUSE OR PARTNER**.

**DIRECTIONS:** Please rank the items below from 1-11 with 1 as having the most impact on your spouse/partner and 11 having the least impact.

<table>
<thead>
<tr>
<th>ITEMS</th>
<th>Rank 1-11</th>
</tr>
</thead>
<tbody>
<tr>
<td>w. Leisure time</td>
<td></td>
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<tr>
<td>x. Sex life</td>
<td></td>
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<tr>
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<td></td>
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<tr>
<td>z. Life as a whole</td>
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<tr>
<td>aa. Social contacts</td>
<td></td>
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<tr>
<td>bb. Relationship with partner</td>
<td></td>
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<tr>
<td>cc. Family life</td>
<td></td>
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<tr>
<td>dd. Ability to self-care</td>
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<td>ee. Finances</td>
<td></td>
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<tr>
<td>ff. Overall ability to communicate</td>
<td></td>
</tr>
<tr>
<td>gg. Physical problems associated with stroke</td>
<td></td>
</tr>
</tbody>
</table>

Are there any other comments that you would like to share about the quality of life for people who have had a stroke and their spouse/caregiver?