

Life Interests and Values: Agreements and Disagreements between Adults with Aphasia and  
Family Members and Friends

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“A thesis submitted to the faculty of the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Science in the Department of Allied Health Sciences in the Division of Speech and Hearing Sciences.”

Chapel Hill  
2008

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## **ABSTRACT**

**RACHEL GOFF: Life Interests and Values: Agreements and Disagreements between Adults with Aphasia and Family Members and Friends**  
(Under the direction of Katarina Haley)

This study is grounded in two approaches: Theory of Self-Determination (Williams, Frankel, Campbell, & Deci, 2000) and the LPAA Project Group's (as cited in Chapey, 2001) Life Participation Approach to Aphasia. The purpose of this study is to determine the overall level of agreement, and areas where agreements are more likely, on rating life interests and values between adults with aphasia and their family members and friends. Participants included five individuals with aphasia and their family members and friends asked to speak for them. The findings showed that overall agreement was low (below 80%). Unexpectedly, agreements for objective behaviors and subjective values are generally equal. Aphasia severity (percentile) and overall level of agreement (percentage) had a significant linear correlation. Further research is needed to enhance our knowledge about agreement and disagreement for ratings of life interests and values between individuals with aphasia and family members and friends.

## **ACKNOWLEDGEMENTS**

This project could not have been accomplished without the cooperation and help of many people. Special acknowledgment and appreciation is expressed to my committee members, Dr. Katarina Haley, Dr. Nancy Helm-Estabrooks, Dr. Sharon Williams, and Dr. Melody Harrison. I also would like to thank the participants in the study for their time and cooperation. To my friends, especially my roommate, Jihan, who were understanding during my periods of hibernation and tribulation, I am grateful. Last, I give my love and thanks to my parents, Bonnie and Richard Goff, and sister, Emily for all their years of support and love which all helped make this experience possible.

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## CHAPTER I: Review of Literature

### Introduction

Approximately one million individuals in the U.S. are survivors of a stroke (Mlcoch & Metter, 2001). According to the National Aphasia Association (2007), 25-40% of stroke survivors have aphasia, a language disorder resulting from damaged brain areas that control language modalities (i.e., reading, writing, speaking, and auditory comprehension) and language domains (i.e., semantics, phonology, morphology, and syntax). Aphasia can result from head injury, brain tumor, or other neurological conditions, but the most common cause of aphasia is a stroke.

Aphasia may impact a stroke survivor's daily life activities and participation. The current framework of the World Health Organization (WHO) International Classification of Functioning, Disability and Health (ICF) describes activities and participation as including the execution of a task or action by individuals and involvement in a life situation (World Health Organization, 2001). The original 1980 WHO framework of Impairment, Disability, and Handicap was replaced with Body, Activity, and Participation in 1997. Body was defined as abnormality of body structure and function. Activity was defined as the abnormality in function at the level of the person. Participation was people's inability to fulfill roles that are normal for them, given their gender and age and their particular social setting (Darzins, Fone, & Darzins, 2006). In the 1997 version, activities and participation were difficult to distinguish (Worrall, McCooey, Davidson, et al., 2001). Although the overall model remains the same, the current version combines activity and participation



(ICIDH-2, WHO, 2001). As in the ICF, activities and participation will be combined throughout the discussion of this paper.

Life activity and participation involves tasks necessary for daily living (e.g., making a phone call) and participation in real life goals (e.g., getting a job) (Chapey, 2001).

Individuals with aphasia may be unable to carry out expected household activities or participate in former family roles. For example, if a stroke survivor with aphasia is unable to perform his/her role of paying the bills, other family members may have to take on this role. Inability to carry out family roles may cause a stressful alteration for the entire family. This, in turn, impacts their health, well-being, and quality of life (Chapey, 2001). Aphasia can also negatively affect a stroke survivor's participation in social interactions with others. For instance, an individual with aphasia may no longer know how to communicate during a club or organization meeting. Another example of the impact of stroke is when a stroke survivor can no longer participate in a favorite hobby (e.g., bike riding) due to a physical impairment. Life activities and participation may need to be regained to achieve a perspective of having a fulfilling life (Hinckley, 2006).

Most previous research on life activities and participation in people with aphasia has been conducted to shed light on changes in quality of life. Quality of life (QoL) has been defined as “an individual's perception of their position in life in context of the culture and value systems, in which they live and in relation to their goals, expectations, standards, and concerns” (World Health Organization, 1993, p. 5). Cruice, Worrall, Hickson, & Murison (2005) have defined QoL as two opposing concepts (e.g., people's objective life conditions versus their subjective interpretation). Measuring the influence of aphasia on aspects of QoL, including measures of life activity and participation, is increasingly considered to be an

important component of aphasia rehabilitation (Engell, Hutter, Willmes, & Huber, 2003).

### Interviewing Individuals with Aphasia about Life Activities and Participation

Interviewing a person with aphasia regarding life activities and participation of can be difficult for several reasons. Respondents are required to read or listen to interview questions, understand the information, and select a response by matching their opinion or perception to one of the choices provided (Cruice et al., 2005). Impairments in language modalities such as speaking, listening, reading, and writing may interfere in interviews for adults with aphasia. For some individuals, aphasia may preclude valid and reliable test results in interviews requiring use of these language modalities. For example, three commonly used survey protocols utilizing administration methods requiring language skills to measure outcomes after a stroke include: *Sickness Impact Profiles* (Bergner, Bobbitt, Carter, & Gilson, 1976), *Burden of Stroke Scale* (Doyle, McNeil, Mikolic, et al., 2004), and *Stroke Impact Scale* (Duncan, Wallace, Lai, et al., 1999).

The *Sickness Impact Profiles* (SIP) (Bergner, et al, 1976) is a self-administered, interviewing tool that requires listening and understanding linguistically complex questions in a written or verbally elicited interview. It is based on reading and replying to yes/no statements by circling responses on a checklist. The tool includes 136 health-related questions about physical and psychosocial changes after stroke. Examples of statements from the SIP include “I am going out less to visit people” and “I am doing more physically inactive pastimes instead of my usual activities”. The administration of this tool would be inappropriate for individuals with aphasia with reading or auditory comprehension

difficulties.

The *Burden of Stroke Scale* (BOSS) (Doyle, et al, 2004) is another example of an interview tool requiring relatively spared auditory comprehension and reading skills. The 112-item pilot version of the BOSS measures the physical, cognitive, and psychological burden of stroke. The administration of the BOSS is based on a verbal interview and simultaneously administered written questions. An example of a question from the BOSS is: “You indicated that you have some difficulties communicating. How much do difficulties communicating prevent you from doing the things in life that are important to you?” No advice is offered on modifications for people with language comprehension problems. The BOSS questions are likely to be challenging to understand and answer for adults with aphasia.

Duncan and colleagues (1999) examined aspects of QoL using the *Stroke Impact Scale* (SIS) (Duncan, Wallace, Lai, et al., 1999). Responding to the SIS questions requires either a verbal response requiring expressive language or a pointing response. “In the past two weeks, how difficult was it to do light household tasks/chores...(1) dust; (2) make a bed; (3) take out garbage; (4) do the dishes?” is an example questions on the SIS. To respond, the participant rated how the stroke affected the aspects of QoL on a scale from 1 (cannot do at all) to 5 (not difficult at all).

Therefore, many researchers exclude participants with aphasia who are unable to respond to their interview questions from studies of life activities and participation. For example, Duncan and colleagues (1999) excluded 13 of 300 individuals from participating in their study because these individuals were “too aphasic or cognitively impaired” to complete the SIS interview. Life activities and participation are important aspects of life quality for

people with aphasia (Cruice, Worrall, & Flickson, 2006). Therefore understanding the life activities and participation of people with aphasia is critical for society, healthcare professionals, and researchers. Par & Byng (2000) state that the exclusion of individuals with aphasia from research studies mirrors their exclusion from life activities and participation in society. In addition, the exclusion of people with aphasia from research studies assessing the effects of stroke on life activities and participation skews the data, producing invalid results. The results may not reflect the actual concerns and desires of stroke survivors as a whole or specifically for individuals with aphasia.

#### Close Family Members or Friends as Informants

A proxy informant, as defined by *Webster's New World College Dictionary* (2001), is a person with authority to act for another. De Haan, Aaronson, Limburg, Hewer, & van Crevel (1993) define a proxy as a patient's caregiver who is asked to answer the questions with responses the patient would give. Typically, proxies are spouses but may be children or other family members or friends (Cruice, et al, 2005, Duncan, et al, 2002, & Engell, Hütter, Willmes, & Huber, 2003). Proxy informants are frequently utilized in studies of life activities and participation when the individuals language or cognition skills are insufficient for standard interview methods (de Haan, Limburg, Van der Meulen, et al., 1995; Duncan, Lai, Tyler, et al., 2002; Epstein, Hall, Tognetti, et al., 1989; Knapp & Hewison, 1999; Magaziner, Simonsick, Kashner, et al., 1988; Sneeuw, Aaronson, de Haan, & Linburg, 1997). For example, using the SIP to study QoL, researchers asked proxy informants to respond in the way they believed the stroke survivor would respond (de Haan et al., 1995; Sneeuw et al., 1997).

It is unclear whether proxy responses accurately reflect the wishes or concerns of stroke survivors (Cruice et al., 2005, Epstein et al., 1989, Knapp & Hewison, 1999). Patient-proxy pairs, often have weak agreement (Cruice et al., 2005). Currently, the factors that cause concordance or discrepancy between participants with aphasia and proxies in ratings of life activities and participation is relatively unstudied (Engell et al., 2003). The remainder of this section of the paper focuses on patients in the fields of stroke, other medical conditions, and normal aging to explain the dynamics of patient-proxy concordance for life activities and participation. In fields outside of aphasiology, severity of impairment has been reported to impact level of agreement between patients and proxies (Knapp & Hewison, 1999). Other factors thought to influence level of agreement between patients and proxies include whether questions about life activities and participation address objective or subjective domains. Definitions for objective versus subjective differ across studies. Generally, when discussing life activities and participation objective domains or physical dimensions are defined as current observable life activities, whereas subjective domains or psychosocial dimensions are based more on satisfaction and desires related to those activities (Brown, Dijkers, Gordon, et al., 2004; Duncan et al., 2002; Sneeuw et al., 1997).

Research studies have found that stroke survivors and their proxy raters have better strength of agreement on questionnaires of objective domains than on subjective domains (Duncan et al., 2002; Sneeuw et al., 1997). Agreement was rated on a scale from “poor/fair agreement” (intraclass correlation of .40 to .81) to “excellent agreement” (intraclass correlation of 1.00). Sneeuw and colleagues (1997) found better response agreement (intraclass correlations of .85) for physical dimensions such as body care and movement than for the psychosocial dimension (intraclass correlations of .61) such as emotional behavior, a

more subjective domain, on the SIP. Duncan et al. (2002) found better agreement between proxy and stroke survivors for objective physical domains of functional status than other domains of life participation. The authors endorse the idea that objective domains are agreed upon more often than subjective values when examining response comparability between the patient-proxy pair in outcome measures, but there still is not sufficient statistical evidence to support or refute the claim. Epstein et al. (1989) found high correlation of responses between proxy and patient in objective, functional status measures of instrumental and personal care aspects of daily living. However, for satisfaction of healthcare in daily living, correlations were also found to be statistically significant.

Research has shown that severity of impairment may influence responses comparability between patients and proxies. Some data indicate that proxy informants underestimate participants' ratings for subjective domains on QoL in the presence of more severe disability. Duncan et al. (2002) found that proxies scored patients as significantly more severely affected than patients scored themselves on the SIS-16. The proxy's bias of overestimating impairments increased as the stroke severity increased. Knapp & Hewison (1999) found similar results. When lower functional abilities occurred, as measured with the *Barthel Index* (Mahoney & Barthel, 1965), greater discordance was reported between the patients and the proxy. Typically researchers have found that as severity of outcomes due to stroke (e.g., functional ability) increases, response disagreement between proxies and patients increases.

Assumptions regarding reliability of ratings between a stroke survivor with aphasia and a proxy are based on the literature associated with stroke without aphasia, other medical conditions, and normal aging. If appropriate interviews, facilitating language modalities, are

used to measure life activities and participation, aphasia severity alone should not impact concordance between individuals with aphasia and family members or friends. Little is currently known about response comparability between individuals with aphasia and their family members and friends. Similar to research by Sneeuw et al. (1997) & Duncan et al. (2002), Cruice et al. (2005) found that participants with aphasia and their family members or friends had generally higher agreements for objective domains (e.g., ratings using *Short Form-36 Health Survey*; Ware & Shelbourne, 1992) than for subjective domains (e.g., ratings using *Global Rating of QoL* (Cruice et al., 2005) or *Ruff Well-Being Scale: How I Feel About Myself* (Ruff, 1989)). Engell et al. (2003) found that relatives of stroke-survivors with aphasia reported higher agreement for the objective physical domain than the subjective psychosocial domain.

Research studies examining the possibility of a correlation between aphasia severity and level of agreement between family members and friends and individuals with aphasia have contradictions. Engell et al. (2003) found that degree of impaired language comprehension (as measured by the Token Test) was not correlated to agreements or disagreements of QoL ratings in people with aphasia. Hilari et al. (2007) had some indication in their research findings that severity of receptive aphasia may influence agreement levels on *Stroke and Aphasia Quality of Life Scale* (Hilari, Byang, Lamping, et al., 2003). Further research is needed to expand on this knowledge base.

### Individuals with Aphasia as Informants

Information about life activities and participation in people with aphasia is ideally obtained directly from individuals with aphasia and possibly accompanied by responses from

a family member or close friend. This is especially important when their responses about daily life activities and participation will be used to set treatment goals. Williams, Frankel, Campbell, & Deci's (2000) found that typically individuals receiving clinical services are not involved in the goal setting process and may not understand the purpose of therapy activities. Studies have shown that when individuals are involved in setting their own intervention goals they are more likely to achieve those goals (Williams, Frankel, Campbell, & Deci's, 2000). The theory of "Self Determination" provides a model for patient-directed health care. If the clinician avoids controlling approaches and instead provides the opposite "autonomy support" through modifications of interviews of life participation, the individual with aphasia is empowered to express their concerns and desires (Williams, Frankel, Campbell, & Deci, 2000). Gottlieb, Golaner, Bar-Tal, & Gottlieb (2001) found that patients with a higher sense of control of life events at their disposal developed fewer handicaps and reported a better quality of life than patients with the same amount of disability and less sense of control of life events.

The Life Participation Approach to Aphasia (LPAA; LPAA Project Group, 2001) "is a consumer-driven, service-delivery approach that supports individuals with aphasia and others affected by it in achieving their immediate and longer term life goals" (Chapey, et al., 2001, p.235). LPAA targeted intervention goals are not only for improvement in language and communication, but also for improvement in life activities and participation and life satisfaction. The LPAA encourages a person with aphasia to be central to the decision making of clinical intervention that targets life activities and participation of specific interest to that individual with aphasia.



## Interview Modifications to Facilitate Individuals with Aphasia Acting as Informants

Interview materials and procedures including pictographic materials, keywords, and Likert scales help eliminate communication barriers for people with aphasia (Kagan & LeBlanc, 2002). Recently some progress has been made using such modifications to enable participation of adults with aphasia in interviews about life activity and participation (Cruice et al., 2005; Engell et al., 2003; Hilari et al., 2007).

Cruice and colleagues (2005) compared responses about life activities between participants with mild to moderately severe aphasia and family members and/or friends who were asked to speak for them. Participants were interviewed on aspects of QoL with four measures: *Global Rating of QoL* (Cruice et al., 2005); *Short Form-36 Health Survey* (Ware & Shelbourne, 1992); *Dartmouth COOP Charts* (Nelson, Landgraf, Hays, et al., 1990); *Ruff Well-Being Scale: How I Feel About Myself* (Ruff, 1989). To aid comprehension for adults with aphasia, the interview included a systematic cueing system. The cueing system involved slowly repeating, rephrasing, and personalizing a test item (i.e. how it might relate to them) until the adult with aphasia was judged to understand the question enough to participate in the study. The study also included an additional health-related QoL measure, *Dartmouth COOP Charts*, because of the high language demands and varying response formats of the SF-36. The *Dartmouth COOP Charts* is generally for aging patients but was found to be relatively easy and quick to use with people with aphasia. A condensed form of *Ruff Well-Being Scale: How I Feel About Myself* was used. This form was developed for people with aphasia. The *Global Rating Scale* is a five point likert scale, requiring little language skills (Kagan & LeBlanc, 2002). Modifications of the response format of the SF-36 (from declarative statements to yes/no statements) and the likert scale point system (from 1-5

points to “no!no”, “? or ½”, “yes/yes!”) were made for participants who needed additional assistance with reading and/or auditory comprehension to respond. The modifications allowed 30 individuals with mild to moderately severe aphasia to report their QoL. After modifications were made to allow participants with aphasia as informants, the modifications did not result in client-centered therapy goals.

Hilari, Owen, & Farrelly (2007) explored the level of agreement between people with aphasia and proxy informants on a modified measure of the *Stroke Specific Quality of Life* scale. The measure was renamed *Stroke and Aphasia Quality of Life Scale* (SAQOL-39) (Hilari, Byang, Lamping, & Smith, 2003). The SAQOL-39 is an interview-administered, self-report scale consisting of 49 items in 12 sub-domains: self-care, mobility, language, social roles, thinking, personality, energy, mood, family roles, and work. The researchers modified the content by adding four additional items that focused on challenges with comprehension of speech, deficits in decision making, and family and social life impacts due to language deficits. The response format was modified by implementing 5-point scales (1=could not do it at all to 5=no trouble at all, 1=definitely yes to 5=definitely no). These modifications allowed people with aphasia the ability to respond and provide valuable information in the interview (Hilari, Byang, Lamping, & Smith, 2003). The measure was not specifically designed to provide treatment goals upon completion.

Engell and colleagues (2003) studied the level of agreement between individuals with aphasia and family members or friends asked to speak for them on rating statements, phrases, or keywords (e.g., often alone) that represent an everyday life situation. The statements, phrases, or keywords exemplified a typical psychosocial or physical problem of adults. The researchers used a written version of *Aachen Life Quality Inventory* (ALQI) for the family

members and/or friends and a modified pictorial self-rating procedure for participants with aphasia. The ALQI is a German language adaptation of the SIP. The SIP was modified in three ways to develop the ALQI. First, the ALQI modified version for people with aphasia used pictures accompanied by key phrases. The response format consisted of pointing to pictures/symbols at the bottom of the picture (“thumbs up” or “thumbs down”; and further with: “doesn’t matter,” “bad,” and “very bad”). These modifications were designed to minimize problems with comprehension of verbal statements and to allow nonverbal responses. Second, the ALQI was specifically validated for brain-injured patients after neurosurgical treatment as well as for their relatives (Hutter & Gilsbach, 1996, in Engel et al., 2003), instead of general health problems as in the SIP. Nine subscales were developed (4 physical and 5 psychosocial categories of 10 items each). Third, items within the subscales were transformed from verbal statements to keywords, to allow nonverbal responses. The modifications allowed 26 individuals with aphasia (17 non-fluent patients and 9 fluent patients with aphasia) to provide information about their QoL. The findings did not set specific intervention goals based on the concerns and desires of life participation, values, and interests of individuals with aphasia.

The Life Interest and Values (LIV) Card Sorting System under development in the UNC Department of Allied Health Sciences (Haley, Helm-Estabrooks, & Womack, in progress) is a pictorial, binary-sorting system that allows the person with aphasia to make personal decisions about specific life interests and values targeted for goals of intervention. The LIV Card Sorting System is comprised of four categories:

1. everyday activities (e.g., laundry)
2. social activities (e.g., entertaining friends)

3. recreational activities with high physical demands (e.g., hiking)
4. recreational activities with low physical demand (e.g., listening to music)

These activities are illustrated with black and white line drawings on 5”x 8”cards. The interviewing process is easy to follow and included in the appendix (Appendix A and B). First, the person with aphasia sorts the cards into what they do now and don’t do now (described as objective behaviors). Second, the cards are sorted into piles of whether they want to start an activity or not (described as subjective values). Third, the cards are sorted into piles of whether they are satisfied with how much they do the activity now or want to do more of the activity (also described as subjective values). This sorting verifies the activities the person desires to do, helps establish a preliminary intervention plan, and provides a basis for strategies with specific suggestions about how to help with these areas of life activities (Haley, Womack, & Helm-Estabrooks, 2007). Using pictures of life activities and sorting the pictures into piles of present and preferred activities greatly facilitates measuring and documenting success of life enhancement changes, life participation desires, and satisfaction in adults with aphasia. In addition, a close family member or friend is asked to complete an interview that mirrors the card sorting process. This additional information provides knowledge for the level of agreement between the person with aphasia and a person close to them which is useful for guiding treatment and clarifying misunderstandings. It is unknown what kind of agreement to expect between a family member/friend and person with aphasia and what areas make discrepancies more likely.

## Statement of Purpose

The purpose of this study was to determine the level of agreement about life interests and values between participants with aphasia and their family members and friends who are asked to “speak for” them. The objective was to enhance current understanding of the level of agreement of ratings for individuals with aphasia and their family members or friends when measuring objective behaviors compared to subjective values. Another area explored was the influence of aphasia severity on agreement of ratings between person with aphasia and their family member or friend. Using the LIV Card Sorting System, the following questions were addressed:

1. What is the percentage of agreement between individuals with aphasia and family members/friends asked to speak for them?
2. Do people with aphasia and family members/friends asked to speak for them agree more when reporting on objective behaviors or subjective values?
3. Is the agreement between the family member/friend and person with aphasia related to aphasia severity?

## Research Hypotheses

It was hypothesized that overall agreement of life activities and participation for the family member/friend and person with aphasia would be below 80% agreement. It was believed that agreement between the family member/friend and person with aphasia would not be related to aphasia severity. It was predicted that people with aphasia and family members/friends would agree more when reporting on engagement in life activities than

when reporting on satisfaction and desires related to those activities

## CHAPTER II: Methods

### Participants

#### *Participants with Aphasia*

There were two sets of participants in this investigation: Stroke survivors with aphasia and family members or friends of these individuals. Five stroke survivors with aphasia secondary to a focal lesion in the left cerebral hemisphere participated in the study. They were all at least four months post onset, at least 21 years of age and right handed. They were asked for permission to review medical records for information about the stroke including neuroimaging.

The criteria for participation included aphasia severity for each participant at or below the 75<sup>th</sup> percentile as determined by the Aphasia Diagnostic Profiles (ADP; Helm-Estabrooks, 1992). The participants had to be pre-morbid speakers of English and could be native speakers of any language. The participants with aphasia could have any education level. Based on observation, the participants had to have reliable motor skills to manipulate the LIV cards. Individuals had to pass a pure-tone hearing screening at 40 dB for 1000, 2000, and 4000 Hz frequency levels (using a portable audiometer). In addition, all participants had to be able to get into set for each subtest of the *Cognitive-Linguistic Quick Test* (CLQT; Helm-Estabrooks, 2001) and *Aphasia Diagnostic Profiles* (ADP; Helm-Estabrooks, 1992). The participants with aphasia were recruited (Appendix VI) from the Triangle area (Raleigh, Durham, and Chapel Hill). Participant characteristics are illustrated below in Table 1.

**Table 1**  
**Characteristics of Participants with Aphasia**

Participant with Aphasia	Age	Gender	Date of Onset (Month/Year)	Months Post Onset	Aphasia Severity (percentile) based on the ADP (a lower number indicates more severe aphasia)	Aphasia Classification
01	44	M	6/03	57	30th	Mixed Nonfluent
02	68	M	2/74	408	73rd	Broca's
03	41	F	11/07	4	58th	Borderline Fluent
04	60	F	9/06	18	19th	Mixed Nonfluent
05	77	M	11/07	4	47th	Mixed Nonfluent



### *Family Member or Friend Participants*

Each participant with aphasia was asked to identify at least one friend or family member who knows him/her well. The criterion for participation of the family members or friends was to be at least 21 years of age and have had no history of language or cognitive impairments. The family members or friends were required to have known the participant with aphasia since before the stroke and for at least one year. The characteristics of the family members or friends are listed in Table 2.

**Table 2**  
**Characteristics of Family Members/Friends and the Nature of their Relationship with**  
**Participants with Aphasia**

Family Member or Friend	Age	Gender (F or M)	Years of knowing each other	Nature of relationship	Live Together (yes or no)	Regularity of Contact during a week	Typical time spent together during a day
01	75	F	44	mother	no (yes on weekends)	2-3 days	More than 8 hours
02	65	F	42	wife	yes	everyday	More than 8 hours
03	31	M	4	boy-friend	yes	everyday	More than 8 hours a day
04	37	F	37	daughter	no	1 day	More than 8 hours
05	72	F	55	wife	yes	everyday	1-4 hours

## Procedures

### *Setting and Forms*

The interviews took place in a quiet setting with limited distractions; either at the home of the participant or a local senior center. Each individual with aphasia was asked to sign a consent form approved by the UNC-Chapel Hill IRB and a UNC-Chapel Hill Authorization for Use and Disclosure of Health Information for Research Purposes.

Each family member or friend was asked to sign a consent form approved by the UNC-Chapel Hill IRB and to complete the family member or friend questionnaire (Appendix III). Along with demographic characteristics (age and gender), the questionnaire asked about the nature of the relationship including how long the family member and person with aphasia had known each other, what the nature of the relationship was (e.g., wife, friend), whether they lived together or not, how often they spent time together (e.g., every day, less than 1 day), and typical time spent during days together.

### *Clinical Testing for Participants with Aphasia*

The participants with aphasia were given subtests of *Aphasia Diagnostic Profiles* (ADP); Helm-Estabrooks, 1992, to determine aphasia severity. The subtests consisted of auditory comprehension, repetition, naming, information units, and personal information. As part of a cognitive battery for another study (results not reported here), they received:

*Cognitive-Linguistic Quick Test*; Helm-Estabrooks, 2001, *Raven's Coloured Progressive Matrices*; Raven, 1998, & *Wisconsin Card Sort Test*; Berg, 1948. Clinical testing for the participant with aphasia took up to an hour and a half.

### *LIV Assessment of Participants with Aphasia*

The examiner sat across a table from the participant with aphasia. On the table, the examiner placed the LIV Scoring Form (Appendix VII) and the LIV cards. The cards were shuffled before each sort. The examiner followed the instructions in Appendix I. The examiner said, “We want to find out what activities are important to you and what kinds of things you do in your life.” The LIV cards are comprised of four categories: everyday life activities, social activities, high physical activities, and low physical activities (Appendix V). Examples of activities (e.g., camping) in each of these categories (e.g., high physical activities) are depicted on four cards. Using these four cards, the categories were explained to the participant with aphasia. The examiner asked the participant, “Which category would you like to start with?” The examiner removed all cards from table other than the category chosen. The detailed instructions listed on Appendix I were followed in the sorting process of the cards into different piles of current life activities and desires related to them.

The participants with aphasia sorted cards into piles: (1) two piles of activities they are currently doing (placed below a card with a drawing of a check mark) or activities they do not do (placed below a card with a X), (2) two piles of activities that they want to start doing (placed below a card with a line drawing of a thumb pointed up) or activities they don’t want to start (placed below a card with a line drawing of a thumb pointed down), (3) activities they want to do more often (placed below a card with a line drawing of upward pointing arrow) or activities they feel okay with how much they are doing the activities (placed below a card with a line drawing of a okay hand gesture). The examiner marked each of the responses from the card sort on a LIV Card Sort Scoring Form (Appendix VII). After sorting all categories, the responses were reviewed to allow the participant with aphasia without the

family member or friend present to correct any responses they indicated as mistakes. No participant with aphasia indicated a mistake in responding.

The examiner verified accuracy of scoring after each session by reviewing the activity cards in each of the resulting four piles: want to start doing, don't want to start doing, want to do more often, and okay with how often their currently doing the activity. Another research assistant verified the cards in each pile and the scoring form. Accuracy was 99%. Any errors detected were corrected.

#### *LIV Assessment of Family Members or Friends*

To avoid bias, the family member or friend was not in the room while the LIV card sorting system was administered to the person with aphasia. Another graduate student examiner interviewed the family member or friend in a different room. The family member or friend of the participant with aphasia was interviewed with the LIV card sort material.

The examiner placed the LIV Card Sort Scoring Form (Appendix VII) and the LIV cards on the table. The LIV cards were shuffled before each card sort. The family member or friend was instructed to answer every question the way the person with aphasia would respond, not as he/she thought the person with aphasia should respond. The examiner followed the detailed instructions on the LIV family member/friend interview and scoring instructions (Appendix II). The examiner continued using the prompt "Remember to answer every question the way Mr./Mrs. X would respond. " or " How would Mr./Mrs. X respond if we asked. ... " The process was repeated for all categories. After sorting all categories, the responses were reviewed to allow participants to correct any responses they indicated as a mistake. The LIV card sort took up to one hour. After sorting all categories, the responses

were reviewed to allow the participant with aphasia without the family member or friend present to correct any responses they indicated as mistakes. No participant with aphasia indicated a mistake in responding. The examiner verified accuracy of scoring after each session by reviewing the activity cards in each of the resulting four piles: want to start doing, don't want to start doing, want to do more often, and okay with how often they currently doing the activity. Another research assistant verified the cards in each pile and the scoring form. Accuracy was 99%. Any errors detected were corrected. This allowed direct comparison between the person with aphasia and a family member and friend.

### *Review of Responses*

Following the completion of the LIV activity with both the person with aphasia and the family member or friend respondent, the dyad met with an experimenter to review the results. One participant with aphasia and chosen family member (01) were unable to participate in the session interview because of housing arrangements. The remaining four participant pairs met with the experimenter who summarized the responses on which the two agreed and pointed out specific disagreements. Both respondents were asked to verify their responses (Appendix IV). If either indicated that one or more of his/her own responses were selected by error, the mistakes were noted and summarized qualitatively. The review session was video recorded. The participants were asked if their friend's/family member's responses for some activities were particularly surprising to them.

### *Data Analyses and Reliability*

A graduate student examiner entered the responses for both the person with aphasia and the family member or friend into a Microsoft Excel data analysis spread sheet after the sessions. For quality of data entry purposes, a second coder inspected all of the entries for errors. Accuracy was 90%. Any errors of data entry were corrected.

Percent agreement between the person with aphasia and the family member or friend asked to speak for them was computed on an activity-by-activity basis as the number of agreements divided by the number of agreements plus disagreements multiplied by 100. Three agreements were estimated; (1) complete rating agreement for the activity at all levels of the scoring (Do now/don't do now, OK or not with current activity involvement, want to do more or not); (2) level of agreement for current engagement in activity (objective behaviors: Do Now) versus desire to engage more in activity (subjective values: Start Doing or Want to Do More); and (3) level of agreement related to aphasia severity percentile. The data analysis for agreements (1) and (2) is demonstrated in the Table 3 below.

**Table 3**  
**Example of Data Analysis of Level of Agreement for Objective Behaviors, Subjective**  
**Values, and Overall Agreement**

<b>Activity Category</b>	<b>Low Leisure Activities</b>	<b>(1) Do Now</b>	<b>(2) No: Start Doing</b>	<b>(3) Yes: Want to Do</b>	<b>Overall Agreement</b>
Lo-LA	Art museum	1	1		1
Lo-LA	Bird watching	0			0
Hi-LA	Sports playing	1	1		1
Hi-LA	Swimming	0			0
SA	Bar	1	1		1
A	Card playing	0			0
EA	Yard work	1		1	1
EA	Cleaning House	1		1	1
Sum of Agreement		5	5		5
Ratio of Agreement		0.625	1		0.625
<b>1 = Agreement 0 = Disagreement</b>		<b>Objective Behaviors</b>	<b>Subjective Values</b>		<b>Overall Agreement</b>
<b>Percentage of Agreement</b>		<b>62.5%</b>	<b>100.0%</b>		<b>62.5%</b>



### CHAPTER III: Results

This paper reports on the interviews of five people with aphasia and their family member or friend using the LIV Card Sort. The small number of participants ( $n=5$ ) prevents the use of inferential statistics. Descriptive statistics of the participant pair's responses were provided. The responses for each of the five pairs of participant were found as a ratio of agreements divided by agreements plus disagreements and converted to percentage of agreement. The pairs of participants were coded as "participant pairs 1-5." For each participant pair, the results were summarized for overall percent of agreement, objective behaviors versus subjective values, and relation of aphasia severity and overall agreement.

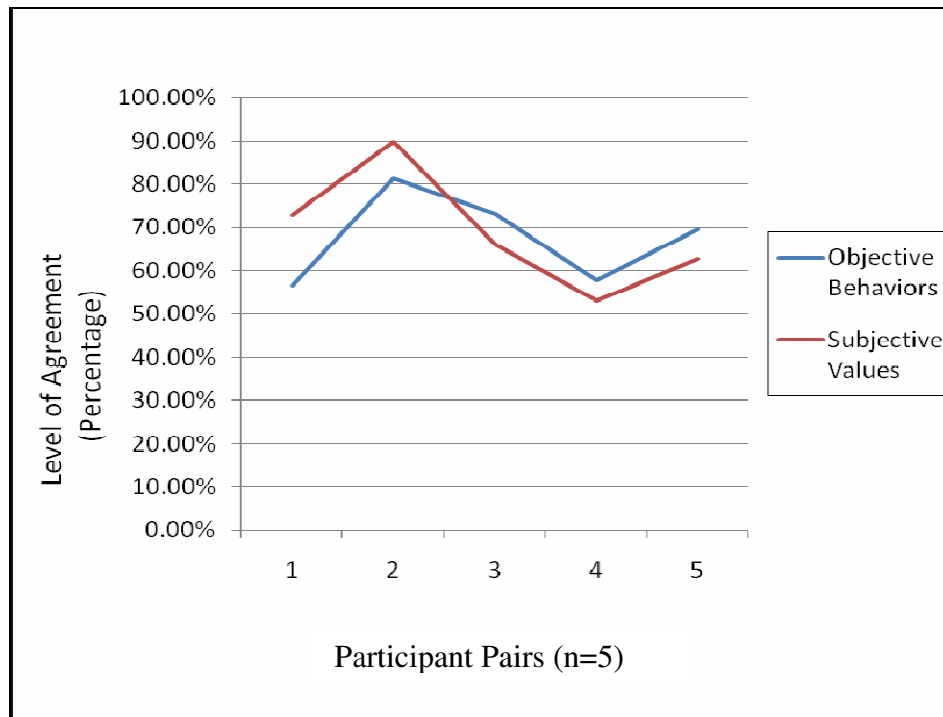
#### Overall Agreement

The percent agreement between the person with aphasia and the family member or friend asked to speak for them was computed for the activity at all levels of the scoring (Do now/don't do now, OK with current activity involvement, not OK with a current activity, want to do more, don't want to do more). Participant pairs 01, 03, and 05 obtained level of agreements (percentages) for overall responses between 41.2% and 48.2%. Participant pair two agreed at a much higher level (72.9% agreement) than the others. Participant pair four had a level of agreement of only 31.6%. The percent agreement for each participant pair and for the group (47.5%) can be seen in Table 3.

## Reporting on Engagement in Life Activities versus Reporting on Satisfaction and Desires Related to those Activities

The level of agreement between the person with aphasia and the family member or friend asked to speak for them compared across rating type; current engagement in activity (objective behaviors: Do Now) versus desire to engage more in activity (subjective values: Start Doing or Want to Do More) can be seen in Table 4. Contrary to our prediction, participants appear to demonstrate equal level of agreements for ratings of objective behaviors (67.5%) and subjective values (68.9%). The first participant pairs 01 and 02 had a higher level of agreement for subjective values, whereas the participant pairs 03, 04, and 05 had a higher level of agreement for objective behaviors. The level of agreement for objective behaviors versus subjective values is illustrated in the line graph below (Figure 2).

**Figure 1**  
**Group Ratings for Engagement in Life Activities versus Satisfaction and Desires**  
**Related to those Activities**



**Table 4**

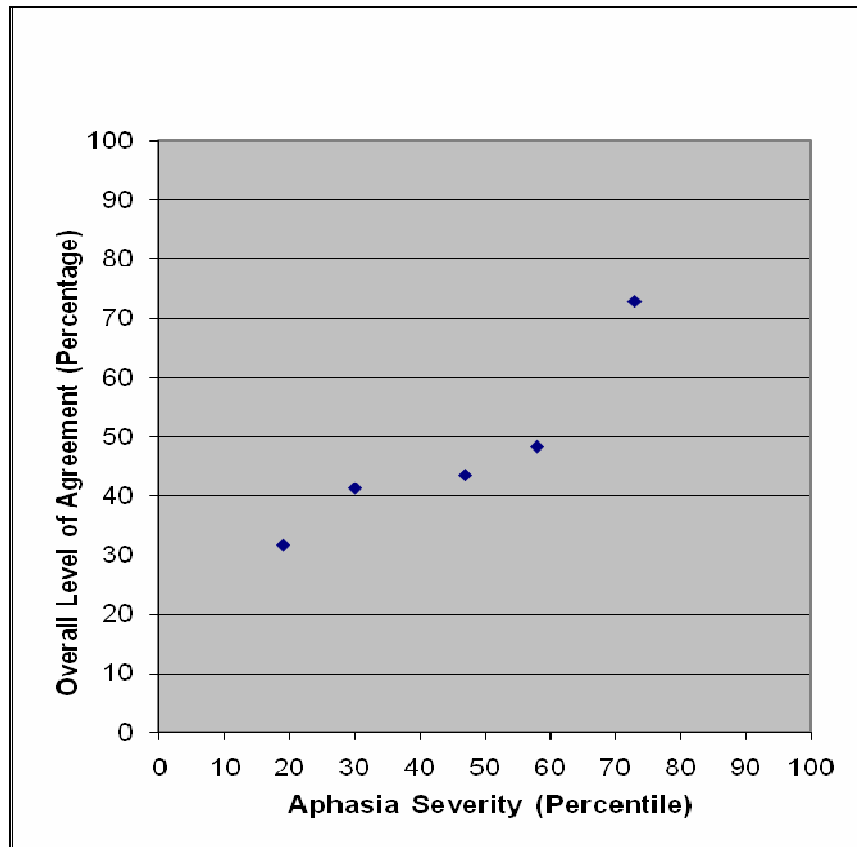
**Level of Agreement between Participant with Aphasia and Family Member or Friend**

Participant Pairs	Overall Percent of Agreement	Percent of Agreement for Objective Behaviors	Percent of Agreement for Subjective Values
P1	41.2%	56.5%	72.9%
P2	72.9%	81.2%	89.9%
P3	48.2%	72.9%	66.1%
P4	31.6%	57.6%	53.1%
P5	43.5%	69.4%	62.7%
<b>Mean</b>	<b>47.5%</b>	<b>67.5%</b>	<b>68.9%</b>

## Relation of Aphasia Severity and Agreement between the Person with Aphasia and the Family Member or Friend

The aphasia severity and overall agreement for each participant pair can be seen in Table 5. A scatter plot (Figure 2) was used to examine the data visually. The sample size is too small to examine the data statistically. From the trend in the scatterplot, agreement between adults with aphasia and their family members/friends and aphasia severity percentile appear to be positively correlated. A positive correlation would signify that when aphasia is less severe (higher aphasia severity percentile) level of agreement is higher. Future data collection will help determine if there is a significant relationship between the two variables.

**Figure 2**  
**Level of Agreement between Person with Aphasia and Family Member/Friend Related**  
**to Aphasia Severity**



**Table 5**  
**Relationship of Aphasia Severity and Agreement between Individuals with Aphasia and**  
**Family Members and Friends**

Participant Pair	Aphasia Severity Percentile (std score)	Percent of Overall Agreement
1	30 (92)	41.2
2	73 (109)	72.9
3	58 (103)	48.2
4	19 (87)	31.6
5	47 (99)	43.5

## Qualitative Comparison between the Responses of Participants with Aphasia and Family Members or Friends

### *True Disagreements versus Responses Errors*

During the review session, the participant pair's disagreements were reviewed. The examiner asked, "Did we understand that right?" Comments about discrepancies between judgments, generated by either respondent, were characterized as either true disagreements or response errors (i.e., indication that one or more of the participants with aphasia or family member's/friend's own responses was selected by error). True disagreements outnumber response errors. Across all participant pairs and disagreements for all activities and categories, the participants reported to make less than seven response errors. Participant pair 02 had zero; 03 had six; 04 had three; 05 had four response errors. More than 80% of the disagreements made by participants were reported as true disagreements.

Although participants reported true disagreements during the LIV card sort, they often changed their mind about life interests and values when persuaded by a family member or friend. The power of persuasion a family member or friend may have on the life interests and values of individuals with aphasia indicates the importance of including both individuals with aphasia and their family members or friends in the LIV Card Sort. For example, one participant with aphasia indicated that she was interested in going to more parties and restaurants. When her boyfriend insinuated that the two of them went to parties and restaurants often, the person with aphasia changed her mind. Another participant with aphasia indicated that she was not interested in camping or traveling more. When her family member said, "You would like to camp more and travel more, wouldn't you?" the participant changed her mind.



### *Life Interests and Values found Surprising*

The participant pairs were asked, “Did you find any of your family member’s/friend’s responses surprising?” Two family members/friends indicated that he was surprised by two (out of 85) life interests and values chosen by the participant with aphasia. The rest of the family members/friends were only surprised about one life interest and values. Participants with aphasia were not surprised about their family member’s/friend’s responses. One participant with aphasia chose the social activity of going to a bar with friends, which she later identified as a response error. The remainder of the participants with aphasia confirmed they either wanted to start doing the activity or do more of a certain activity. Family members and friends indicated that they had no idea the chosen activities were of interest to the individuals with aphasia. For example, one participant with aphasia wanted to start discussing politics and doing photography. Her boyfriend said that she never was interested in politics before. He also stated that she never tried to take pictures with his camera. The participant with aphasia assured her boyfriend that she wanted to do photography and discuss politics now. Another participant with aphasia said that he was interested in starting to get massages. His wife said that she was unaware of his desire to get massages. The results of the review session illustrated the benefit of the LIV card sort in providing a means of sharing surprising life interests and values of individuals with aphasia with their family members/friends and a rehabilitation team. It would be interesting to find out if the participants changed the way they did activities as a result of sharing and learning about these desires. The life interests and values can become the basis of an informed client-centered, interdisciplinary treatment plan.

## CHAPTER IV: Discussion

### Practical Implications

Five adults with aphasia and family members and friends asked to speak for them were interviewed about life interests and values using the LIV card sort. Level of agreement was examined, along with its relationship to aphasia severity and difference in objective behaviors versus subjective values.

As expected, overall agreement between adults with aphasia and family members and friends was low (below 80%). Previous research (Sneeuw et al., 1997) suggested that family members or friends were reliable informants. This sample of family members and friends did not provide, accurately, the life interests and values of adults with aphasia. There are a number of explanations to support these preliminary findings. Perhaps characteristics of family members and friends (e.g., education level, quality of life) influence agreements or disagreements of responses. These findings may indicate the need to assess family members or friends before allowing their participation. Perhaps some family members or friends are better informants than others. Another plausible explanation would be that the characteristics of the individual with aphasia (e.g., personality, age) influence agreements or disagreements using the LIV cards. Participants with aphasia may not complete the interview in ways that accurately reflect their concerns and desires. For example, patients may seek to respond in ways that present themselves favorably.

Unexpectedly, participants agreed equally on objective behaviors and subjective values. Participant pairs 01 and 04 had generally equal and low agreement for objective behaviors and subjective values. The dyads did not live together. Equal and low level of agreement across subjective values and objective behaviors for these dyads may mean that the family members or friends know little about the actual behaviors and values of the participants with aphasia.

Research studies support the idea that severity of impairment influences agreement between stroke survivors without aphasia and family members/ friends on ratings of life activities and participation (Duncan et al., 2002; Sneeuw et al., 1997). A search of literature uncovered no research studies of my knowledge indicating a significant correlation between severity of aphasia and agreement of ratings for stroke survivors with aphasia and family members/friends (Cruice et al., 2005; Hilari et al., 2007). The findings in the present study did not confirm this relationship. The positive correlation illustrated in the scatterplot of our findings indicates that with a larger sample size a relationship may be present. It is possible that participants with more severe aphasia may not be able to communicate accurately outside of the interview with their family member or friend to provide concordance of responses. Another possible confounding variable could be that individuals with more severe aphasia that are more dependent on family members or friends communicate less about life interests and values and more about life needs. It is also possible that the interviewer/clinician could cause response errors because of limited experience working with people with aphasia. Perhaps the severity of aphasia indicates the need for experienced clinicians to administer the interview. Maybe reliability of participant responses could be

checked continuously, even days or weeks later using the LIV card sort, to verify that therapy activities are client-centered.

A research study by Sprangers & Aaronson (1992) found that agreement, between family members/friends and patients, depends on the importance of the activities chosen. One participant with aphasia in the current study pointed to movies, puzzles, and reading when asked, “Which of the activities that you indicated as being things you want “to do more often” are the most important?” Another participant with aphasia said that starting to drive was of top priority. Similar to Sprangers & Aaronson (1992) findings, the family members/friends of the individuals with aphasia agreed about these activities that were reported to be the most important. A larger sample size could examine if this trend is significant.

### Theoretical Implications

The theory of “Self Determination” provides a model for patient-directed health care emphasizing the importance of empowering the person with aphasia to express their concerns and desires (Williams, Frankel, Campbell, & Deci, 2000). The findings of this pilot study indicated that the family members/friends may not be able to express the concerns or desires of individuals with aphasia accurately. The low level of overall agreement between adults with aphasia and family members/friends indicated that modifications should be made so that the individual with aphasia can be informants. Their inclusion in interviews of life interests and values provides a more accurate description of concerns and desires and follows the theory of self-determination. The idea of allowing both people with aphasia and their family members/friends to express concerns and desires in achieving their immediate and longer

term life goals directly reflects the LPAA (Chapey et al., 2001, p.235). As previously mentioned, LPAA targeted intervention goals are not only for improvement in language and communication, but also for improvement in life activities and participation and life satisfaction. The findings from the current study could provide specific life activities and participation of interest for the sample of adults with aphasia and specific areas that could be targeted in therapy.

### Limitations and Future Research

Characteristics relating to participant pairs are known to affect agreement in aspects of life activities and participation (Addington-Hall & Kalra, 2001). The sample size of five participants is too small to explore the impact of characteristics of participant pairs on agreement of life activities and participation. A larger sample size would allow statistical analysis of characteristics, for example in relation to: severity of aphasia; type of participant pair relationship, particularly wives, husbands, children, boyfriends; years post-onset; age and/or gender of participant pairs; and living arrangements. Future research specifically focused on: 1) examining the characteristics of people with aphasia and their chosen family members/friends; 2) examining the relationship between certain characteristics and ratings of agreement or disagreement for life activities and participation is needed. Also, future research could examine the relationship of the characteristics of clinicians or researchers (i.e., years of experience with the clinical population) interviewing the participant pairs on agreement or disagreement. Further research is needed to advance our knowledge in the type of bias provided by family members/friends. For example, researchers tend to report that family members/friends typically have negative bias by underestimating ratings of life

interests and values (Cruice et al., 2005; Hilari et al., 2007). It is possible that participants with aphasia may actually have a positive bias by overestimating their life interests. With a larger sample size, examining areas of bias in estimating life interests and values using the LIV cards, by both adults with aphasia and their family members or friends asked to speak for them, is needed.

## APPENDICES

### Appendix I: LIV: Sorting and Scoring Instructions

#### **Life Interests and Values (LIV): Sorting and Scoring Instructions** (Total estimated administration time: 2-3 hrs)

##### **1. Introduce activity**

*We want to find out what activities are important to you and what kinds of things you do in your life.*

##### **2. Introduce the 4 sets and select activity type**

- *Everyday Life Activities*
- *Social Activities*
- *Leisure Activities that take a lot of physical strength*
- *Leisure Activities that are not as physical*

*Which would you like to talk about first?*

Start with the set the person identifies and remove all others from the table.

**Mark the order of the selected set**

##### **3. Find activities the person does now (column 1).**

Place card with the “check mark” on the person’s right and card with the “X symbol” on person’s left.

*We are going to talk about \_\_\_\_\_ Activities. For each activity, tell me if it is something you do now in your life. If you do it now, put the card here (check mark symbol card). If you never do it, put it here (the X symbol card).*

**Circle “yes” or “no” for do**

**now**

Label activities and verify sorting as needed.

Remove the activity cards under “check mark” from the table with the “check mark” card on top

##### **4. For No Responses: Determine whether the person wants to start doing any of the activities he/she is not doing (column 2).**

Place card with “thumbs up” symbol card on the person’s right and “thumbs down” symbol card on the person’s left.

*These cards all show things you don’t do now. Are there any of these things you want to do in the future? If you want to start doing the activities, put them here (point to thumbs up symbol). If you do not want to start doing the activities, put them here (point to the thumbs down symbol).*

Circle “Start” or “don’t start”

Remove the activity cards from the table with the “thumbs down card” and “thumbs up card” card on top of each pile. ---Note: These can be scored at a later time or scoring checked if necessary---.

**5. For Yes Responses: Determine whether the person wants to do more of the activities he/she is doing (column 3).**

Place card with “an okay hand gesture” symbol card on the person’s right and “up arrow” symbol card on the person’s left.

*These cards all show things you do now. I want to know how much you want to do them in the future. If you feel OK with how much do them now, put them here (point to the okay hand gesture symbol). If you want to do more of these things, put them here (card with up arrow).*

Circle “OK now” or “more”

Remove the activity cards from the table with the “okay hand gesture” and “up arrow” card on top of each pile. ---Note: These can be scored at a later time or scoring checked if necessary---.



## **Family Member or Friend Interview and Scoring Instructions**

(Total estimated administration time: 40 min.)

### **1. Introduce activity**

*We want to find out what activities Mr./Mrs. X would choose as being important and what kinds of things he/she does in his/her life.*

### **2. Introduce the interview and activity type**

- *Everyday Life Activities*
- *Social Activities*
- *Leisure Activities that take a lot of physical strength*
- *Leisure Activities that are not as physical*

**Mark the order of the selected set**

The activity types will be counterbalanced for each family member or friend (Appendix ).

### **3. Find activities the person does now (column 1).**

Place card with the “check mark” on the person’s right and card with the “X symbol” on person’s left.

*We are going to talk about \_\_\_\_\_ Activities. Remember to answer every question the way Mr./ Mrs. X would respond. How would Mr./Mrs. X respond to the question, are you currently doing these things now, yes or no? If Mr./Mrs. X would respond with do it now, put the card here (point to the check mark). If you never do it, put it here (point to the X card).*

**Circle “yes” or “no” for do**

**now**

Label activities and verify sorting as needed.

Remove the activity cards under “check mark” from the table with the “check mark” card on top

### **4. For No Responses: The family member or friend states whether the person with aphasia would want to start doing any of the activities he/she is not doing (column 2).**

Place card with “thumbs up” symbol card on the person’s right and “thumbs down” symbol card on the person’s left.

*Remember to answer every question the way Mr./Mrs. X would respond. These cards all show things you said Mr. X/Mrs. X doesn’t do now. How would Mr./ Mrs. X respond if we asked Mr. /Mrs. X, “Are these things that you want to do in the future?” If Mr. X/ Mrs. X would say he/she wants to start doing the activities, put them here (point to thumbs up). If Mr. X/Mrs. X would say he/she does not want to start doing the activities, put them here (point to thumbs down).*

Circle “Start” or “don’t start”

Remove the activity cards from the table with the “thumbs down card” and “thumbs up card” card on top of each pile. ---Note: These can be scored at a later time or scoring checked if necessary---.

**5. For Yes Responses: The family member or friend states whether the person would want to do more of the activities he/she is doing (column 3).**

Place card with “an okay hand gesture” symbol card on the person’s right and “up arrow” symbol card on the person’s left.

*These cards all show things you said Mr./Mrs. X does now. I want to know how much he/she would want to do them in the future. If he/she would feel OK with how much he/she does them now, put them here (point to okay hand gesture). If he/she would want to do more of these things, put them here (card with up arrow).*

Circle “OK now” or “more”

Remove the activity cards from the table with the “okay hand gesture” and “up arrow” card on top of each pile. ---Note: These can be scored at a later time or scoring checked if necessary---.

### Appendix III: Study 2: LIV Card assessment with family members and friends

#### DEMOGRAPHIC INFORMATION

1. Age: \_\_\_\_\_
2. Gender: Male\_\_\_\_\_ Female\_\_\_\_\_

#### NATURE OF RELATIONSHIP

1. Approximately how many years have you known the person with aphasia? \_\_\_\_\_
2. What is the nature of your relationship? You are his/her...  
wife/husband/partner \_\_\_\_\_ daughter/son\_\_\_\_\_ parent\_\_\_\_\_ friend \_\_\_\_\_  
other (describe) \_\_\_\_\_
3. Do you live together?: \_\_\_\_\_yes \_\_\_\_\_no
4. In a typical week, how often do you spend time together?  
Every day\_\_\_\_ 4-6 days\_\_\_\_ 2-3 days\_\_\_\_ 1 day\_\_\_\_ Less than 1 day \_\_\_\_\_
5. On days you spend together, how much time to you typically spend with each other?  
Less than one hour\_\_\_\_ 1-4 hours\_\_\_\_ 4-8 hours\_\_\_\_ More than 8 hours\_\_\_\_\_

#### Appendix IV: Study 2: LIV Card assessment with family members and friends

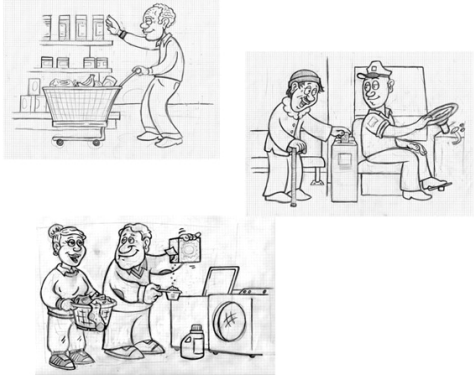

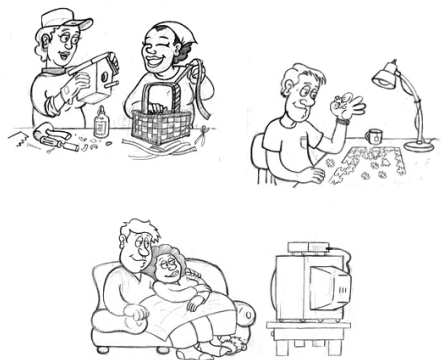

Interview script for 20-30 minute dyad review session following LIV card testing (comparison of information provided by the individual with aphasia and his/her appointed family member or friend).

1. The two of you gave different responses to (describe activity and explain difference)\_\_\_\_\_. Did we understand that right?
2. You also gave different responses to (describe activity and explain difference)\_\_\_\_\_. Did we understand that right?




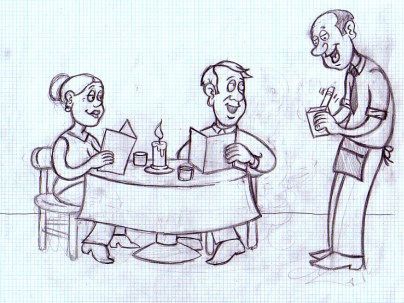
*Continue with any additional activities for which there were disagreement.*

3. Did you find any of your family member's/friend's responses surprising? Please explain.





Appendix V: Example of artwork for the life activity sorting task (1)

	
<p>Everyday Life Activities</p>	<p>High Physical Demand Leisure Activities</p>
	
<p>Social Activities</p>	<p>Low Physical Demand Leisure Activities</p>

Example of artwork for the life activity sorting task (2)

	
<p>Going to the Beauty or Barber-shop</p>	<p>Cooking</p>
	
<p>Dancing</p>	<p>Eating Out</p>

Example of artwork for the life activity sorting task (3)

 <p>A line drawing of a man standing in a library. He is looking at a book on a shelf. There are many bookshelves filled with books in the background.</p>	 <p>A line drawing of two men sitting on a couch, playing video games. They are holding controllers and looking at a television screen. A video game console is on a stand next to them.</p>
<p>Going to the Library</p>	<p>Playing Video-games</p>
 <p>A line drawing of two men hiking. They are wearing backpacks and holding walking sticks. They are walking on a path.</p>	 <p>A line drawing of a man swinging a golf club. A woman is standing next to him, and a golf bag is on a cart nearby.</p>
<p>Hiking</p>	<p>Playing Golf</p>

## Appendix VI: Recruitment Flyer

*Helping people with aphasia rediscover their lives*  
**The Life Interests & Values (LIV) Cards**  
*An interdisciplinary research project at the Department of Allied Health Sciences, 2008*  
*UNC-Chapel Hill School of Medicine*

### Seeking Research Participants

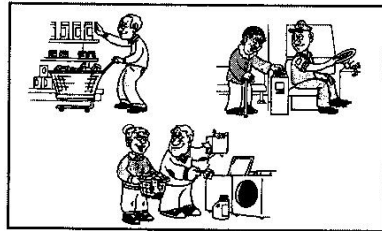
**We are currently seeking participants in the Triangle area for a research project to find out how a new assessment tool helps people with aphasia communicate about their experiences and interests in different kinds of life activities.**

Designed for practicing speech-language pathologists, occupational therapists, physical therapists and people with aphasia, the LIV-cards consist of four sets of easily-recognizable pictures of common life activities:

- Everyday activities and chores, such as washing dishes or doing laundry.
- Social activities, such as eating in restaurants or giving a party.
- Leisure activities, such as doing puzzles or listening to music
- Physical activities, such as hiking or exercising.

The participant sorts the cards into two piles: one with activities they want to do, the other with activities they aren't interested in pursuing. This simple "binary" sorting procedure allows stroke survivors with language problems to communicate about the things they are interested in doing--without actually having to talk. Clinicians can learn quickly what is important to the patients they work with. This information can then be integrated into the therapy plan.

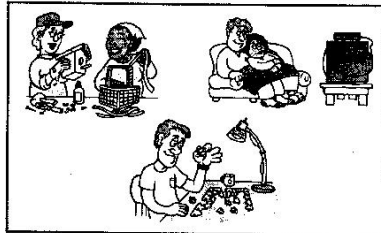
*Everyday activities*



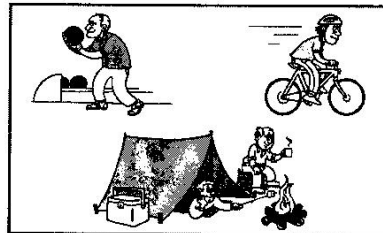
*Social activities*



*Leisure activities*



*Physical activities*



To learn more about the project, please contact Denise Caignon by email ([denise\\_caignon@med.unc.edu](mailto:denise_caignon@med.unc.edu)) or telephone (919-843-3699)



# Appendix VII: Example of LIV Card Sort Scoring Form

Name:		1. Do Now				Date:	
High Leisure Activities	No ↓	2. For "no": Start doing	Yes ↓	3. For "yes": Want to Do			
Boating	No	Start	Don't Start	Yes	OK Now	More	
Bowling	No	Start	Don't Start	Yes	OK Now	More	
Camping	No	Start	Don't Start	Yes	OK Now	More	
Cycling	No	Start	Don't Start	Yes	OK Now	More	
Exercising indoors	No	Start	Don't Start	Yes	OK Now	More	
Fishing	No	Start	Don't Start	Yes	OK Now	More	
Golfing	No	Start	Don't Start	Yes	OK Now	More	
Group Exercise	No	Start	Don't Start	Yes	OK Now	More	
Hiking	No	Start	Don't Start	Yes	OK Now	More	
Hunting	No	Start	Don't Start	Yes	OK Now	More	
Sports playing	No	Start	Don't Start	Yes	OK Now	More	
Swimming	No	Start	Don't Start	Yes	OK Now	More	
Traveling	No	Start	Don't Start	Yes	OK Now	More	

Clinician:		1. Do Now					
High Leisure Activities	No ↓	2. For "no": Start doing	Yes ↓	3. For "yes": Want to Do			
Walking	No	Start	Don't Start	Yes	OK Now	More	
Woodworking	No	Start	Don't Start	Yes	OK Now	More	
Yard games	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	
	No	Start	Don't Start	Yes	OK Now	More	

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