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## The Psychosocial Effects of Aphasia On The Caregiver

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# THE PSYCHOSOCIAL EFFECTS OF APHASIA ON THE CAREGIVER

by

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A thesis submitted in partial fulfillment of the requirements  
for the Honors in the Major Program in Communication Sciences and Disorders  
in the College of Health and Public Affairs  
and in The Burnett Honors College  
at the University of Central Florida  
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## **Abstract**

Studies have investigated the physical and emotional wellbeing of family members and spouses who care for persons with stroke (Bakas, et al. 2006). Literature shows burden of care is high in role reversal and depression is frequent. Variables that affect the caregiver burden with persons with aphasia (PWA) have not been identified prior to this study. Results from caregiver interviews found six themes, some which have not been identified prior, such as feelings of optimism.

*Keywords:* psychosocial, caregivers, stressors, stroke, aphasia

## **Dedications**

For my late grandfather, Ronald ‘Ron’ Wallace, who lived the last 3.5 years of his life filled with compassion, determination, and strength after being diagnosed with aphasia. Granddad, thank you for demonstrating that a purposeful life can go on even when your voice, as you once knew it, is taken from you. Thank you for guiding to me my true passion of becoming a speech-language pathologist.

For my parents, grandmother and immediate family, thank you for your encouraging words and for providing me the platform to reach my potential.

## **Acknowledgements**

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## **Introduction**

Studies have investigated the physical and emotional wellbeing of family members and spouses who care for persons with stroke (Bakas, Kroenke, Plue, Perkins, & Williams, 2006).

Aphasia, the loss of language from a stroke, exacerbates the caregiving burden. There is an enormous body of literature for caregiver, but a lot of the literature is written for dementia caregivers. There is also literature about aphasia and stroke recovery, but there is limited literature about caregivers of persons with aphasia. Literature shows that burden of care is high in role reversal and depression is frequent. However, variables, which affect the caregiver burden with persons with aphasia, have not been identified. This study examined caregiving burden as it relates to stroke survivors with aphasia.

## **Literature Review**

The term “psychosocial” reflects the dynamic relationship between psychological and social processes. Psychological processes are internal; they include thoughts, feelings, emotions, understanding and perception. Social processes are external; they are comprised of social networks, community, family and environment. It is important to remember that what happens in one of these areas will affect aspects of the others (Williamson, & Robinson, 2006). The psychosocial wellbeing is a very broad concept. It is a sense of control, supportive social relations, and general satisfaction with life. However, the psychosocial well being of an individual is vulnerable to circumstances like medical problems.

Cerebrovascular accident (CVA), also referred to as a stroke, is a sudden disabling attack caused by either an interruption in the flow of blood to the brain or a bleed in the brain. More than two thirds of the nation’s 4.6 million stroke survivors require the daily assistance of a family caregiver (Bakas, et al., 2006). Stroke is a major cause of chronic disability that has a considerable impact upon family caregivers. Family members are also prone to experience a variety of psychosocial consequences after the onset of stroke (Worrall, et, al., 2016).

Thirty-one percent of first-time stroke survivors will have a communication problem known as aphasia (Worrall, et al., 2016). Aphasia is a loss of language secondary to stroke. Aphasia can affect the survivor’s ability to find the right words, read, write, and understand what others are saying (“National Stroke Association”, 2014). After stroke, rehabilitative efforts have focused on the stroke survivor. But more recently, rehabilitative efforts have broadened to include the survivor’s family both in education and training of aphasia.



## **Caregiving**

Reports address a large number of difficulties faced by caregivers of survivors of neurogenic diseases, including Parkinson's, dementia and CVA, and the effect of those difficulties on the caregiver. The physical and emotional effects that a neurogenic disease causes can be overwhelming for both the survivor and their families. The caregiver experiences considerable disruption to professional, social and family life. Often there is a decline in social contact with friends, which frequently leads to depression, loneliness, frustration, and aggression. Zraick & Boone's (1991) investigation evaluated the attitudes of individuals towards their aphasic spouse. They reported that due to lack of previous experiences families are "often poorly prepared to cope with their new situation, and the resulting stress may negatively influence family dynamics, particularly spouse attitudes toward the person with aphasia" (Zraick & Boone, 1991).

**Negativity.** It is important to measure the quality of life for the caregiver because without the happiness and contentment of the caregiver, the survivor's quality of life and contentment are greatly diminished (Tellier, Rochette, & Lefebvre, 2011; Hilari, Owen, & Farrelly, 2007; Worrall et al., 2016). Zraick & Boone (1991) compared spouses' attitudes of their aphasic loved one to spouses' attitude of their non-aphasic loved one. One group was made up of 30 participants all spouses of PWA. The second group, the controlled group, was spouses who were similar in age, level of education, and gender to the spouses of PWA. Zraick & Boone (1991) found attitudes expressed by spouses of persons with aphasia to be negative. However, attitudes expressed by the control group were the polar opposite than that of the spouses of PWA. However, the results found from the controlled group of spouses were the polar opposite of the spouses with PWA. Attitudes most often expressed were demanding, temperamental, immature, worrying, and

nervous (Zraick & Boone, 1991). Hence, caregivers are at risk of decreased quality of life with fatigue, role conflict, social isolation, and a sense of burden (Williams, 1993).

**Role Conflict.** One of the changes in the family dynamics is role reversal. In addition to the anxiety and fear of suddenly finding normal communication difficult, family members, particularly spouses, often talk about the impact of role change. This affects not only spouses, but also children, suddenly finding themselves in a caregiver role. Changing from spouse to caregiver or child to caregiver can be a difficult process, particularly if the role is unfamiliar. Taking on such responsibilities is made all the more difficult for family members because of the communication difficulties of the person with aphasia (Worrall et al., 2010).

**Access of Services & Isolation.** Most studies conclude caregivers of aphasic stroke patients are more stressed, with symptoms of depression, loneliness and other emotional problems than caregivers of non-aphasic stroke patients (Draper et al., 2007). Tellier et al., (2011) found that half of spouses perceived themselves as having no access to services that could meet their needs despite support from their immediate circle. With the focus on their spouse, the caregiver may become isolated. Often times caregivers feel as though all eyes and attention are now on their spouse and they have no way of receiving help and support for how they are feeling. Additionally, there is no one who asks about the caregiver and their needs. However, caregiver interventions have been reported as effective in reducing caregiver isolation (Draper et al., 2007).

**Stress Related to Communication.** Navigating the world requires the ability to communicate. When a loved one struggles to communicate, the caregiver's impulse is to speak for the PWA. Not being able to communicate with lifetime partners or spouses can be difficult.

Communication difficulties between caregivers and PWA can cause the caregiver to have anxiety, anger, confusion, despair, and depression (Fucetola, & Connor, 2015; Burns, Baylor, Dudgeon, Starks & Yorkston, 2015; Brown, Worrall, Davidson & Howe, 2011b).

**Stress and Depression.** Dealing with unexpected medical needs beyond scheduled doctors appointments can also become very stressful for caregivers. The majority of survivors continue to live at home and often need practical help and emotional support creating a tremendous burden on the caregiver. Many caregivers, from the early post stroke period to 3 to 5 years after stroke, experience considerable stress. In the study by Berg et al. (2005), they found 11% to 42% of caregivers showed signs of depression. Despite the extensive research shown in identifying depression occurring in stroke patients, little attention has been focused on the emotional outcome and depression of caregivers of stroke survivors (Berg et al., 2005).

**Lack of Knowledge.** Studies have reported how important it is to include the family in management programs of the person with aphasia. The lack of knowledge family members have of the effect of aphasia makes it difficult to be successful at taking care of there loved ones. Counseling of family members and their loved one with aphasia has resulted in positive changes (Purdy & Hindenlang, 2005). Programs have focused specifically on educating PWA and their family members on stroke, aphasia, and communication strategies (Linebaugh & Young-Charles, 1978; Simmons-Mackie, 2001). Though lack of knowledge has been an issue and is a caregiver's stressor, research has been done to address this issue.

**Lack of Education Training.** Often, friends and family of the survivor avoid communicating with the persons with aphasia (PWA) because of uncertainty of how to communicate with them. However, Simmons-Mackie (2001) identified that just knowledge of

the nature of aphasia alone does not necessarily improve communication or assist with coping with the subsequent problems. Rather, one needs a strategy for communicating, such as the Supported Conversation for Adults With Aphasia (SCA) (Kagan, 2015). SCA is a communication method, which uses a set of techniques to help encourage conversation with someone with aphasia. Kagan (2015), Director of the Aphasia Institute, describes SCA as a technique designed to help people who “know more than they can say” express their opinions and feelings in a way that makes them feel valued and heard.

By increasing the family members' understanding of aphasia, it is hoped their interactions with the person with aphasia will become more satisfying (Linebaugh & Young-Charles, 1978; Simmons-Mackie, 2001). A study done by Purdy & Hindenlang (2005) investigated the benefits of caregiver education and training on communicative performance, knowledge, attitudes and levels of confidence during communication using an experimental learning model in a group setting. Purdy & Hindenlang's (2005) study found when caregivers had the training in strategies and methods to communicate, it helped them to better communicate with the PWA. “The caregivers reported a better understanding of aphasia, increased knowledge of facilitating strategies, and improved confidence using the strategies, at least in the home” (Purdy & Hindenlang, 2005).

In the recent decade, the Life Participation Approach to Aphasia (LPAA) has redefined the scope of aphasia rehabilitation (Chapey et al. 2008) to be inclusive of not only impairment reduction but also the PWA's quality of life. This encompasses the patient's desired activities and his level of participation rather than only his impairment level. Furthermore it is inclusive of not only the PWA but also all those close to the client who are also affected by aphasia.

Therefore, this paradigm shift is inclusive of working with the caregiver, both in education, training and their wellbeing. More recently, Attard et al., (2017), developed a 12-week course for community aphasic groups designed for PWA and their caregivers. The Interdisciplinary Community Aphasia Group (InterD-CAG) facilitator program manual discussed research from many researchers (Brown et al., 2010, 2011a, 2011b, 2012; Brown et al., 2013; & Grohn et al., 2012, 2014) and compiled a list of factors which contribute to living successfully with aphasia: participation, meaningful relationships, support, communication, positivity, interdependence and autonomy, and living successfully with aphasia as a journey over time. (See Appendix B: Figure 1).

**Conclusion.** There is a call for greater involvement of family members in the rehabilitation process and better support services for caregiver needs alongside those of the individual with aphasia. There are many stressors for caregivers of PWA that affect their Quality of Life (QoL) (Worrall et al., 2010). The stressor of lack of education has been addressed and strategies have been taught to help improve conversation between spouse and caregiver; however, there is still a great deal of stress that caregivers face. One major aspect, lacking in terms of caregiving, is the psychosocial aspect.

### **Psychosocial Instruments**

There are a number of different instruments used to assess the QoL. Examining all related scales of quality of life is outside the scope of this paper but there are a number that are directly relevant. Research has assessed the QoL for stroke and aphasia survivors, using instruments such as the Successfully Living with Aphasia Rating Scale (SLARS) and the Quality of Communication Life Scale (ASHA-QCL). They also have assessed how the caregiver perceives

their loved one with aphasia. There are a number of scales that deal with caregiver burden but none specifically focus on the quality of life of the caregivers of PWA. Below is an examination of some of these instruments.

**Caregiver Based Burden Assessment.** A widely used instrument for the burden of care is the Zarit Burden Interview. The Zarit Burden Interview is a 22-question interview, graded on a scale from 0 to 4, according to the presence or intensity of an affirmative response, and measures the caregiver's health, psychological wellbeing, social life, finances, and the relationship between the caregiver and patient. The scores of each of the 22 questions are then added together to form the caregiver's burden level (Zarit & Zarit 1990).

**Patient Based Questionnaires.** The Successfully Living with Aphasia Rating Scale (SLARS; Brown, Worrall, Davidson, & Howe, 2010) is a self-report consisting of a nine-point pictographic Likert rating scale. Participants rate themselves on the scale anchors from 1-9 ranging from not at all successful to very successful (Grohn, Worrall, Simmons-Mackie, & Hudson, 2014).

The Quality of Communication Life Scale (ASHA-QCL) emerged from a widespread need for a reliable and valid instrument designed specifically for assessing the quality of communication life for adults with communication disorders (Paul, & Paul, 2005). The ASHA-QCL gathers information about the influence of a communication disorder on an adult's relationships; communication; interactions; participation in social, leisure, work, and education activities; and overall quality of life. The ASHA-QCL was found to be a valid measure of the quality of communication life for use with adults with aphasia and dysarthria (Paul, & Paul, 2005).

**Questionnaires Completed by Caregivers for How the Caregiver Perceives the PWA.** The SAQOL-39 is a comprehensive, health related quality of life measure designed for and validated based on how the caregiver perceives the PWA (Simmons-Mackie et al., 2014). It uses an interview format of 39 different items to rate from 1-5 on how they think their partner with aphasia would answer (Hilari et al., 2007), and covers four different domains: physical, psychosocial, communication and energy.

The Functional Assessment of Communication Skills for Adults (ASHA-FACS) by Frattali & Frattali (2003) is another way to measure functional communication of adults with speech, language, and cognitive-communicative disorders. The ASHA-FACS is measured with two populations: adults with aphasia resulting from left hemisphere stroke and adults with cognitive-communicative disorders resulting from traumatic brain injury (Frattali & Frattali, 2003; Frittali, Thompson, Holland, Wohl, & Ferketic 1995). The ASHA-FACS consists of 43 items addressing four domains: social communication; communication of basic needs; reading, writing and number concepts; and daily planning.

**Questionnaires Specific for Caregivers.** The BELA-A-k measures physical, emotional, social and family functioning for Parkinson's disease (PD) caregivers. The BELA-A-k assesses both the amounts to which a caregiver is bothered by a specific psychosocial problem related to PD-caregiving as well as the Need for Help for this specific problem (Spliethoff-Kamminga, Zwinderman, Springer, & Roos, 2003). There are psychosocial instruments for caregivers, such as the BELA-A-k, which is specific to PD caregivers and their burden, as stated previously, but none specifically for the caregiver of PWA.

**The Breach in the Literature.** There have been studies that involve psychosocial intervention for stroke caregivers but none have targeted the caregiver of a PWA. Even though using a generic QoL scale allows for comparison with other groups of caregivers, a scale that contains items specifically for aphasia caregivers would provide more information to doctors and health care providers concerned with the well being of the caregiver. For example, there has never been a scale created for the psychosocial effect of aphasia on caregivers. This study seeks to further delineate stressors of caregivers of persons of aphasia in order to provide support for caregivers of PWA.



## **Data And Methods**

### **Research Design**

Exploratory data were gathered through personal interviews, transcribed and coded for themes using iterative analysis. Member checking to validate the data was done through focus groups.

During the planning stage, the research involved conducting a review of literature, identifying a pool of participants, creating a question framework, and submitting to the IRB. After IRB was obtained (See Appendix D: IRB Approval), interviews were scheduled. Prior to the beginning of the interview, participants were provided with the explanation of research and the Zarit Burden Scale outlined in Appendix C: Interview 2. Explanation of research was reviewed, the Zarit Burden scale was reviewed, and then the interview preceded using fourteen semi-structured interview questions. Interviews were audio recorded and transcribed.

Transcriptions were coded in *rapid reduction*. The codes produced themes. Content experts from UCF faculty were brought in to review the list. Codes and themes were brought back to a group of participants to verify understanding of the narrative. The Zarit Burden scale was not used as a screener for risk; however, there was a licensed clinical social worker to verify that there was minimal risk per the IRB. One participant expressed tearfulness and symptoms of depression during the interview and was assessed afterward by the LCSW for risk. No risk was identified, and she was offered information for a mental health support referral.

### **Individual Interviews**

***Participants.*** All participants were over the age of 18 and spoke English as their first language. Participants varied by age, gender and time post onset of the family member's CVA.

Participants were caregivers of persons with aphasia who seek therapy at the UCF Communication Disorders Clinic in Orlando, Florida.

***Instrument.*** The interview questions and discussion are outlined in Appendix C:

#### Interview 1

***Procedure.*** The interviews were approximately an hour and a half long. Beverages and light food were provided upon request. The intention was to interview until saturation was reached which suspected was to be 10. Saturation was determined when caregivers began to give the same information. However, due to timing with IRB, the pool of participants was restrained to seven. Informed consent was secured. Once consent was given, participants were asked to complete the Zarit Burden scale. After, the LCSW scored the test to identify the level of burden. After the Zarit Burden scale was administered, participants were interviewed individually using a semi-structured 14-question interview. There were two different types of questions. One set of questions consisted of roles and responsibilities as a caregiver and the other addressed the personal domain. Audio recordings were transcribed throughout the process and coding was initiated as part of an iterative analysis.

#### **Focus Group (Member Check)**

***Participants.*** The purpose of the focus groups was to validate findings after coding. The participants for the focus group were the original people interviewed. The focus group allowed participants to clarify any misunderstandings.

***Instrument.*** The questions and discussion are outlined in Appendix C: Interview 1

***Procedure.*** Participants were handed a paper with the identified themes. They then decided if the identified words were what they would agree were relevant. Additional time was allocated for discussion.

### **Sample**

The sample for this study was caregivers of persons with aphasia that seek therapy at the UCF Communication Disorders Clinic in Orlando, Florida. The purpose of this study was to assess caregiving psychosocial issues as it relates to stroke survivors with aphasia. Spouses were chosen as the focus of the study because they constitute a large number of caregivers for persons with aphasia. As such, they play the primary role in day-to-day activities. The goal of this research was to examine the themes found after interviewing caregivers. Participants were all Caucasian, English speaking, and at least 40 years of age. The study engaged a total of seven semi-structured interviews (two men and five women) and one focus group.

### **Data Analysis**

The qualitative analysis was guided by a team approach (Watkins, 2012b) supervised by the outside mentor. A spreadsheet technique was used to organize, manage, and analyze the data (Stockdale, 2002; Swallow, Newton, & Lottum, 2003; Watkins & Gioia, 2015). A word processing program was the first step in the data analysis; all data were transcribed into a table with multiple columns. After the data table was created, a data reduction technique (Watkins & Gioia, 2015), was employed to produce shorter, more concise data tables. In order to reduce the table, the primary investigator and mentor reviewed the all-inclusive data table, made notes about areas of commonality and overlap across groups or between participants, and eliminated sections of text that were unrelated to the research question.

A two-level coding process was used (Watkins, 2012b). The first level of coding was preliminary coding. The first level identified important text. The important text was used to identify concepts and themes important to the overall goal (Leech & Onwuegbuzie, 2008; Watkins, 2012b). Secondly, codes were collapsed and consolidated and transcript tables were double coded using the focused codes. The purpose of this study was to further delineate stressors of caregivers of persons of aphasia in order to provide support for caregivers of PWA.

## **Results**

### **Sample Demographics**

The Participant pool was of seven Caucasian caregivers, aged 40 and older, who had a family member attending therapy at the UCF Communication Disorders Clinic in Orlando, Florida. (See Appendix A: Table 1). The final sample included two men and five women caring for spouses ranging in age from 54 to 83 years of age. The majority of these individuals were retired, although the younger participants self-identified as having careers in business or labor (indicating a range of unique experiences and perspectives in the workforce).

### **Study Themes and Subthemes**

Findings from this study centered around six major thematic clusters: attitudes and expectancy about caregiving for a person with aphasia, participation with their spouse, recognition of change in both negative and positive ways, burden and independence on the caregiver, support for the caregiver, and communication. Next, each theme will be further developed and direct quotes will be used to clarify. (See Appendix A: Table 2).

#### **Theme 1: Attitudes and expectancy about caregiver for a person with aphasia**

Many participants found themselves as the primary supporters for their spouse with aphasia. Within this role, they recognized their own attitude as a determinate for their spouses. Their caregiver positivity directly affected their spouses' quality of life. When discussing what things have changed in the relationship with their spouse one female said *"I saw my job as being a cheerleader from day one and I just told him that he has to work and he'll get better."* While discussing advice that caregivers would give to a new aphasia caregiver, one woman said, *"You*

*have to...readjust those expectations because it's totally not what you thought... it just takes a really long time for the brain to heal."*

## **Theme 2: Participation with their spouse**

Participants frequently commented about their daily schedule with a spouse with aphasia. Spousal independence was reduced. They expressed a "need to protect the spouse," or being "confined to home," "being the driver."

***Protecting their spouse.*** Participants discussed the need to protect their spouse. One participant felt if she left her spouse home he might get hurt. She stated, "I always take him with me." Another participant discussed how she tries to find the balance between her husband interacting with others and protecting him from feeling embarrassed. She said, *"I try to find the balance on that and so that's been our biggest adjustment because ... I'm trying to do what I think he would want me to do and I don't think he would want people that he worked with to know ... he's not able to talk."*

***Exercise and getting out of the house.*** Participants felt it was important for their spouse to not just sit around the house for the day. Hence, the caregiver intentionally planned activities outside the home. One woman, when asked to describe her day, stated, *"I try to have an activity that we do. ... If we don't, we just go for a ride in the car or go to the bank or something to get him out of the house."*

***Driving for their spouse.*** Many female participants shared their role of being the primary driver. One woman, when asked about any increased burden, shared, *"Well, I do all the driving. I never realized how many things that involved. ... If he had a dental appointment or if he had a haircut or whatever... he just went and now I do all that so that's a big change."*

Another woman expressed how she had relied on her husband to do all the driving prior to his stroke. She stated, *“I’ve learned how to drive ... its been a few years now since he had his stroke so I’ve learned how to drive. Prior to that, I didn’t do any driving. I just relied on him and I’d go to sleep. Well now, I have to actually pay attention but I have become a much better driver.”*

### **Theme 3: Recognition of change**

Participants recurrently discussed the changes that have come after the incident.

Subthemes emerged from the data through two constructs: positive traits of change and negative traits of change. Positive subthemes that emerged were: returning control to spouse of PWA, changing roles, and acceptance and developing personal qualities. Fear, worry of unknown, and loss were negative subthemes that emerged with change.

***Positive: Returning control to their spouse.*** After the incident, many caregivers assume both their roles and their spouse’s roles. One participant discussed how she purchased a planner so they could begin to make decisions together again. She said, *“I got him a day timer and he has his schedule for the next six weeks. He’s very used to controlling his schedule... Now, I can talk to him about why I think we should up this or up that. We have a really good discussion and he feels in control of his decisions...”*

***Positive: Roles changing.*** One woman shared the difficulty she experienced preparing her home for the hurricane. She shared her husband used to bring in all the outside furniture and help secure down the house. Now since his stroke, he was not able to take care of the house, *“I mean, that’s when I feel burden... I’m used to him doing a lot.”* Another women discussed the difficulty of keeping up with the house *“The biggest burden is taking care of the house, because he always took care of fixing everything and took care of the outside. I always*

*just made sure the inside was clean and did the laundry and that kind of stuff. Well now I have to do it all. I hate yard work and I can't afford to pay ... a lawn guy and a pool guy and a this and a that and then also have things fixed ... so that's a struggle just because ... I hate dealing with that stuff ...*

**Positive: Acceptance and developing personal qualities.** One gentleman discussed the challenges in accepting his “new” loved one since her stroke by saying, “I would say that I haven't accepted it... I don't know if that's true or not but I expect her to recover substantially more ... whether I am just kidding myself or uh that is the case... I don't know but I do see her progressing ... most days ... I haven't accepted that she is where she is. I've accepted that she will not be where she was ... she will not go back to work but I still think that she could ... have a rewarding and eventful life.” Though some caregivers have trouble accepting their spouse with aphasia, one participant stated she has really delved deeply to create change in herself, “I really have dug deep... I don't sweat the small stuff because it doesn't matter any more. It's just in the grand scheme of things, after this has happened, ... there would be so much more that's worse that I just don't stress about stuff that would ... irritate me that he did before. I just tell myself, well that's the way it is. I can't yell at him, he can't help it.”

**Negative: Fear.** After returning home from the hospital or rehabilitation therapy center, many caregivers said they were afraid of taking care of their spouse with aphasia. Many participants shared they had two fears: they were afraid to confuse medication dosages, and they were afraid of their spouse falling and hurting himself or herself while walking. “*We wanted to stay,*” said one family who was scared of the next step. Some participants said they wanted to stay at the hospital simply because they were afraid of the unknown or possibly hurting their



spouse. *“I was scared; oh yeah I was scared because you know I wasn’t... you know... he wasn’t nearly as responsive ... speaking in garbles and you know he could walk with a quad cane but it wasn’t like ... steady. So I was scared that I was going to let him get hurt.”*

At times the caregivers expressed that they felt their loved one was afraid which then influenced their independence. An example of this was with one spouse who took a trip to Europe with her husband. She explained that it was different traveling with him through Europe since his stroke. The following quote illustrates how the client disengaged from his environment and would not look at anything around him, *“It’s different ... Before I would say, ‘I’ll meet you back here in about 15 minutes’ ... But this time it was kinda like being with a child ... I’d say, ‘Stay right with me.’ and he didn’t want to much, ... he was just so afraid of being lost.”*

**Negative: Worry of unknown.** Some participants worry about leaving their spouse alone. *“I still worry ... because he’s not capable of using the phone. I don’t know why. So I always think, if something happened, would he call or would he know? I don’t know. But I always just tell him, ‘Stay in. Stay safe. Don’t do anything crazy while I’m gone.’ And I don’t stay gone to long.”* Another participant worries if something happened with her husband would he be able to seek help. She said, *“I just worry that if I am gone for too long and something were to happen, would he even... though we talk about it know how to call 911 or how to call me.”*

**Negative: Loss.** One participant shared how taking care of her husband has affected her personal life with her family and friends. She shared how some people have detached from being around her and her husband because they are uncomfortable and feel they do not know how to communicate with him because he has aphasia, *“I think, other than our really tight nit close friends and family, ... other people that normally would’ve ... spent more time with us are*

*a little bit more... withdrawn ... because ... it makes them uncomfortable. They don't know how to talk to him or ... there's not a lot that we can just pick up and do like we used to. So I think ...that group of individuals has just gotten smaller."*

#### **Theme 4: Burden and Independence for the caregiver**

Participants during their individual interviews raised concern about lack of time. The subtheme of time emerged from the data into two further subthemes: personal time, and therapy schedules.

**Time: Personal time.** One participant discussed missing the freedom to go out of the house and run errands by herself. She said, *"I guess I miss maybe just being able to run around by myself and do some errands."* She later went on to discuss the demand of her spouse and how it has become difficult to have time to work around the house, *"I kinda find it hard to get into something. I probably let some stuff go ... something that would have taken all day or some things... I just tend to not get into that anymore."*

**Time: Therapy schedules.** It can be very difficult to balance therapy schedules into caregivers' busy life and possible work schedule. One gentleman explained the importance of making time for therapy, *"We have rehab everyday; whether its speech, or physical or occupational. We have occupational and physical and wellness everyday so I know that's difficult for a lot of people who are not in the situation that I am in. Again my company has been very very good to me... but you've got to make those kind of sacrifices."* During the conversation, the gentlemen acknowledged he has seen his spouse with aphasia improve with therapy. Another participant shared that it is hard for her to fit her personal time into his busy therapy schedule.

## **Theme 5: Support for the caregiver**

Different types of support for the caregiver emerged as prominent factors to help the caregiver on a daily basis. Subthemes emerged into four constructs: family and friend support, paid help and support, therapy and ancillary services, and partnership with the caregiver and care recipient.

**Family support.** One participant shared how much her family has helped with caring for and communicating with their family member who has aphasia. One woman clearly explained the unbelievable support she has had especially from her patient grandchildren, *“I must tell you my friends and my family are unbelievable with him. They really ... try to get him to talk and the grandchildren especially, they sit with their video games and ... they show him and say “grandpa try this” so that’s very helpful.”* Another participant said once she started back to work she made sure there was someone with her husband so that the information from the doctors was relayed back to her. She said, *“I started back ... half days and ... I made sure that somebody was there, either my mom or his sister came, one time his niece came. I just always made sure someone was there because these doctors are coming in, and I know he’s the patient and they are talking to him, but he doesn’t understand anything you’re saying. He’s not going to be able to tell me ... so I just made sure I had somebody there that was taking notes and just writing stuff down letting me know how he was doing and that kind of stuff.”*

**Paid support.** In response to how often one leaves the house alone, one woman said she had paid support to help her so that she could feel comfortable running to the store and he had help to walk, *“We had caretakers 24 hours the first 6 months because when ... we were at ORMC in downtown Orlando for 2 months, I drove back and forth for the first week or two and*

*then I moved over there. And so when he came home, he was walking with a large quad cane but he was very shaky. We had 24-hour help because the main thing was that he didn't fall."*

**Therapy and ancillary services.** While discussing what sort of disconnects she sees with her husband, one caregiver said, *"At the end of the day, I think you know, I've been thinking for two people. I mean we can converse and eventually we usually get it, whatever he tries to tell me. But it's harder and it's helped me so much to sit in on his therapy because I realize a lot of stuff I say it doesn't go through."* Another caregiver shared, *"I usually stay in the therapy sessions with him. I think that's helped him a lot."* One participant discussed the difficulty balancing therapy and work and often has to work later at night. She said, *"Besides coming to speech, he also does physical therapy twice a week and then sometimes we have doctors appointments, so I just try to work that into my day."*

**Partnership.** Many caregivers shared, that while they do encounter difficulties communicating with their spouses, they are able to get past those disconnects as a result of their long history together and experiences of communicating as partners. One participant, when characterizing the relationship she has with her spouse with aphasia, said, *"We're much closer now than we were before. It did bring us together closer because you know we've been married a long time."* One participant shared, *"You go back to the vows that you said you know better or for worse, richer or poor, or sickness and in health... you just kinda... that's what you signed up for so you just kind of do it."* Another participant shared how she has managed to get around the roadblocks of communication with her spouse. She stated, *"It's very difficult at times to ... get him to understand something but what I have to do ... is go way back ... we've been married 63*

*years. We go way back into our past and start building on that to get him to know what I'm talking about."*

### **Theme 6: Communication**

Many participants have difficulty communicating with their spouse. One gentleman shared how much things have changed for him and disconnects he has with his spouse. He said, *"It's a real pain considering we were both very verbal in our relationship. We talked about what we did during the day we talked about people we knew, we talked about the world events ... we talked about work, and we read you know so we were talkers. And now she can't talk so it is a massive disconnect."* One participant discussed that one major burden is her difficulty communicating with her husband she said, *"The major burdens is just trying to talk sometimes to him."* Another participant shared how she has noticed her husband has trouble communicating with strangers but does better when he is more familiar with the person he is talking to. She said, *"I see it's hard for him to communicate and he becomes quiet. But around the family he does try to express himself."*

After the themes were identified, participants attended focus groups to verify the findings and add anything they felt was missing. Within the groups, caregivers identified there were several things not accurately reflected within the list of themes and codes. Below are the additional items to be considered for further investigation:

- The theme of Attitude and Expectancy should include learning curve. Participants felt the learning curve was about what to expect next in their journey of rehabilitation.
- Advocacy needs to be added to the subtheme of protecting. Participants felt they were the advocate for their spouse, especially through out the medical process. The participants

felt doctors had trouble understanding the PWA and the caregiver needed to be there to be the advocate for their spouse.

- Financial needs to be added to theme of Burden and Independence. Some participants felt, though they did not personally feel financial difficulties attending therapy one to two times per week, they could not financially afford to attend therapy everyday of the week. Some participants shared they wished they had more time and money to afford for their spouse to attend intensive therapy.

## **Discussion**

Common themes addressed in the literature on stressors of caregivers of stroke survivors with aphasia include: lack of educational training, lack of knowledge, negativity, role conflict, limited access to services and isolation, stress and depression, and stress related to communication. This study adds to the literature with some unique and different findings than what was previously addressed.

The first difference was in regards to the attitude of the participants. In the study conducted by Zraick & Boone (1991), they found attitudes expressed by spouses of patients with aphasia were exclusively negative. However, these findings suggest many caregivers were not exclusively negative toward their spouse with aphasia. Although, no specific question was asked during the interview about their attitudes toward their spouse with aphasia, many caregivers felt they were closer with their spouse after the stroke.

With regards to the protection of spouses and driving for their spouses, all caregivers discussed the need to protect and drive for their spouse. Worrall et al., (2010) found, from the combination of three qualitative studies, one of the changes in the family dynamics is role reversal. In this study, several participants discussed assuming the roles their spouse had prior to the incident. Participants did not identify them as role reversal but as added responsibility (e.g. paying the bills). One caregiver discussed how shy she used to be and how outgoing her husband had been. Now, she has become more outgoing because her husband is not able to communicate as easily.

Findings did not concur with Draper et al., (2007) and Tellier et al., (2011) about lack of access to service. Participants in this study had access to services through three means of

services. First, participants receive individualized feedback per therapy session, either by sitting in the therapy session or immediately after the therapy session. Secondly, there is group mental health counseling available weekly for the caregivers. Additionally, the therapy facility provides SCA training for family members. Two participants discussed, during the interviews, they use SCA specifically to communicate with their spouse.

Many caregivers discussed they have communication difficulties with their spouse with aphasia. Research studies by Fucetola, & Connor, (2015); Burns et al., (2015) believed communication difficulties between caregivers and PWA can cause the caregiver to have anxiety, anger, confusion, despair, and depression. Only one particular caregiver felt angry after his wife had her stroke because he did not understand why it had to happen to his wife and why they had to suffer dealing with aphasia. No other caregiver addressed they had feelings of anxiety, anger, confusion, despair or depression. In fact, three participants addressed specifically they do not feel they have any signs of depression. In the study by Berg et al. (2005), they found 11% to 42% of caregivers showed signs of depression. Nearly all participants showed signs of grief and depression. One participant expressed tearfulness and symptoms of depression during the interview, and was assessed afterward by the LCSW for risk. No risk was identified, and she was offered information for a referral to a mental health counselor. Purdy & Hindenlang (2005) suggested counseling of family members and their loved one with aphasia has resulted in positive changes.

As we know from the LPAA approach, Linebaugh & Young-Charles (1978), Simmons-Mackie (2001) & Chapey et al., (2008) have developed programs which focused specifically on educating PWA and their family members on stroke, aphasia, and communication strategies.



LPAA approach includes anyone who is a vested communication partner (Chapey et al., 2008). Regarding communication partner training, two caregivers in the present study identified receiving training in (SCA) and the usefulness of the training. These findings concur with the meta-analysis conducted by Simmons-Mackie et al (2010), which indicated training was effective in improving communication. However, their meta-analysis revealed insufficient data on its effect on quality of life (QoL) for either the PWA or communication partner. This study suggested that if trained, QoL was improved. One participant, trained in SCA, commented he did not have the frustration or difficulty he saw in others.

There were topics not addressed in the literature that were found within interviews. These topics are the feeling of optimism, which is unique to caregivers of persons with aphasia, recognition of change, and burden of independence. Many other chronic diseases worsen over time making it harder but PWA improve with time. This knowledge of improvement is what gave the caregivers and PWA hope and optimism, which was unique to caregivers of PWA.

### **Limitations**

These findings should be interpreted in the context of the following limitations. First, participants were from a university communication disorders clinic. Hence, participants had been proactive in finding continued sources of therapy for their client. Furthermore their spouses were currently receiving services. Thus the findings are not generalizable to all caregivers.

Additionally, all participants were Caucasian so it did not represent a diverse population.

Thirdly, the participant pool was limited to fewer than 10.

Furthermore, the Zarit Burden Scale which caregivers completed indicated participants experienced little to no burden, although they shared stories of varied levels and types of burden.

The Zarit Burden Scale measure may not have accurately captured the type of burden related to spouses of PWA. Barring these limitations, the present study is well positioned to help clinicians and professionals move toward more targeted assessment tools for caregivers of PWA.

### **Implications for practice**

The first manual that discusses a need for caregivers, the InterD-CAG, was developed in Australia. More training programs should address the needs of the caregiver. Unfortunately caregivers of aphasia patients do not have the same burdens and issues as other caregivers of chronic disorders. Therefore, there needs to be a unique tailored assessment to measure burden for caregivers of PWA. During the interviews, participants discussed things that burdened them but it was not captured within the Zarit Burden scale. Similarly, participants discussed feeling sad, stressed, depressed, and burdened after the incident but are no longer issues.

The findings of spousal hope and improvement should be investigated further. The Zarit Burden Scale showed low burden for caregivers but during the interviews they indicated burden. There needs to be a modified scale to capture improvement and hope as a mitigating factor for caregivers of PWA. So the scale should capture identified stressors and feelings on a time continuum.

## **Conclusion**

There is a call for greater involvement of family members in the rehabilitation process and better support services for caregiver needs alongside those of the individual with aphasia. There are many stressors for caregivers of PWA that affect their Quality of Life (QoL) (Worrall et al., 2010). Literature shares that studies have investigated the physical and emotional wellbeing of family members and spouses who care for persons with a dementia, stroke, cancer, Parkinson's disease and other chronic diseases. However, there is not research investigating the physical and emotional wellbeing of family members and spouses who care for persons with aphasia. Additionally, there is not research about the difference of chronic disease from aphasia. This study established themes that were common across the caregiver's of PWA interviewed. The themes discovered in this study were: attitude and expectancy, participation, recognition of change, burden and independence, support and communication. There are still factors affecting the psychosocial wellbeing of caregivers of PWA that have not been addressed.

Similar to the difficulty of learning to speak a foreign language, learning to speak with an aphasic can be just as difficult. The spouse can choose from two options; choose to learn how to speak aphasic to better communicate with their spouse, or, pretend the incident never happened, which is not a healthy option. If researchers and professionals are proactive in training, educating, and assessing well being of family members, the PWA may expect to experience a better QoL along with the family.

## **Future Direction**

There are several directions for future studies in the realm of psychosocial wellbeing of caregivers for persons with aphasia. The finding of spousal hope and improvement should be

investigated. A modified burden scale needs to be created to assess burden levels for caregivers of PWA along a time continuum. The attitude and expectancy of what their role was not found in the literature. There is an expectation of getting better which is not in literature that maybe specific to caregivers of PWA. Aphasia is a chronic disease but it does not get worse. ALS, Parkinson's disease. Therefore, if caregivers are educated and trained on what they need to support, this may mitigate subsequent negative feelings and they can support their spouse with aphasia.

## **Appendix A: Tables**

**Table 1: Demographics**

N=7	
Gender	71% female (n=5)
Age of CG's	40+
Age of CR's	Range: 45-83
Years Married	47, 48, 52, 63, 25, 43 (n=6)
Zarit Burden Scale	25.42857 (SD: 9.466734)*

\*All scores fell at or below mild to moderate range of burden.

**Table 2: Themes and Subthemes**

Theme	Subtheme
1. Attitude / Expectancy / Learning Curve	
2. Participation	<ul style="list-style-type: none"><li>• Protecting and Advocacy</li><li>• Exercise/Getting Out of the House</li><li>• Driving</li></ul>
3. Recognition of Change	<ul style="list-style-type: none"><li>• Positive: Returning Control</li><li>• Positive: Roles</li><li>• Positive: Acceptance / Developing Personal Qualities</li><li>• Negative: Fear</li><li>• Negative: Worry of Unknown</li><li>• Negative: Loss</li></ul>
4. Burden / Independence	<ul style="list-style-type: none"><li>• Financial</li><li>• Time: Personal Time</li><li>• Time: Therapy Schedules</li></ul>
5. Support	<ul style="list-style-type: none"><li>• Family Support</li><li>• Paid Support</li><li>• Therapy / Ancillary Services</li><li>• Partnership</li></ul>
6. Communication	

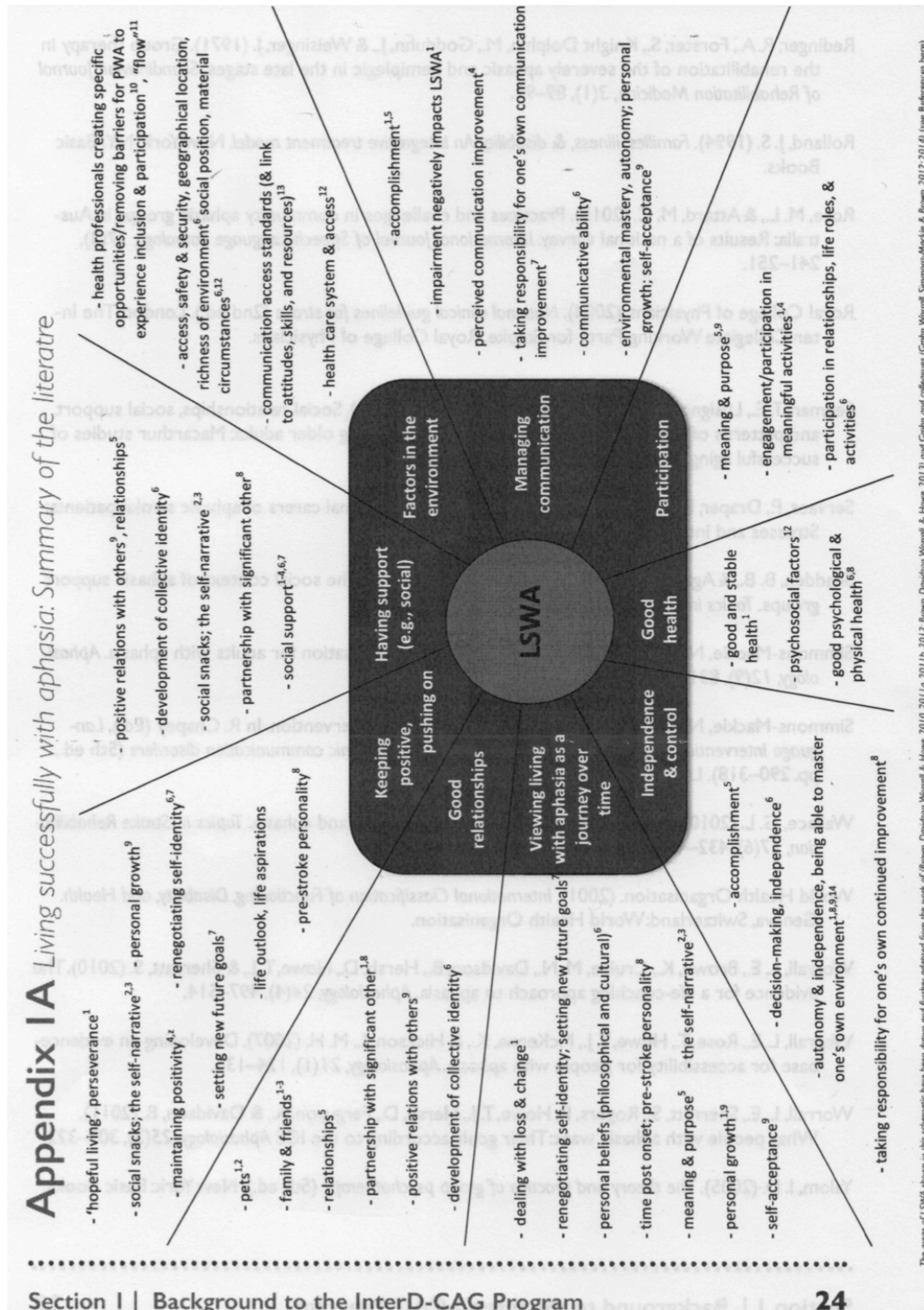
**Table 3: Subthemes and Selected Participant Quotes**

<b>Subtheme</b>	<b>Context</b>	<b>Selected Quotes</b>
Attitude / Expectancy / Learning Curve	One gentleman described the advice that he would give to a new caregiver of PWA.	<i>"I don't think you should give up would be the biggest thing and that support ... to work everyday."</i>
	One woman when discussing what activities her and her spouse participated in together prior to her husband's incident provided this example.	<i>"I tried I took the attitude its like you know you hear when there is a death in the family you should never make any changes the first year. So I basically just kept everything status quo."</i>
	One gentleman, when discussing the 'gaps' or a lack of knowledge before bringing his wife home from the hospital he provided this example.	<i>"It's the whole notion that your life now begins with stroke. Not with what it was. You don't look back to what it was like before. You look at from the day of the stroke. That's hard for people to accept ... I never included her in the really bad news."</i>
Recognition of change: Positive (acceptance/ developing personal qualities)	When asked to list five words that come to her mind now, one woman gave the word mystery and elaborated by providing this example.	<i>"I frequently find myself I look at him and think "How can this man that was so smart you know its just like somebody just clicked a button and everything went?" The mind, the reading, the memory, but so much of that has come back. But every now and then I look at him I think you know I just can't believe that something just like in a second can just erase like 70 years of what you've known and done and lived."</i>



## **Appendix B: Figures**

Figure 1: Living Successfully with aphasia: Summary of the literature from InterD-CAG Program



## **Appendix C: Interview**

## **Interview 1: Interview and Focus Group Questions**

### **Individual Interview Questions**

Participants Name:

Date:

Interviewer:

Proctor:

Welcome and consent will be before asking any interview questions

Question 1: What is your relationship with the person your caring for?

#### **Part I: Roles and Responsibilities as a caregiver**

- Can you walk me through what your day entails from when you wake up in the morning to when you go to bed at night.
- What burdens do you have now and what is required of you?
- What sort of disconnects do you find on a daily basis with your (CR)?
- Overall how are you doing with your roles and responsibilities? Are you doing as much as you want?

#### **Part II: Personal Domain**

- How many days do you leave the house?
- What activities did you partake in prior to your loved ones stroke? Are any of those discontinued now? Do you mind sharing with me why you have stopped?
- How would you characterize your relationship (with care recipient)? Have things changed with your relationship?
- Can you tell me how this has affected your personal life? (For example: What is different about your life today versus before the event?)
- How do you think your (CR) and others would evaluate you as a caregiver? What grade would you give them?
- Do you perceive ‘gaps’ or a lack of knowledge before bringing your spouse home? Where you prepared?
- What five words come to mind when thinking about your life currently? Why?
- Has it been challenging to accept your “new” loved one trapped inside of the old loved one?
- What is your experience in caring for someone with a disability?
- What advise would you give to someone who has just recently become a caregiver of a person with aphasia?

## **Focus Group Questions**

Participants Names:

Date:

Interviewer:

Proctor:

## **Focus Group**

- Here are the themes I found. Did I get it right?
- Are there any themes listed that you would change?
- Did I misinterpret anything?
- Do you have any other thoughts about this?
- Is there anything you think I should add to this list?

**Interview 2: The Zarit Burden Interview**

Participants Name:

Date:

Interviewer:

Proctor:

0: NEVER

1: RARELY

2: SOMETIMES

3: QUITE FREQUENTLY

4: NEARLY ALWAYS

Please circle the response the best describes how you feel.

1. Do you feel that your relative asks for more help than he/she needs? 0 1 2 3 4
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself? 0 1 2 3 4
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work? 0 1 2 3 4
4. Do you feel embarrassed over your relative's behavior? 0 1 2 3 4
5. Do you feel angry when you are around your relative? 0 1 2 3 4
6. Do you feel that your relative currently affects our relationships with other family members or friends in a negative way? 0 1 2 3 4
7. Are you afraid what the future holds for your relative? 0 1 2 3 4
8. Do you feel your relative is dependent on you? 0 1 2 3 4
9. Do you feel strained when you are around your relative? 0 1 2 3 4
10. Do you feel your health has suffered because of your involvement with your relative?  
0 1 2 3 4
11. Do you feel that you don't have as much privacy as you would like because of your relative? 0 1 2 3 4
12. Do you feel that your social life has suffered because you are caring for your relative?  
0 1 2 3 4
13. Do you feel uncomfortable about having friends over because of your relative? 0 1 2 3 4

14. Do you feel that your relative seems to expect you to take care of him/her as if you were the only one he/she could depend on? 0 1 2 3 4
15. Do you feel that you don't have enough money to take care of your relative in addition to the rest of your expenses? 0 1 2 3 4
16. Do you feel that you will be unable to take care of your relative much longer? 0 1 2 3 4
17. Do you feel you have lost control of your life since your relative's illness? 0 1 2 3 4
18. Do you wish you could leave the care of your relative to someone else? 0 1 2 3 4
19. Do you feel uncertain about what to do about your relative? 0 1 2 3 4
20. Do you feel you should be doing more for your relative? 0 1 2 3 4
21. Do you feel you could do a better job in caring for your relative? 0 1 2 3 4
22. Overall, how burdened do you feel in caring for your relative? 0 1 2 3 4

Interpretation of Score:

- 0 - 21 little or no burden
- 21 - 40 mild to moderate burden
- 41 - 60 moderate to severe burden
- 61 - 88 severe burden

## **Appendix D: IRB Approval**





University of Central Florida Institutional Review Board  
Office of Research & Commercialization  
12201 Research Parkway, Suite 501  
Orlando, Florida 32826-3246  
Telephone: 407-823-2901 or 407-882-2276  
[www.research.ucf.edu/compliance/irb.html](http://www.research.ucf.edu/compliance/irb.html)

## Approval of Exempt Human Research

From: **UCF Institutional Review Board #1  
FWA00000351, IRB00001138**

To: **Janet D. Whiteside and Co-PIs: Lauren Anne Ferrara & Tracy C. Wharton, PhD**

Date: **November 22, 2016**

Dear Researcher:

On 11/22/2016, the IRB approved the following activity as human participant research that is exempt from regulation:

Type of Review: Exempt Determination  
Project Title: The Psychosocial Effect of Aphasia on the Caregiver  
Investigator: Janet D. Whiteside  
IRB Number: SBE-16-12465  
Funding  
Agency:  
Grant  
Title:  
Research ID: N/A

This determination applies only to the activities described in the IRB submission and does not apply should any changes be made. If changes are made and there are questions about whether these changes affect the exempt status of the human research, please contact the IRB. When you have completed your research, please submit a Study Closure request in iRIS so that IRB records will be accurate.

In the conduct of this research, you are responsible to follow the requirements of the [Investigator Manual](#).

On behalf of Sophia Dziegielewski, Ph.D., L.C.S.W., UCF IRB Chair, this letter is signed by:

A handwritten signature in black ink that reads "Kamille Chaparro". The signature is fluid and cursive, with a long horizontal line extending from the end.

Signature applied by Kamille Chaparro on 11/22/2016 01:04:36 PM EST

IRB Coordinator

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