IMPACT OF PERSONALITY ON BURDEN OF CAREGIVERS WITH APHASIA

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LIST OF ABBREVIATIONS

ADL	Activities of Daily Living
ASHA	American Speech-Language Hearing Association
CBS	Caregiver Burden Scale
FWC	Family-Work Conflict
HRQoL	Health Related Quality of Life
IADL	Instrumental Activities of Daily Living
NEO-PI	Neuroticism, Extroversion, Openness to Experience Personality Inventory
WHO	World Health Organization
WFC	Work-Family Conflict

ABSTRACT

IMPACT OF PERSONALITY ON BURDEN OF CAREGIVERS OF PERSONS WITH APHASIA

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The relationship between personality and caregiver burden in aphasia is thus far understudied, with most research being qualitative in nature (Gillespie, Murphy, & Place, 2010; Nätterlund, 2009). Further understanding personality could potentially impact the way we assess caregivers and use interventions to support someone with a high score in a personality trait. Using an online platform, this research explored the personality-burden relationship quantitatively using the M5-50 (Mccord, 2002) and the Caregiver Burden Scale (Zarit, Reever, & Bach-Peterson, 1980). Participants included unpaid caregivers of persons with aphasia recruited via paper or electronic invitation and provided to facilitators of aphasia support groups and speech-language pathologists analyzed from a sample of N=78. Data included an overall score of burden and five scores of personality (i.e., extroversion, agreeableness, conscientiousness, neuroticism, openness to experience). Pearson correlation was conducted to investigate the relationship between each of the five domains and the caregiver burden score. No statistical associations were observed. Even though it was not significant, the correlation between openness to experience and the caregiver burden score had a medium effect size (Cohen, 1988). Results of this study suggest that there is no relationship between personality and caregiver burden for caregivers of people with aphasia; the sample size and demographics (e.g., those participating in support groups) suggest that there are limited applications of findings to the aphasia caregiver population. Undoubtedly, the unpaid caregiver workforce is critical to managing the long-term consequences on society of stroke and aphasia. Further research needs to be conducted to further investigate personality and caregiver burden in a broader demographic to increase the likelihood of capturing applicable results, such as a longitudinal study database throughout different points in recovery and rehabilitation, as well as capturing those who refused treatment and do not have access to speech language pathologists.

CHAPTER ONE: INTRODUCTION

Stroke and Aphasia

Stroke occurs when there is an interruption of blood flow, and thus oxygen, to the brain due to a blocked or ruptured blood vessel. It is reported that approximately 795,000 people in the United States have a stroke each year, and stroke is reported as the fifth most common cause of death in the U.S. (Benjamin et al., 2018). The consequences of stroke are largely dependent on lesion location and size, and aphasia often occurs following stroke in the peri-Sylvian cortex of the left hemisphere. Aphasia is an acquired language impairment affecting multiple communication modalities, including speaking, listening, reading, writing (Fridriksson et al., 2018), and it is estimated that 20% to 38% of strokes result in aphasia (Engelter et al., 2006).

Severity and presentation of aphasia varies due to personal factors as well as those associated with the site and size of lesion. Often, the manifestation of the aphasia allows for classification into a specific type. These classifications have been disputed and modified over the years to reflect new findings about normal language processing, aphasia, and the lesions causing aphasia. Currently, two larger schemas of aphasia classification have emerged. The first focuses on brain lesion and the patho-linguistic features of the aphasia, while the other continues to reflect the classical syndrome-based system (Henseler et al., 2014). The former suggests that a brain lesion in a specific location is predictive of the language impairment, whereas the latter suggests that classification is based exclusively on the language profile that emerges post-stroke.

Although described as focal, a stroke can cause remarkable interruptions in cortical and subcortical networks. Consequently, a left hemisphere lesion causing aphasia will almost always cause other concomitant impairments. For example, hemiparesis (i.e., weakness) and spasticity of the right side of the body can occur. Also common is apraxia, an impairment of motor planning and programming prior to the execution of movement; apraxia can be specific to speech production, limb movements, and non-speech oral movements. Another concomitant impairment are visual field cuts that occur following more posterior lesions. Although less common, some persons with left hemisphere stroke present with visual neglect (Beume et al., 2017). Cognitive impairment is also common following left hemisphere stroke, and has been observed in working memory, attention, and executive functions (Patel, Coshall, Rudd, & Wolfe, 2002).

These consequences of stroke and aphasia often lead to decreased quality of life (Levine, et al., 2015). Quality of life is defined by the World Health Organization (WHO) as "a state of complete physical, mental, and social well-being not merely the absence of disease" (WHO, 1997). There is an abundance of literature suggesting that persons with stroke-induced aphasia have decreased quality of life (Mahesh, Gunathunga, Jayasinghe, Arnold, & Liyanage, 2018; Mahesh, Gunathunga, Jayasinghe, Arnold, Haniffa, & De Silva, 2017; Carod-Artal & Egido, 2009; Opara, Jaracz, 2010). Although a unique experience, there are myriad factors that contribute to this, including increased stress (DuBay, Laures-Gore, Matheny, & Romski, 2011), increased risk of depression (Grajny et al., 2016), decreased functional outcomes (Lee et al., 2015; Ellis & Urban, 2016), and increased level of care required (Winstein, et al., 2016). It has also been suggested that stroke survivors have fewer coping resources than those who have not had a stroke (DuBay et al., 2011). However, these changes in quality of life are not limited to the person with aphasia; those in the immediate family are also affected.

Aphasia Management

Post-stroke therapies are person- and family-centered, and they are largely dependent on the presence and severity of impairments. Ultimately, the goal of aphasia therapy is quality of life for the person with aphasia and the family unit, and this is accomplished through various mechanisms. Per the American Speech-Language-Hearing Association (ASHA), aphasia therapy is often a combination of restorative and compensatory treatments. Restorative treatments are impairment-based interventions that target the impaired function, with the goal being restoring that function to as close to previous levels as possible. Compensatory interventions address strategies that help with the person with aphasia and the communication partner exchange information efficiently and effectively despite the communication impairment. Given the chronic nature of aphasia, treatment should also address community support and reintegration. This is accomplished through support and activity groups for those with the aphasia and their communication partners. Aphasia groups often incorporate emotional support through community, social networks for engagement, and opportunities to explore and practice strategies, which includes groups specific for caregivers of persons with aphasia to establish their own network of support (Galletta & Barrett, 2014).

Caregiver Experience

When a person is affected by chronic disease or disability, their families are often faced with the responsibility of providing care to the individual, leading to the new title of *caregiver*. According to Reinhard, Given, Petlick, and Bemis (2008), the terms *family caregiver* and *informal caregiver* refer to a voluntary family member or friend who provides assistance to a person with an acute or chronic illness in need of assistance to fulfill daily tasks. Referred to from here as *caregiver*, this individual may help with activities of daily living. Activities of daily living (ADLs) are daily routines that uphold a standard of living that are often automatic, however instrumental of activities of daily living (IADLs) require a higher level of functioning. ADLs; for example: hygienic activities such as brushing teeth or bathing; dressing; feeding and instrumental ADLS (IADLs), for example: planning and executing a grocery trip, check writing, budgeting, as well as help the person with disability cope with his or her circumstances (Mlinac,

& Feng, 2016). Caregivers of stroke patients tend to be Caucasian (56%), women (79%), older in age (average age: 63), and spouses of the patient (53%) (Haley et al., 2009).

Stages of Caregiving

Because of the acute onset, the experience of the stroke caregiver is unique from other more insidious disease processes, such as dementia due to Alzheimer's disease. Cameron and Gignac (2008) suggest that during the transition from the hospital to the home, a stroke caregiver's experience can be broken down into three stages: 1) event/diagnosis, stabilization, and preparation; 2) implementation; and 3) adaptation. Stage 1 is a period during which the family is coping with fear and uncertainty while the individual regains medical stability. In stage 2, the stroke survivor and family return home, and the changing family roles become increasingly apparent. Caregivers report that their emerging fears and anxieties of caregiving are related to safety, functional deficits, and the psychosocial consequences of the stroke. As in the previous stage, coping with communication deficits as well as other difficulties arising post-stroke are of paramount importance to caregivers (Cameron & Gignac, 2008). In many cases, caregivers are unable to maintain their current employment after returning home, contributing to the financial burden experienced by families. (Shulz et al., 2017). Stage 3, adaptation, reflects stroke as an undeniably chronic condition, and those involved are forced to adapt to the new normal when recovery has dramatically slowed, and symptoms appear to plateau. Some caregivers note that they have ongoing symptoms of stress, (i.e., fatigue, headaches, upset stomach, etc) well into the adaptation period (Cameron & Gignac, 2008).

Caregiver Burden

Caregiver burden is often used to describe the overwhelming stress experienced by caregivers as a result of the caregiving role (Rigby, Gubitz, & Phillips, 2009). Caregivers experiencing burden may report a variety of symptoms including feeling overwhelmed, worried, chronically fatigued, irritated, angry, or sad. Burden is often associated with changes in sleep, weight, or interest in activities once enjoyed. Many caregivers also report headaches, body aches, and increased substance use. If symptoms are left unmanaged, caregivers may experience depression and anxiety (Sherwood, Given, Given & Von Eye, 2005). Furthermore, there is also evidence to suggest that caregiver burden can lead to neglect and even abuse of the person receiving care (Orfila et al., 2018).

Several factors can contribute to caregiver burden, for example, dramatic shifts in the relationship roles, lack of control, unreasonable demands, family conflicts, loss of employment, and financial difficulties. It is not uncommon for caregivers to find themselves in need of care as their personal and health needs are often overlooked. Caregivers experience an array of problems as they adjust to new roles and challenges, including "fatigue, emotional distress, restricted social life, changes in family life, relationship difficulties, balancing responsibilities, and obtaining services (Bugge, Alexander, & Hagen, 1999; Grant et al., 2004; Ilse, Feys, deWit, Putnam, & deWeerdt, 2008; MacKenzie et al., 2007; Periard & Ames, 1993)" as in (King, Ainsworth, Ronen, & Hartke, 2010, p. 302). Stroke caregivers also report not having adequate education and training to help their loved-one through the recovery process (King & Semik, 2006). Ultimately, the combination of variables (e.g., chronic distress, depression, physical demands) results in greater caregiver burden and decreased caregiver quality of life (Visser-Meily, Post, Schepers, & Lindeman, 2005).

Importantly, one variable with positive impact on life satisfaction post-stroke is the mutuality of the relationship (Ostwald, Godwin, & Cron, 2009). Mutuality refers to the degree to which the caregiver and care-recipient love and enjoy one another and the strength of the relationship. (Archbold, Sewart, Greenlick, & Harvath, 1990). Ostwald and colleagues (2009) explained that stroke occurs in a larger context of a pre-existing relationship, which may or may not be mutually enjoyed. It has been suggested that caregiver experience in this role led to a greater appreciation of life (Haley et al., 2009).

Aphasia is a disorder unlike many other consequences of stroke because it interferes with communication, with the potential for devastating interpersonal and functional consequences as the stroke-survivor attempts to reintegrate into society. In 2012, Rombough and colleagues conducted a systematic review of articles exploring the burden experience by aphasia caregivers. After two literature reviews of three databases, only 14 articles were identified on the topic, suggesting that this body of literature is yet underexplored. However, general findings were observed and are worth reporting. For example, it has been clearly demonstrated that "female caregivers, especially wives, had significantly higher perceived burden than male caregivers (Jeng-Ru et al., 1998), Kao & McHugh, 2004; Morimoto, Schreiner, & Asano, 2003; van den Heuvel et al., 2001)" as in (Rombough et al., 2012). Three studies identified conditions such as depression and emotional distress in caregivers (Macnamara, Gummow, Goka, & Gregg, 1990; Morimoto et al., 2003); Scholte op Reimer, de Haan, Rijnders, Limburg, & van den Bos, 1998). Gillespie, Murphy, and Place, (2010) suggested that caregivers are more overprotective of their loved-one with aphasia, possibly due to lack of confidence in the loved-one's abilities, the aphasia itself, or the perception that the caregiver is doing more than is necessary. Additionally, it has been suggested that higher degrees of burden were observed in those caring for individuals suffering more severe strokes, and thus requiring a greater level of care (Bugge, Alexander, & Hagan, 1999; van den Heuvel et al., 2001).

Personality

According to Costa and McCrae (1992), personality is defined as one's patterns of thought, behavior, and feelings. Classic theories of personality have suggested that personality may be biological (link between personality and genetics), behavioral (interaction between person and environment), psychodynamic (emphasizing the influence of the unconscious mind), humanist (emphasizing the importance of free will and personal experience), or trait-based (5-factor theory of personality). Undeniably, personality is multi-faceted. Although many theories exist, the trait-based theory has been used frequently in the literature. According to this 5 factor model, personality is narrowed to five domains: openness to experience, conscientiousness, extroversion, agreeableness, and neuroticism. Openness to experience is defined as someone who is intellectual, imaginative, and perceptive, and open to and finds value in new experiences. Conscientiousness refers to those who are more moral and displays more dutifulness, whereas extroversion is used to describe someone who prefers the company of others and is outgoing. Agreeableness is defined as someone who is not critical, and sympathetic towards others. Neuroticism refers to someone who is more prone to responding to obstacles and challenges with anxiety, depression, and worry.

Personality and Caregiver Burden

Research suggests that personality affects the way a person may handle relationships, change, and adversity (Paulson & Leuty, 2016; Ebstrup, Eplov, Pisinger, & Jørgensen, 2011). Paulson and Leuty (2016) for instance, conducted a study that focused on personality and how it interacts with conflict in family and work environments. Relationships between dispositional characteristics and work-family conflict (WFC) and family-work conflict (FWC) were studied. Results indicated that different personalities meant coping with adverse consequences in different ways; those who react negatively when faced with obstacles are more likely to be involved in avoidance coping strategies, and intervention can be designed to reduce negative strategies (Paulson & Leuty (2016). Ebstrup and colleagues (2011) investigated associations between perceived stress and the personality types of neuroticism, extroversion, openness, agreeableness, and conscientiousness. Results suggested that higher perceptions of stress were positively correlated with neuroticism. Together, it appears that neuroticism is the personality trait most strongly associated with a negative coping response towards stressors and thus a greater stress experience.

This is applicable to the caregiver experience. It has been reported previously that caregivers of persons with dementia experience higher levels of caregiver burden when personality trait of neuroticism is elevated (Welleford, Jarkins, & Taylor, 1995). As a part of the study, caregivers completed the self-form of the Neuroticism, Extroversion, Openness to Experience Personality Inventory (NEO-PI) and an index of burden. Regression analyses revealed caregiver neuroticism predicted objective and subjective caregiver burden, consistent with previous studies suggesting that neuroticism was correlated with greater stress responses. The finding suggests that dementia caregiver interventions are likely to reduce caregiver burden and improve quality of life.

Similarly, Reis and colleagues (1994) investigated the influence of caregiver personality on negative outcomes of caregiving, health complaints, and burden. It was found that caregivers with higher scores in neuroticism experienced higher levels of burden and more health complaints at initial and final evaluations. Similarly, seeing the care recipient as more difficult amplified adverse consequences. Caregiver extraversion did not change the experience of caregiving, and the ability to enjoy some aspects of caregiving, as well as hobbies and family/friend support, helped lessen the adverse consequences of caregiving.

More recently, Kim and colleagues' (2017) data revealed that higher levels of neuroticism as well as extraversion influenced how caregivers experienced caregiver burden. In a large clinic-based national study in South Korea, researchers examined the relationship between caregivers' personality and health related quality of life (HRQoL). With depression and burden as mediating factors, associations among five personality traits and HRQoL of family caregivers were observed. Burden was higher if they presented with qualities of neuroticism, whereas individuals who had higher levels of extraversion were less likely to experience higher levels of burden.

Statement of Purpose

The literature suggests a relationship between personality and caregiver burden in various circumstances of disability, and with this understanding, practitioners can better support caregivers to prevent burden (Lilly, Robinson, Holtzman, & Bottorff, 2012). More specifically, to identify caregivers who need more support. However, to the authors' knowledge, the relationship between personality and caregiver burden in aphasia has yet to be investigated. The purpose of this research is to explore the relationship between the five domains of personality (i.e., openness to experience, conscientiousness, extroversion, agreeableness, and neuroticism) and aphasia caregiver burden as measured using the M5-50 personality measure and the Caregiver Burden Scale. It is hypothesized that there will be no relationship between aphasia caregiver burden and the personality domains of personality openness to experience, conscientiousness, and agreeableness. It is also hypothesized that there is a relationship between aphasia caregiver burden and the personality domains extroversion and neuroticism, specifically that higher levels of extroversion are associated with decreased burden and higher levels of neuroticism are associated with increased burden.

CHAPTER TWO: METHODS

Participants

Participants of this study were unpaid caregivers of persons with aphasia. Those who qualified were family members, spouses, children, and other unpaid care providers. Participants were not eligible to participate if they were compensated for their services, and minors were not eligible to participate.

Participants were invited to participate via three mechanisms. First, the primary investigator contacted facilitators of aphasia support groups identified from the National Aphasia Association website. Support groups were contacted if meeting the following criteria: contact person(s) listed, support group status (rather than therapy-based), and caregiver inclusion. Seventy-six support group facilitators were contacted by the investigator regarding the research opportunity, and 18 responded with a willingness to distribute recruitment flyers. Another method of recruitment included social media (i.e., Facebook) or direct contact with speech-language pathologists asking them to share information about the research opportunity with caregivers.

Surveys

Data collection was completed entirely online using the survey platform Qualtrics, and surveys included the Measure of Personality (M5-50; McCord, 2002) and the Caregiver Burden Scale (CBS; Zarit, Reever, & Bach-Peterson, 1980). Surveys provided an overall score of burden and five scores of personality. Caregiver burden scores range from 0 (little to no burden) to 88 (severe burden). The five scores of personality were separate scores for neuroticism, openness to experience, conscientiousness, extroversion, and agreeableness. Each individual of the 5 personality scores range from 50-250, with higher scores indicating higher probability of the participant possessing this personality trait. Demographic and stroke/aphasia history data were also obtained.

M5-50: This survey was chosen because while there are other multifaceted inventories to assess personality traits, this survey has been consistently used in previous studies. There are other personality inventories that could have been used, for example, the Meyer's Briggs, and others. The purpose of this survey is to gather information allowing for a description of an individual's personality. Using the broad domains established by Costa and McCrae (1992), the M5-50 measures the following: extraversion (E), agreeableness (A), conscientiousness (C), neuroticism (N), and openness to experience (O). The M5-50 consists of 50 items, each item describing a personality trait, such as "have a vivid imagination" suggesting the individual is more open to experiences. Using a 5-point Likert scale ranging from *inaccurate (1)* to *accurate (5)*, the participant reports the degree with which the description is an accurate representation of self. Higher scores suggest the individual identifies with the personality trait described. The M5-50 is reliable and valid; however, more research is needed to capture more diversity in the sample (Socha, Cooper, & McCord, 2010).

CBS: The CBS is used to quantify level of burden when caring for a person with a disability. The CBS consists of 22 questions, such as "Are you afraid for what the future holds for your relative?" Participants respond on a Likert scale ranging from *never (0)* to *nearly always (4)*. The caregiver burden score has a possible range of 0 to 88, with higher scores indicative of greater burden. A cumulative score of 0-20 indicates little-to-no burden, 21-40 mild-to-moderate burden, 41-60 moderate-to-severe burden, and 61 to 88 severe burden. The CBS is reliable and valid (Hérbert, Bravo, & Préville, 2000).

Procedure

The study was approved by the Western Carolina University Institutional Review Board prior to initiation (1246606-3). All participants provided informed consent prior to completing the research tasks. Completion of the research required approximately 15 minutes, and data were collected anonymously.

Data Analysis

Demographic data and stroke/aphasia history are reported in terms of means and standard deviations. For each participant, a caregiver burden score was calculated. Each participant received five personality ratings from the M5-50 corresponding to each of the five domains (i.e., extraversion (E), agreeableness (A), conscientiousness (C), neuroticism (N), and openness to experience (O)). A Pearson correlation coefficient was calculated for each comparison to determine the correlation between each of the five domains and the caregiver burden score.

CHAPTER THREE: RESULTS

Participant Demographics

Forty-one surveys were initiated, and 40 provided consent to participate. Of those providing consent, 19 were eliminated from the data set because they did not meet research criteria.; 6 were paid caregivers, 5 did not complete the survey past consent, and 7 did not complete personality or caregiver burden surveys. Ultimately, data from 21 participants were included in the analyses. Because of the method of recruitment, the response rate for total participants could not be calculated.

The age of the participants in the study ranged from 20 to 81; with an average of 56.6 years. The gender of the respondents is 1 male, 19 females, and 1 other (non-binary). The persons with aphasia were male (52%), and female (48%). The relationship of caregiver to care receiver was most commonly spouses/partners (38%) or child-parent (23%). Most caregivers had provided care for more than 5 years (57%), and (38%) provided care for less than 5 years. Sixty-one percent reported no previous caregiving experience (61%); caregiving previous experience was providing care to a family member with dementia. Most caregivers indicated providing care about 50% of the day; however, this ranged from 20% to 100% of the day.

Caregiver Burden

The mean CBS score was 32.4 (SD = 14.99), suggesting an average of mild-to-moderate severity of burden. The minimum reported burden score was 9 (suggesting no burden), and the maximum reported score of 56 (suggesting moderate-to-severe). In total, 6 reported little-or-no burden, 5 mild-to-moderate burden, 8 moderate-to-severe burden, and 0 severe burden. These data can be seen in Table 3.1.

Personality

The mean score and standard deviation for each of the five personality domains can be seen in Table 3. 1. Extraversion has a mean of 3.2 (SD = .26), with a range of 2.7 to 3.6. A mean of 3.1 (SD = .35) was calculated for agreeableness, and the range was 1.4 to 2.6. Conscientiousness has a mean of 3.0 (SD = .33); the minimum score for conscientiousness was 2.4, and the maximum score was 3.8. Neuroticism has a mean of 2.8 (SD = .44), with a range of 2.1 to 4.0. Lastly, the mean of openness to experience ratings is 3.2 (SD = .43), with a minimum score of 2.5 and maximum score of 4.2. Scores range from 1-5, with 1 suggesting "very inaccurate" and 5 suggesting "very accurate".

Table 3.1

Comparison of Caregiver Burden and Personality Traits

Categories	Mean (SD)	Minimum	Maximum
CBS	32.4 (14.99)	9	56
Extraversion	3.2 (.26)	2.7	3.6
Agreeableness	3.1 (.35)	1.4	2.6
Conscientiousness	3.0 (.33)	2.4	3.8
Neuroticism	2.8 (.44)	2.1	4.0
Openness to experience	3.2 (.43)	2.5	4.2

Relationship Between Caregiver Burden and Personality

No statistical correlation were observed. Extraversion (r(19) = -.165, p = .501), conscientiousness (r(19) = -.094, p = .702), neuroticism (r(19) = -.23, p = .343), and openness to experience (r(19) = -.359, p = .131) showed a negative trend with caregiver burden score. Agreeableness (r(19) = .006, p = .982) was the only domain showed a positive trend with the caregiver burden score. Therefore, extraversion, conscientiousness, neuroticism, and openness to experience scores went up, caregiver burden scores went down. Conversely, as agreeableness scores went up, caregiver burden scores went up. Even though it was not significant, the correlation between openness to experience and the caregiver burden score had a medium effect size (Cohen, 1988).

CHAPTER FOUR: DISCUSSION

The purpose of this research was to explore the relationship between the five domains of personality (i.e., openness to experience, conscientiousness, extroversion, agreeableness, and neuroticism) and aphasia caregiver burden. The results of this study suggest that there is no relationship between aphasia caregiver burden and any of the five personality domains. This contrasts with previous studies involving dementia and cancer caregivers in which neuroticism was shown to be negatively correlated with, and extraversion positively correlated with, caregiver burden (Lilly, Robinson, Holtzman, & Bottorff, 2012).

Aphasia is a different disorder, compared to things like cancer and dementia, and this may be the reason for the lack of significant findings in this study. For example, aphasia is not life-threatening, whereas diseases of cancer and those causing dementia inherently include that risk. Aphasia is relatively chronic, meaning that there is little potential for recovery after the first-year post-onset, especially in the absence of intensive aphasia treatment. Cancer can be cured, and dementia is progressive, following a relatively consistent pattern of cognitive, behavioral, and functional decline. Aphasia is caused by an acute event, the stroke, which has the potential to leave the inflicted person with post-traumatic stress disorder (Garton, Sisti, Gupta, Christophe, & Connolly, 2017). Aphasia differs from dementia in the level of awareness of help needed and function lost; by middle stages, most people with dementia are unaware of the severity of their impairments. In addition, persons with dementia present with psychiatric and behavioral complications over the course of the disease that add to the caregiver burden in unique ways. These are very different clinical profiles and very different pathologies. Thus, it is possible that there are in fact no associations between personality and caregiver burden in the aphasia caregiver population, contrary to other groups.

Another possible explanation for the lack of significant findings is simply the subject pool included in this study. Not only was there a small sample size, but most of these participants were recruited because of their support group involvement and connection with a group facilitator or speech-language pathologist. This group did not include those that have refused or been unable to access a support system in the chronic stages of recovery, nor did it include an adequate sampling of those with moderate-to-severe caregiver burden. Consequently, this recruitment approach did not capture the full breadth of aphasia caregivers. Studies casting a larger recruitment net may provide different findings.

A third possible reason for the lack of significant findings is perhaps the response to disability of the person with aphasia. Lam and Wodchis (2010) completed a study of people living in long-term care facilities in Canada (n=66,193) to compare the HRQoL associated with 60 diseases. Aphasia exhibited the largest negative relationship to HRQoL followed by cancer and Alzheimer's disease. People with aphasia themselves report significantly worse HRQoL than stroke survivors without aphasia, even when physical disability, support, and well-being were comparable (Hilari, 2011). This is especially evident in the areas of independence, social relationships, and access to their environment (Ross & Wertz, 2003). Clearly, aphasia has a profound impact on people’s lives. However, people’s reactions to aphasia and their psychosocial adjustment to living with aphasia differs (Code, Mueller, Herrmann, 1999). It is not unusual for two patients with aphasia, appearing similar in clinical profiles and personality, to have contrasting perceptions and psychosocial adjustment post-onset. Further, severity and recovery are not always indicative of positive psychosocial adjustment; Code and colleagues (1999) described a patient who improved performance on standardized assessments of aphasia but decreased in quality of life, mood, and social participation. Quite possibly, the outcomes observed in the present research occur because caregiver burden is influenced more so by the aphasic person's psychosocial adjustment and less so on caregiver personality.

Limitations

This study is not without limitations. The recruitment procedures did not capture a wide range of caregivers in a variety of caregiving experiences. Efforts should be taken to recruit participants at different time points post-onset, those with different financial status, culture, ethnicities, those with different education levels, and those with different relationships to the person with aphasia. Most importantly, it should capture the experience of those not involved in aphasia support groups and not receiving the resources for adjusting to life with chronic aphasia. This effort will address two limitations, the first being sample size and the second the heterogeneity of the sample.

Future Directions

Given limitations in the current recruitment and inclusion procedures, and the strong literature support for associations and the potential for predicting caregiver burden given personality traits, this line of research is far from complete. It will be important to address the limitations identified in future studies for additional contributions to the literature. In the future, it may be beneficial to assess resiliency in caregivers, in order to investigate other protective mechanisms to keep a caregiver from feeling extreme levels of burden. Questions to consider in the future might be, how does understanding personality help predict or anticipate those with high neuroticism, and the fact that those individuals may require more support in the beginning of the caregiving process. Also, burden may impact the outcome of client's prognosis.

Conclusions

The data on caregiver burden in aphasia are limited, and this is quite possibly the first study investigating the impact of personality on caregiver burden in this population. Although there were no statistically clinical findings, the data still contribute to a better understanding of the personality-burden dynamic. Undoubtedly, the unpaid caregiver workforce is critical to managing the long-term consequences of stroke and aphasia. To the extent that the personality-burden relationship is understood, supportive interventions are likely to improve quality of life for those affected by stroke and aphasia. Of equal importance is the possibility of preventing of caregiver burden in this population through education about stroke and aphasia; counseling and support; and communication strategies. Quality of life is the ultimate goal of aphasia therapy, and this topic of caregiver burden is an integral piece of that management puzzle.

CHAPTER FIVE: REFERENCES

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