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**Living Well With Aphasia:
Spousal Involvement as an Integral Component in Stroke Recovery**

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Report

Presented to the Faculty of the Graduate School of

The University of Texas at Austin

in Partial Fulfillment

of the Requirements

for the Degree of

Master of Arts

The University of Texas at Austin

May 2011

Dedication

I dedicate this paper to the courageous men and women who have endured stroke and to their gracious caregivers who support and provide for them on their journey towards recovery.

Acknowledgements

I would like to thank Dr. Joyce Harris for her dedication and support in putting this report together, as well Shilpa Shamapant for inspiring me to strive for greatness and to expect nothing less from my clients. Thank you to my parents and brother for helping me to become a strong, confident and independent woman who can achieve anything I set my mind to. I would also like to acknowledge my roommate April for keeping me sane throughout graduate school and for being a truly amazing friend. Lastly, I want to thank the Slater family for showing me that, even in the face of adversity, love prevails.

Abstract

Living Well With Aphasia: Spousal Involvement as an Integral Component in Stroke Recovery

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Stroke has the ability to chronically alter both a person's understanding and or use of language. Aphasia is a term that represents the loss or impairment of language function as a consequence of brain damage caused by a stroke and current data reveal that at least 25% of all strokes result in aphasia. Spouses often play a pivotal role in a stroke patient's journey towards recovery. For this reason, there is a dire need for increased knowledge regarding spousal psychosocial welfare and increased insight into the experiences of these individual's altered life situations. This paper considers aphasia, by nature of its deficits, a family disorder. Additionally, the contents of this paper explore the significance of caregiver coping strategies and ongoing caregiver involvement in recovery as a mechanism towards increased well being. Evidence to confirm the effects of stroke on spouses, as well as to support involvement of spouses in speech-language treatment to facilitate living well with aphasia, was obtained through primary and secondary research. Primary research was compiled through a telephone interview with the spouse of a 62-year-old male with aphasia while secondary research was conducted through an extensive literature search from 2000 to 2011.

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An Introduction to Stroke and Aphasia

Stroke, which is currently the fourth leading cause of death in the United States, has the ability to chronically alter both a person's understanding and or use of language. Aphasia is a term that represents the loss or impairment of language function as a consequence of brain damage caused by a stroke. Current data reveal that at least 25% of all strokes result in aphasia. Statistics from the National Aphasia Association suggest that approximately 80,000 individuals acquire aphasia annually due to stroke and that one million people in the United States are currently living with aphasia (United States Department of Health and Human Services, 2008). Anyone can potentially acquire aphasia over his or her lifetime; however, it is to a larger extent more prevalent in people middle-aged or older. In 2005, the prevalence of stroke was 5.8 million among adults age 20 years and older; furthermore, the risk of stroke increases with age. For each decade after age 55, a person's risk of experiencing stroke doubles. With this in mind, the prevalence of stroke is expected to increase dramatically with the lengthening of life expectancy and advancing age of our population (Demaerschalk, Hwang & Leung, 2010).

At the most basic yet essential level, a communicative act occurs when one person expresses a thought or idea and another person effectively receives this message. As high functioning, cognitive human beings, we rely on our ability to effectively and efficiently communicate in order to function within modern society. When an individual in some way loses the capacity to communicate as they once did, the results can be devastating. Successful communication is often taken for granted by those who experience minimal to

no barriers; however, impairment in any aspect of communication is among one of the most disabling effects of stroke.

In fact, stroke is considered the leading cause of long-term disability (Baldwin, Orr, Briand, Piazza, Veydt, McCoy, 2010). Few patients that are discharged from rehabilitation centers with substantial aphasia will regain pre-stroke language function (Holland, 2007). Disturbances in an individual's production or comprehension of language typically produce enduring change into the lives of the individuals with aphasia and their immediate support network with whom they regularly communicate. In 2010, the National Stroke Association released information stating that four out of five American families encounter a relative who requires lifelong care due to a stroke and its ensuing effects (National Stroke Association, 2010). Moreover, despite the ample services that a stroke survivor receives, the majority of long-term care provided to a person with chronic aphasia is from either a spouse or adult child.

Through recognizing and acknowledging the above information, readers can form an understanding of aphasia as a family disorder. Due to the chronic nature of language deficits that characterize the impairment, all members of a family or communicative partnership are likely to experience the negative affects of aphasia's presence in their daily lives. Nevertheless, the ability of a spouse, or other informal caregiver, to cope successfully and remain informed is an integral component of the rehabilitation process. By accepting the idea that individuals don't frequently overcome all of the consequences associated with aphasia, treating speech-language pathologists must appreciate that learning to live successfully with this impairment is typically a lengthy process that

should involve not only the patient, but their spouse, or other primary communication partner, as well.

Methods and Procedures for Acquisition of Research

Each year more than 22.4 million persons serve as informal caregivers, or individuals providing unpaid help, to older persons living within the community (Allen, 2008). With today's changing healthcare environment, speech-language pathologists are being asked to achieve functional patient outcomes in shorter amounts of time (Baron, Hatfield & Georgeadis, 2005). This shift in healthcare delivery, coupled with a knowledge that the majority of long-term stroke care is provided by an informal caregiver, provides support for familial involvement in a patient's rehabilitation efforts. Moreover, when speech-language pathologists provide emotional and physical support to a caregiver, they can indirectly affect the performance and psychosocial outcomes of the person who experienced the stroke.

Research has indicated that the majority of strokes occur in persons over the age of 20. For this reason, spouses often play a pivotal role in the patient's rehabilitative journey. Previous research has demonstrated that the risk for depression seems to be higher for spouses than for other involved support persons; therefore, there is a dire need for increased knowledge regarding spousal psychosocial welfare and increased insight into the experiences of these individual's altered life situations. In the following sections of this paper, the assumption that aphasia is by nature of its deficits a family disorder will be explored in depth. Additionally, the significance of caregiver coping strategies and ongoing caregiver involvement in speech-language treatment will also be supported as a mechanism towards a lasting road to recovery.

Both primary and secondary research was analyzed in order to provide evidence to confirm the effects of stroke and aphasia on spouses, as well as to support the involvement of spouses in speech-language treatment as a constructive means towards living well with aphasia. Primary research was compiled through a telephone interview with the spouse of a 62-year-old male with aphasia; Grace's husband was diagnosed after experiencing a hemorrhagic stroke in November 2008. Identifying names were altered in order to ensure the privacy of those involved with or mentioned during the interview. Topics that were addressed during the interview include background and medical information; current and past speech, language and cognitive functioning; psychosocial functioning; availability and utilization of educational and support resources regarding stroke and aphasia; methods of coping; speech-language treatment; and considerations for the future.

The above case study served as a comparison for empirical evidence obtained via an extensive literature search concerning the effect of stroke and aphasia on spouses as well as the spouse's role in the rehabilitation process. While a singular case study provides limited views on these effects, it does provide a beneficial way of supporting or refuting the existing literature on this subject. A literature search of pertinent books and research articles spanning from 2000 to 2011 was conducted in order to find supporting information for this report. Secondary resources were chosen based on their ability to enhance knowledge about stroke, aphasia, counseling, education, support and speech-language treatment as they relate to the caregiver experience and a couples' ability to move forward following the experience of stroke and of its resulting deficits.

To reiterate, the bidirectional nature of communication results in speech-language impairments affecting more than just the individual with aphasia. For this reason, stroke is becoming increasingly viewed as a family-based impairment. The primary communication partner of the stroke survivor, or spouse for purposes of this paper, must learn to cope with their new realities while trying to establish a positive path towards recovery. Within the literature, it is well documented that spouses of stroke survivors are particularly vulnerable to the introduction of stroke and aphasia into their lives. Spouses are often susceptible to perceived upsets in their quality of life, decreased emotional well being, and decreased psychological health among the many other effects. To start, information obtained from the literature search will be used to provide support for the effect of stroke and aphasia on spouses and the effects of their involvement in the rehabilitation process. This current research will then be compared to the information presented from the primary case study. Together, this information will be synthesized and analyzed in order to form conclusions about similarities and differences, draw clinical implications and provide future directions for the field of speech-language pathology.

The Effects of Stroke on the Spousal Caregiver

Even in the year 2011, with so many medical and scientific advancements, healthcare delivery systems continue to lack continuity across services. As a result, healthcare facilities are often criticized for shortening hospital lengths-of-stay and for offering limited community services. These gaps also exist at a time when the world is experiencing trends in aging populations and communities find increasing numbers of people surviving serious, age-related health impairments such as stroke. Currently, after individuals experience the sudden onset of a chronic health condition, they are discharged from hospital and must rely on family members, or informal caregivers, for continued assistance (Cameron & Gignac, 2008).

Within the medical and rehabilitation professions, stroke is widely accepted as a disease with severe consequences for not only the patients, but also their families or main communication partners. Primary caregivers, the majority of whom are spouses, are often responsible for a large amount of support to the stroke patient within the community, domestic life and personal activities of daily living. For this reason, caregivers of stroke patients may be viewed as collaborators with the treating professionals in sharing patient care and management. Additionally, because of the abrupt changes faced by a stroke patient's family, caregivers should be regarded as an extension of the client with problems and special considerations of their own. Immediately post-stroke, spouses of stroke survivors can expect to experience role changes, alterations in daily activities, differences in social interactions, affected partner relationships, and changes in their

emotional and/or physical well being (Forsberg-Wärleby, Möller & Bloomstrand, 2004).

As part of the medical community responsible for treating stroke patients, speech-language pathologists must take special interest in how spouses are affected by stroke as well as the caregiver's role in facilitating rehabilitation goals. One example of how caregivers may affect recovery is that caregiver depression has been shown to worsen the depression of a stroke survivor and predict poor response to rehabilitation (van Heugten, Visser-Meily, Post & Lindeman, 2006). For these reasons, detailed knowledge and appreciation for the changing needs of stroke caregivers across different care environments and care continua is an integral component in providing optimal outcomes for both a stroke patient and their primary caregiver (Cameron & Gignac, 2008).

To begin, the process of caring for a person who has had a stroke will be explored in regard to its impact on the psychological health of the caring partner. A nursing study, conducted in the United Kingdom, acknowledged that a stroke patient's spouse is particularly vulnerable to the effects of stroke (Draper & Brocklehurst, 2005). In response to this realization, researchers set out to investigate the impact of stroke on the patient's spouse with particular emphasis on psychiatric morbidity and caregiver strain; the impact of speech impairment was also investigated. As part of this study, the *Caregiver Strain Index* (CGSI) was used to explore the impact of stroke on spouses (Draper & Brocklehurst, 2005). The CGSI was developed to measure the stress or strain arising from caring for physically ill and functionally impaired adults in the community. The scale elicits yes/no responses to a range of 13 questions covering a range of items. 40.9% of spousal participants responded 'yes' to the question: "Have there been emotional

adjustments?” Additionally, 65.9% of these participants responded with ‘yes’ when asked if changes in their spouse post-stroke are upsetting. Overall results of the study indicated that spouses had a greater degree of psychiatric morbidity than a control group and a large proportion of them found caregiving to be stressful. Spouses of partners whose communication was affected post-stroke were also more likely to experience strain than those who were unaffected in this way.

Similarly, a longitudinal study, conducted within the Netherlands, assessed five domains of psychosocial functioning in stroke caregivers (Visser-Meily, Post, van de Port, van Heugten & van den Bos, 2008). Results indicated that 51% of the spousal participants reported significant strain one year post-stroke. Other domains that were explored included life satisfaction, depression, harmony in the relationship and social support. Substantial changes in psychosocial functioning were reported by 27%–57% of the spouses across the three-year study. While burden seemed to decrease past the one-year mark, other domains worsened over time. At three years, the percentage of spouses reporting significant strain decreased from 51% to 44%, while caregiver depression increased from 50% to 52% (Visser-Meily et al., 2008). The decrease in caregiver strain may be attributable to increases in patient functioning or to caregiver adjustment over time. Conversely, the slight increase in spousal depression indicates that depression is a potentially ongoing psychosocial symptom in spouses. In a similar two year longitudinal study, *The Geriatric Depression Scale* (GDS) was used to measure depression of the caregiver and stroke survivor at 1, 6, 12, 18, and 24 months after discharge (Chumblor, Rittman & Wu, 2008). Researchers also investigated several factors that contributed to

caregiver depression. Study results revealed that caregivers taking care of patients with higher functional independence reported lower levels of depression over 24 months. Although the overall sample of stroke survivors was moderately disabled, the fact that patients' functional motor impairment was associated with caregiver depression is notable. Two other factors were also associated with caregiver depression. Poor self-rated health status predicted greater depression over 24-months. Caregiver education also played a role. Caregivers with a minimum of high school education experienced lower levels of depression (Chumbler, et al., 2008). Researchers noted that this education variable was most likely representative of socioeconomic status, which has been associated with depression. These findings from the present study were consistent with results from a recent nationally representative study of the US population, which found that less than a high school education was associated with increased risk for high depressive symptoms.

To reiterate, levels of psychological distress amongst primary caregivers appears related to the level of distress in stroke survivors. In regards to treatment, it's critical that healthcare professionals monitor ongoing levels of caregiver psychological functioning on a consistent basis, as well as explore possible contributors to observed distress. For example, increasing or persistent levels of caregiver depression, which were demonstrated in the above studies, should be addressed as needed in order to facilitate optimal patient recovery and to protect against future patient and caregiver decline.

Support and Educational Resources During Stroke Recovery

Another significant finding from the literature is that caregiver support relates to a family's ability to cope with the consequences of stroke, as well as the patient's ability to reintegrate back into the community (Ozge, Ince, Somay, Cakmak, Uludüz, Bulkan, Tasdelen, & Kaleagasi, 2009). In a randomized, controlled study that assessed the impact of family support on stroke patients and caregivers, the intervention group results showed that family support was significantly beneficial to caregivers in terms of social activities and quality of life; increased satisfaction with a family's understanding of stroke was also demonstrated. Likewise, intervention families generally made slightly more use of stroke clubs, and received greater financially covered medical benefits (Mant, Cater, Wade & Winner, 2000).

The National Social and Applied Gerontology Society (NSAGS) of Turkey held free caregiver courses that drew significant attention and high participation rates. The aim of a subsequent research study was to evaluate participant outcomes and compare them with outcomes of people who did not participate in the course (Tufan, Tokgöz, Kiliç, Akdeniz, Howe & Yaman, 2011). Surveys were mailed to women who enrolled in the course with an approximate 45% return rate. The average age of participants was 39.4, \pm 9.6 years. The majority of participants had low education levels. Approximately 80% of participants lived with the elderly person in the household and approximately 84% held jobs on top of their caregiver role. Results showed that following caregiver training,

participants felt more at peace when caring for their loved one and approximately 40% of the participants felt more efficient in caregiver duties. In comparison, approximately 55% of participants who did not attend the course made more negative statements concerning their caregiver duties. Awareness of stress was also improved in the group of participants that attended the course and more attendees (43%) believed that they could cope better with stress.

A comparable study, conducted within the United States, assessed the outcomes of a two-day educational program by comparing performances of participants and non-participants (Hinckley & Packard, 2001). Researchers investigated if attendance affected knowledge ratings, community integration, functional abilities or family adjustment. The seminar was a two-day workshop organized in a conference format. The conference originated in 1991 and was designed to address the issues of living with aphasia for patients and their caregivers. Pretest scores on all measures were subjected to statistical analysis to assess the comparability of the two groups. Self-selected non-participant pairs did not change on any measure of knowledge, community integration, functional activities, or family adjustment over a 6-month period. Within the participant group, there was a statistically significant difference between pre/post knowledge ratings, family adjustment ratings and levels of functional activities.

In the age of information technology, support and educational resources for stroke survivors and their families is also available via the Internet. Despite its availability, relatively little research has been conducted on computer technology and its role in assisting stroke caregivers in the home. In a nursing study, researchers examined the

experience of caregiving and the effects of Caring-Web©, an online intervention resource offering education and support for stroke caregivers (Steiner, Pierce, Drahuschak, Nofziger, Buchman & Szirony, 2008). The intervention's components included: 1) Ask the Nurse, which is an e-mail service where caregivers could ask confidential questions and receive answers from a nurse specialist; 2) Caretalk, a support group through email where caregivers could discuss areas of interest with and receive help from other caregivers and the nurse; 3) Tip of the Month, which offered easily accessible, customized information about stroke and caregiving; and 4) Educational Links offering information on a topics such as reliable websites to help meet caregiver needs. Previous research has demonstrated that social support, which includes both emotional support and physical help, erodes over time for a majority of caregivers for people with chronic conditions. Results from this study showed that ratings of physical help decreased steadily at each time period from a lot to not at all for the non-Web users, but remained stable for the Web users. The need for emotional support to cope with the challenges of caregiving has also been well documented within the literature. Outcomes from this nursing study indicated significant, moderately positive relationships between emotional support and caregiver health at 6 and 12 months (Steiner et al., 2008). This present study serves to validate the assumption that support from an informal network may act as a buffer and protect against poor health outcomes in caregivers. The positive correlation between emotional support and caregiver health occurring during the later months of the interview process demonstrates that providing care is a long-term process, and continuous support is needed throughout these more difficult times.

Surveyed literature indicates that caregiver support can significantly improve psychosocial and physical outcomes, facilitate positive coping mechanisms, and help reintegrate stroke survivors and their loved ones back into functional routines. These outcomes are particularly relevant to the field of speech-language pathology. They demonstrate how programs or resources incorporating education and support can act as constructive and useful tools in promoting recovery and well being in stroke patients and their caregivers who are willing and able to participate in and take advantage of these resources (Hinckley & Packard, 2001).

Barriers in the Caregiving Process

While positive educational and support resources do exist, not every stroke patient and spouse has the knowledge or ability to obtain or make use of these resources. The first barrier to educational and support access is the public's general lack of knowledge concerning stroke and its potential consequences. Within the United Kingdom, a telephone survey was conducted by an aphasia charity on 1005 participants (Code, Simmons-Mackie, Armstrong, Stiegler, Armstrong & Bushby, 2001). Surveyors found that only 3% of respondents had even heard of aphasia, which is an extremely common consequence of stroke. Similar findings emerged from a survey of 978 members of the general public in the UK, North America, and Australia. Researchers discovered that a mere 13.6% of respondents had encountered the term "aphasia" and fewer than 6% knew any basic knowledge about the impairment (Code et al., 2001). Among those who had knowledge, the extent of their knowledge differed. Professionals at the intermediary level, many of which were employed in healthcare or education, as well as students and retirees, scored higher than other groups of survey participants.

The lack of general public stroke knowledge directly affects stroke patients and those who provide informal care. In a study aiming to identify the educational needs of family members at the onset of hospitalization, initial rehabilitation and chronic phases of aphasia, researchers determined that relatives reported a need for information (Avent, Glista, Wallace, Jackson, Nishioka & Yip, 2005). Nearly 80% of stroke survivors are

discharged home after receiving short-term care services at the hospital, leaving informal caregivers in charge of the patient's continuing care. A consequence of this unrelenting responsibility is that family members are feeling the effects of little to no caregiver preparation or training. In another study examining the level of information needed by caregivers, the proportion of caregivers who reported needing information related to clinical aspects of stroke caregiving ranged from 15.3 to over 50 percent (Hinojosa & Rittman, 2007). The greatest proportion of caregivers (51.3%) reported needing information on stroke and stroke risk, followed by prescriptions or medications (41.2%), managing behavior (36.4%), safety at home (33.6%), functional changes (30.4%), communication (18.5%), physical manipulation (15.4%), and managing confidentiality (15.3%). The proportion of caregivers who reported needing information related to social aspects of stroke caregiving ranged from 22.2 to 35.9 percent. The highest percentage of caregivers reported needing information about managing emotional fluctuations (35.9%), followed by receiving financial assistance (30.0%), protecting the veteran (26.9%), and changes in family relationships (22.2%). The lack of caregiver preparedness is detrimental mainly because the presence of a competent, knowledgeable caregiver is a critical determinant of whether a stroke survivor's psychological and physical health improves and whether he or she is institutionalized or remains at home or in the community.

In general, a lack of exposure to the effects of stroke, coupled with a lack support in regards to knowledge about stroke care, leads to several negative consequences. A lack of adequate or sufficient information only increases the barriers faced by persons with

aphasia and their families within the community. A comment provided in a public aphasia awareness study served to highlight the negative effects of limited public awareness on caregivers and their loved ones with aphasia (Flynn, Cumberland & Marshall, 2009). One person stated that, “awareness would help so when you experience it yourself it's not such a shock. It fazes people if they don't know him ... (we) meet lots of people who say, ‘I thought you recovered from a stroke’ which really bugs me. I just wish people knew more about aphasia and how it affects things” (Flynn et al., 2009, p. 399). Aside from negative effects on the caregiving experience, a low level of knowledge is also likely to impede efforts to attract funding and improve services for people with aphasia and their families. Limited funding only perpetuates existing barriers to stroke and aphasia awareness and restricts access to resources, which have been found to have an encouragingly positive impact on the lives of stroke patients and their familial caregivers.

“Our New Normal” A Spousal Case Study on Living Well With Aphasia

A great proportion of research presented in the earlier sections of this paper originated from fields outside of speech-language pathology such as neuroscience, nursing and occupational therapy; furthermore, a majority of the research was conducted in regions outside of the United States. In order to compare and contrast ideas supported in the literature, a speech-language pathologist graduate student from the University of Texas conducted a primary case study interview. The interview was conducted to gain first-hand insight into the life of a spouse whose husband experienced a stroke and is currently living with aphasia. The two-hour interview was carried out over the telephone and electronically recorded; participant names have been altered for purposes of confidentiality.

Grace and Harry are a couple residing in a suburban community in the Northeastern part of the United States. They are both in their early sixties and have been married since 1977. During their long partnership, Grace and Harry have furthered their educations, achieved success in their careers, and parented two children. Grace currently works as a resource specialist at New York University and Harry owns his own cleaning supply company. When asked to describe the overall state of their relationship, Grace explained that they're union has been “open and supportive” over their 34 years as husband and wife.

Grace revealed that as a couple, she and Harry enjoy activities such as dining out, entertaining friends and family, watching television programs and going to the theater. When describing their partnership, Grace discussed her predominant roles and responsibilities. She reported that, from an outsider's perspective, people mistook her for being dependent on her husband in that Harry customarily took care of the food preparation and household finances. Although these were their recognized roles, Grace said that she and Harry always considered themselves to be equal contributors in maintaining a household and raising their two daughters.

Although Grace and Harry's individual expectations within the marriage became well established throughout their years together, a major, life-changing event took place in November 2008 that reshaped the stability and structure of Grace and Harry's partnership. Over the course of the two-hour interview, Grace chronicled her experiences as the wife of an individual with aphasia from the initial onset of stroke to present day functioning. Information from this case study interview is presented below and then further analyzed in regards to similarities and differences compared to findings obtained through the literature review.

In November 2008, Grace's husband Harry was rushed to the hospital after experiencing life-threatening medical symptoms. Upon his arrival, physicians determined that he was experiencing a 3cm hemorrhagic stroke in the left hemisphere of his brain. Prior to her husband's stroke, Grace explained that Harry produced fluent and concise speech and was a confident speaker who utilized an extensive vocabulary and descriptive, complex sentences. Grace's description of Harry's communication prior to stroke was

vastly different than her description of his speech and language after brain injury. Grace admitted that “tremendous changes” occurred post-stroke in that her husband had frequent word-finding difficulty, exhibited greater difficulty in effectively conveying his messages, and required greater effort and time to process conversational speech. In light of these disturbances, Grace also noticed that Harry became increasingly frustrated and impatient with his deficits.

As a result of her husband’s stroke, Grace made it clear that role changes within the marriage occurred immediately following hospitalization. Her husband gave up certain roles while she found herself taking on new roles acting as primary caregiver. New and unfamiliar responsibilities taken on by Grace included medical advocate, communication liaison, financial manager, and primary breadwinner. While these role changes were significantly life altering, Grace explained how her husband’s post-stroke deficits resulted in changes into their day-to-day functioning. For example, even Harry’s minor and less noticeable cognitive deficits had an effect on the couple’s living situation, as well as Grace’s psychological welfare.

Grace confided that throughout their many years together, Harry would take pots off the stove before turning off the burner. Post-stroke, Grace reported that her husband engaged in this same routine, but his inability to remember the final step caused serious safety risks. In turn, Grace admitted that even these small-scale cognitive changes created regular sources of stress and concern for her as Harry’s primary caregiver. In addition to cognitive changes, Grace also noticed deficits in Harry’s auditory comprehension. During their usual time spent watching TV together, Grace shared that she often paused the

television in order to ensure that her husband was following along. These added responsibilities, coupled with the stress of experiencing psychological and social changes within the marriage, highlights how both small- and large-scale changes post-stroke can greatly impact the life of a loved one providing care for an individual with aphasia.

Beyond the added daily responsibilities and expected strain associated with caring for an individual with communication and cognitive deficits, Grace also presented her personal journey of evolving emotions and navigation through the healthcare system and resources from the earliest post-stroke days to her present day management of her husband's chronic deficits.

She divulged that during the first 24-48 hours in the hospital, Harry's condition was critical. She admitted to strong feelings of fear and shock. She also admitted to feelings of anger upon realizing that her husband's stroke was most likely the result of a medical error. Grace went on to explain how her initial emotions changed over time. Two and half years have passed since Harry's stroke and the couple has had time to adjust to their altered life situation. During the interview, Grace stated that she is no longer angry or frightened. She admitted that in the earlier stages post-injury, if Harry so much as complained of a cramp, she would go into a state of panic. Currently, she finds it easier to relax as Harry's health stabilizes and she adjusts to his chronic deficits and learns to embrace their new reality together.

At one point in the interview, Grace pointed out a major lesson that she took away from her husband's stroke, which is that life is unpredictable and can change at any given moment. In spite of life's volatility, an overall positive outcome was noted in Grace's

experience. As Harry's primary caregiver over these past few years, Grace recognized that by managing her husband's stroke, she gained confidence in herself and fostered a desire to become a medical advocate and share her acquired knowledge with others about stroke and aphasia.

While Grace shared these individual developments and the personal gains that she made, she made sure to attribute her ability to manage and endure these life changes to personal factors such as the couple's positive pre-stroke functioning, her husband's high level of motivation to recover, her willingness and ability to advocate for educational resources, and her willingness and ability to seek support systems. Grace also revealed that her ability to adjust to her new roles as caregiver, as well as cope with her husband's sudden disabilities, arose from both her and her partner's willingness to define their post-stroke life as a "new normal" and leave behind their pre-stroke reality.

In regard to what Grace knew about stroke and aphasia prior to becoming a spousal caregiver, she revealed that her level of information was "general" in that she could provide a brief definition and a few possible causes of stroke. Grace admitted that this initial knowledge was due in part to her experience with teaching English as a second language and obtaining a PhD in linguistics. Despite these less common exposures, Grace still confessed to having had limited information about stroke and its subsequent effects.

When obtaining information post-stroke, Grace revealed that if she wanted to know something from any of the involved professionals (i.e. doctors, nurses or therapists), she typically had to be the one to ask for it. Post-stroke, Grace was eager to ask questions, gain knowledge and help both herself and her husband recover as fully as possible. On

the quest to do exactly this, Grace maintained three full notebooks of important knowledge, joined the Well Spouse Association (WSA), which is a caregiver support group, enlisted the physical support of local friends and family and turned the internet in order to cope emotionally. While Grace admitted that in times of frustration and loneliness it was difficult for her to find the strength to reach out for support, she knew that it was an integral part of living well in spite of Harry's impairments.

During the interview, Grace recounted about a group of ladies in their community whom she deemed "angels of the neighborhood" A few close by females would take turns driving Harry to his outpatient rehabilitation appointments while Grace commuted back and forth to work each day to provide for the family. Grace directly attributed this external support to helping her husband stay faithful to his rehabilitation efforts and allowing her to stay afloat as the primary breadwinner for the family. In regards to her own personal psychological well being, Grace mentioned that she found solace and strength in caregiver Internet chat-rooms as well as private psychological counseling. Her ability to not only recognize the importance of physical community support in addition to the importance of emotional support, contributed to helping Grace provide financially and emotionally for her husband and daughters during a period of tremendous adjustment. In turn, Grace's sense of stability also allowed Harry to focus most of his energy on his rehabilitative efforts.

While Grace viewed some of her husband's speech-language therapy during his time as an inpatient, she was unable to attend his weekly outpatient therapy due to her work schedule. She was, however, able to attend Harry's initial outpatient speech-language

evaluation. During this meeting, therapists discussed that Harry was already functioning at a high level and that the prognosis for further improvement was guarded. During the interview, Grace admitted to feelings of frustration in reaction to this discussion. She felt that her husband presented with perceptible communication deficits that were affecting their day-to-day life together.

In March 2009, Harry was readmitted to the hospital for a surgical procedure. Once he recovered and returned home, Harry wished to continue with the remainder of his speech-language therapy; however, when he contacted the therapist, they once again stated that they lacked the materials for a higher functioning client and would be discharging him from therapy prematurely. Once discharged, Harry did not receive any further speech-language treatment. While Grace and her husband were both extremely bothered and perplexed by his abrupt discharge from treatment, they continued to work at home on whatever they could to aid in Harry's speech-language recovery.

Toward the end of the interview, Grace commented on how she feels that "the medical community does not include family enough in trying to improve the patient." While Grace wanted to be a part of Harry's rehabilitation in any way that she could, she stated that therapists didn't expect her to be there or do anything while he recovered. In fact, the only time Grace was asked to participate was when the Visiting Nurses of America came to assess Harry's post-stroke functioning. Grace speculated that this request was most likely for liability purposes and not patient welfare.

Grace is now in a place where she feels more comfortable and less strained as an informal caregiver, although, she did admit that frustration lingers because she still feels

that Harry is willing and able to make improvements in his expression and reception of conversational speech. During the final segment of the interview, Grace stated that the problem with stroke recovery is that it's not often linear. With so many simultaneous life events occurring during the recovery, Grace's hope for the future is that her husband remains at his current level of functioning and if full recovery is not possible, that he not decline.

While these hopes are valid, readers must remember that aphasia is characteristically a chronically disabling condition. While patients are able to make tremendous strides in therapy, even smaller scale deficits may persist on a daily basis. For this reason, facilities are beginning to recognize the importance of incorporating options for high-level clients and offering programs and treatments that incorporate the needs and desires of the primary communication partners of stroke patients. These more currently available options will be presented in the final section of this paper.

Coping With the Long-Term Consequences of Stroke

Stroke is regarded as the most common cause of adult disability within United States and many other industrialized nations. Providing care for stroke survivors can have an enormous, often adverse impact on informal caregivers; therefore, it is extremely important for healthcare professionals to recognize the experiences and needs of these individuals. Caregivers of stroke patients often have to cope with the patient's physical and cognitive impairments, communication and behavioral changes, and emotional setbacks of their own. Coping strategies refer to psychological and behavioral efforts used to manage the external or internal demands and challenges involved in difficult tasks such as providing care for a person with disabilities (Qui & Li, 2008). Previous stroke research has revealed that some caregivers cope well after their loved one's stroke while others experience stress and depression.

Despite increasing acknowledgment of caregiver significance in relation to the affects of stroke, their central role is often given low priority in the management of stroke consequences. There is also limited evidence-based guidance available concerning effective strategies for providing caregiver support throughout the ongoing journey towards recovery (Forster, 2005). Previous research studies have focused on the adverse consequences and negative experiences of caregiving; however, positive outcomes and positive experiences have been recognized as attainable through adopting a number of strategies and coping mechanisms (Greenwood, Mackenzie, Wilson & Cloud, 2009).

These positive strategies are useful in managing the day-to-day and long-term stressors involved with caring for a loved one post-stroke

Over the last decade there has been a significant increase in research involving caregivers of stroke survivors; nevertheless, inadequate descriptions of caregivers and under recognition of the tremendous diversity between caregivers, survivors and their personal circumstances makes it difficult to individually predict what impact caregiving will have on each person. Upon discharge from the hospital, a family caregiver serves as the most-likely individual to care for the patient. Caregivers of stroke patients often have to learn to cope with the patient's impairments and psychosocial changes on top of their own altered life experiences. Caregivers differ in personal experiences and ability to cope; some caregivers are able cope under their new realities post-stroke whereas some experience negative effects.

While a majority of research studies focus on the negative aspects of caregiving such as decreased psychosocial functioning or lack of adequate information on stroke and aphasia, there are also those caregivers who express encouraging caregiving experiences through use of successful coping mechanisms. The case study described in the previous chapter demonstrates one example of how a female caregiver, Grace, was able to positively cope with life changes and future uncertainties after her husband's stroke and the onset of aphasia. Research obtained from the original literature search serves to support individual circumstances and specific coping mechanisms that enable a caregiver to manage new realities post-stroke, and more specifically, which ones Grace used to successfully cope while serving as her husband's caregiver following his stroke in 2008.

In a longitudinal nursing study, 31 caregivers from the United Kingdom were interviewed to investigate the experiences of informal caregivers of stroke survivors over the process of one year (Greenwood et al., 2009). The majority of caregivers, 71%, were living with the stroke survivor both before and after the stroke. During the later interviews, with the patients back at home, practical uncertainties dominated; these uncertainties mainly concerned services, rehabilitation and conflict with employment. The unreliability of formal support was also presented as particularly challenging. Over time, caregivers involved in the study were able to identify coping strategies that were helpful in relinquishing these issues.

Upon returning home after hospital discharge, establishing routines was one way of reducing uncertainty. Routines and planning were seen as better for survivors and caregivers and gave them greater control over their lives and were important and beneficial after a caregiver and patient initiate their post-stroke lives at home. In the case study interview, Grace discussed several routines that enabled her to function on a day-to-basis and manage her caregiver role more effectively. These routines included organizing her husband's medication each week to ensure that his health remained stable and calling upon neighbors to set up driving routines for Harry's rehabilitation appointments. The latter routine was important in that it enabled Grace to maintain her role as primary wage earner and support the family financially. Furthermore, both of these routines served to alleviate Grace's stress and uncertainty as her husband's primary caregiver, allowing her to feel more in control of her surrounding environment.

Another coping strategy identified in the literature was gathering information. With additional information, caregivers expressed that they were able to better predict their loved one's behavior (Greenwood et al., 2009). During the case study interview, Grace revealed that she maintained information by keeping three full notebooks containing facts and recommendations from healthcare providers concerning stroke and aphasia. She also revealed that she was not hesitant about asking questions that she felt were important in her husband's recovery process and sought out information via the Internet and her caregiver support group to connect with people enduring similar circumstances.

Overall, Greenwood et al. (2009) found that encouraging caregivers to identify positive aspects of caregiving, which enabled them to cope with the stressors of caregiving, may allow the caregiver to push away from the challenges and the uncertainties created by the stroke. Grace's firsthand account of her successful coping mechanisms, such as use of routines and information seeking, is a primary example of how positive coping benefited her in managing and controlling the dominating uncertainties and life changes associated with stroke and its ensuing consequences.

In her literature review, Forster (2005) summarized previous research on the impact of caring for patients after stroke. The review indicated, as introduced throughout the paper, that the burden of care is considerable and can potentially accumulate over time. The review also indicated that caregivers of stroke patients have higher psychological morbidity and perceived strain compared with the general population. Forster (2005) discussed a recent study from Finland reporting that, in a cohort of 95

caregivers of stroke survivors, 33% were depressed in the first month after the stroke, with the rate remaining steady to 18 months follow-up. The study also revealed that depression was more common in caregivers than in patients. In addition to depression, anxiety and emotional distress were noted in approximately 50% of caregivers at 6 months post- stroke. In regard to living well in spite of the consequences from stroke, research showed that a caregiver who is initially well-informed about stroke and not depressed is predictive of a satisfactory home situation (Forster, 2005). This verifies the importance of immediately obtaining information and continuing to be an active advocate for information throughout different phases of the aphasia recovery process. In Grace's situation, her persistent collection of resourceful information enabled her to feel more comfortable and satisfied when she returned home with her husband and acquired the role of his primary caregiver.

In a Turkish study, 47 spouses of first ever stroke patients living in the community, and 26 healthy controls of the same and age sex range, participated in a study that compared the quality of life of spouses of chronic stroke patients with healthy controls (Gündüz & Erhan, 2008). The researchers also investigated some objective characteristics of patients and spouses that may negatively affect their quality of lives. Results indicated that the subscale scores of social functioning and mental health were lower in the spouses than in the healthy controls; furthermore, summary scores indicated that being a female and being less educated were associated with both lower physical and mental health. In terms of caregiver sex, females reported more deterioration in social functioning, role limitations due to emotional problems and physical functioning than

their male counterparts. In terms of education, the researchers determined that educational level is important for access to information, which has been proven to affect the caring process. Study outcomes suggested that caregivers with higher education levels might find it easier to seek information and apply it to their daily life (Gündüz & Erhan, 2008). In terms of Grace's experience, her background in teaching English as a Second Language (ESL) and obtaining a PhD in linguistics provided her with the background knowledge and the motivation to examine educational resources and support groups to obtain as much useful information as possible. While not all caregivers have this level of knowledge or sufficient access to information, Grace's high level of education was an advantage when she became a primary caregiver.

Gündüz and Erhan (2008) speculated that better outcomes could be expected with family centered care. They recommended that a family centered approach, striving to meet the entire family's needs, be utilized throughout all phases of the rehabilitation process. After confirming that spouses of stroke survivors had lower quality of life, the researchers recommended that professionals support the mental health of spousal caregivers of stroke patients. Also, because female caregivers and less educated spouses were verified as being more prone to deterioration in quality of life, Gündüz and Erhan (2008) argued that special emphasis should be given to this group. Grace divulged that, as a caregiver, she attended individual counseling sessions as needed, which she said were beneficial in providing her with an unbiased outlet through which she could discuss the burden of caregiving and stressors of life changes post-stroke. Grace's awareness of these certain vulnerabilities facilitated her to seek out this professional support and enabled her

to decrease her stress levels and provide better care for her husband. The information collected through this research study, along with information provided from Grace's case study interview is beneficial in encouraging future rehabilitation services to offer family caregivers with additional education and emotional support. Through providing counseling and offering educational programs, spouses can become better equipped to cope with their altered realities.

To reiterate, while attempting to manage their own reactions and emotions regarding their spouse's stroke, caregivers of these patients have to cope with the patient's potential physical, cognitive, communication, behavioral and emotional changes. The process of coping begins with a person adopting strategies that are either active or passive regarding their partner's impairments. The effectiveness of certain coping strategies used to deal with patient changes has potential to influence a caregiver's social functioning, mental well being and physical health. Resources such as information, assertiveness, and social support play an important role in the coping process. Indirectly, these resource variables influence a stroke caregiver's overall well being. Several caregiver studies have reported the positive influence of these resources on caregiver strain. Grace is a prime example of a spouse who used the above resources to cope with daily stressors and reduce caregiver burden. Again, she actively sought out information, was assertive in both her and her husband's needs, sought out multiple avenues for social support and acquired material resources through her caregiver support group and internet websites. As a result of using successful coping strategies, Grace's strain has decreased overall since the initial day of Harry's stroke. Two and half years

later she is able to accept her and Harry's post-stroke reality as a couple living with aphasia and can embrace the future more readily with less uncertainty.

van den Heuvel, Witte, Schure, Sanderman and Meyboom-de Jong, (2001) conducted research to identify which caregivers of stroke patients in the home exhibited the highest levels of strain and risk for burnout. They also investigated how and when support for caregivers of stroke patients could best be organized. Caregivers of stroke patients were recruited in four regions of the Netherlands and a total of 212 caregivers were interviewed. Multiple stepwise regression analyses were performed to determine the effects of patient and caregiver characteristics, resources, coping strategies and duration of the caregiver role on caregiver strain, mental well being and vitality. The majority of the caregivers were female spouses. Their mean age was 64 years, their socioeconomic status middle class, and their spouse's stroke had occurred, on average, 3.5 years ago. This participant description is similar to Grace's profile in that she is a 60 year old, middle class female caring for her husband for 2.5 years following his November 2008 stroke. In the research study, van den Heuvel et al. (2001) determined that severe cognitive, behavioral and emotional changes in the patient represented the main risk factors for caregiver burnout. While these conditions represented the greatest risk factors for burnout in the research study, these factors do not describe Grace's circumstances in that her husband was high functioning and did not exhibit severe emotional or behavioral changes.

On the other hand, van den Heuvel et al.'s (2001) study identified that caregivers who exhibit high self-efficacy, are satisfied with social supports, and frequently use the

coping strategy confronting, experience less strain, higher mental well being and greater vitality. A reoccurring theme in the literature was that high confidence in self-competency; high satisfaction with available social support, and frequent use of the coping strategy confronting had a generally positive influence on the caregiver experience.

Grace's case study solidifies these findings in that, during the interview, she divulged that she views herself as a stronger, more informed individual after caring for her husband and navigating through the United States healthcare system. To this day, Grace has used different variations and degrees of support systems while acting as Harry's caregiver for the past 2.5 years. This primary example may serve as an indication that caregiver support is a critical, long-term component of providing care for a spouse with aphasia. If caregivers understand the importance of making time for themselves, their hobbies, and their social lives in addition to knowing where and when to ask for support, they may experience less strain and provide better care for their partner post-stroke. In regard to treatment, results from van den Heuvel et al.'s (2001) study confirm that stroke programs should focus on self-efficacy, social support, and coping through confronting to enhance caregiver well being and patient vitality.

Research conducted by Larson, Franzén-Dhalin, Billing, von Arbin, Murray and Wredling (2005) aimed to identify predicting factors for the general quality of life among spouse of stroke patients, and to determine whether these predictors change during the first year after the initial stroke. One hundred spouses were followed three times throughout one year to assess the dependent variables of caregiver illness, economic

situation, well being, life situation, sense of coherence social network and the patient's activities of daily living skills. Stepwise multiple linear regression analyses were conducted at baseline, 6 months and 12 months respectively. Due to the rising number of spouses of stroke patients that become informal caregivers at home post-stroke, the researchers felt that quality of life was an important outcome to measure.

Although most participants in the study were spouses of patients who were independent in their activities of daily living, researchers highlighted that the spouse's characteristics can potentially affect the level of perceived caregiver burden in addition to the stroke patient's characteristics. Findings indicated that psychosocial factors such as general life situation, well being, social network, education and economy are important in predicting general quality of life among spouses of stroke patients. Outcomes revealed that the existence of emotional contacts in the spouse's social life positively affected their quality of life. Emotional support is essential in reassuring the spouse, sharing emotional burdens through sympathy or empathy, expressing concern and providing encouragement. It also contributed to the feelings of being loved and cared for, which helped to maintain self-esteem and reinforce feelings of self-worth in the caregiver (Larson et al., 2005). During the interview, Grace shared that she found Internet chat rooms helpful because they were anonymous mediums through which she could post her feelings, concerns and questions about her husband's aphasia and other stroke related issues. Grace also used email to converse with family and friends who wanted updated information on Harry's condition and Grace's well being. Grace admitted that, as a primary spousal caregiver, these outlets helped her to maintain a preserved quality of life

and achieve higher levels of self-confidence while caring for Harry.

Luis de Leon-Arabit (2008) also presented evidence that socializing is a positive coping method used by spousal caregivers of stroke patients. In his study, participants socialized with family and friends to alleviate feelings of stress and burden involved in the caregiving process. Through these conclusions, the author encouraged healthcare professionals to appreciate the value of socializing with family and friends as a way of dealing with the consequences of stroke and he encouraged healthcare professionals to assist and support spouses in their changing role into primary caregiver.

Green and King (2009) examined perceptions of factors that impacted a patient's quality of life and wife caregiver burden over 12 months following minor stroke. They defined successful adaptation as a process that involves the re-evaluation of life plans, reordering of life priorities, and integration of residual disabilities into current and emerging life situations. The researchers argued the value of healthcare professionals in providing follow-up to people living the community after a minor stroke in order to ensure that resources and required information are available as needed throughout the recovery process.

Green and King (2009) also asserted that timely and clear discharge communication between acute care health professionals and primary care physicians is helpful in ensuring that patients and caregivers are given appropriate post-discharge assessments and opportunities to discuss persistent or newly arising issues. These pertinent discharge concerns presented in the literature were also present in Grace's report of outpatient rehabilitation services provided to her husband. Harry's speech-

language pathologist considered him as high functioning, and felt that with the resources she had, further rehabilitation efforts would not facilitate substantial gains. Despite Harry's premature discharge from speech and language services, Grace and her husband still felt that there were room for improvement and they desired resources that could continue to enhance Harry's existing communication deficits. While Harry's stroke may have been minor and his deficits were decreasing, he represented a motivated client ready to take advantage of available resources for higher functioning aphasia patients. This conundrum characterizes a frequently reported gap within the healthcare system. As Forster (2005) emphasized in her literature review, there is often a disparity between health professionals and families in perceptions of the recovery process. Patients and caregivers tend to measure recovery in relation to their lives before and after stroke rather than to the stroke event itself, which can lead to disappointment when intervention is cut-off. Despite Grace and Harry's disappointment with their discharge from speech-language pathology services, appropriate resources within the community do exist and should be offered to a client and their caregiver if they wish to take advantage of them.

Even with the most motivated, valuable caregiver support, and utilization of resources, a couple's outlook on aphasia recovery must be realistic. Aphasia is an impairment that does not disappear entirely with time. Under the best care and greatest effort put forth by the person with aphasia, some degree of disability is likely to remain. Within today's healthcare environment, rehabilitation efforts on the part of speech-language pathologists are intended to enhance current levels of functioning, but not eliminate dysfunction completely. As a result, the caregiver's role is a large part of a

stroke patient's ongoing recovery. Within the profession, speech-language pathologists must recognize the experiences and needs of these informal caregivers are extremely important in the success of long-term caregiving (Greenwood et al., 2009).

In appreciating that rehabilitative efforts are not meant to be fully restorative, and that social support is a critical component in living well with aphasia, a transformation has occurred within the field regarding the aphasia treatment. Furthermore, in recognizing that patients are often disappointed when traditional therapy is discontinued, newly evolving aphasia community resources will be discussed in depth as they pertain to the future of managing the chronic illness of aphasia and caregiver well being.

Future Directions in Aphasia Treatment and Caregiver Inclusion

Aphasia centers are a comparatively recent addition to the continuum of services available for people with aphasia and their family members. In 1979, Pat Arato founded the first independent, community-based center for aphasia, which is located in Toronto. Now called the Aphasia Institute, the founder desired services for her husband after his stroke resulted in aphasia. The institute started small; however, it now provides direct services to more than 600 people with aphasia and their families annually.

The Aphasia Center of California (ACC) was the first independent, community-based aphasia center created in the United States approximately 15 years after the center in Toronto first opened. The ACC currently provides more than 4,600 annual visits to 160 people with aphasia and their family members. Following suite, during the 1990s and early 2000s there was a dramatic growth in the establishment of independent, community-based aphasia centers (Elman, 2007). These include the Connect program in the United Kingdom; the Adler Aphasia Center in New Jersey; the York-Durham Aphasia Centre in Toronto; and the West Texas Aphasia Center in Midland.

Prior to the institution of these community centers, the vast majority of services for people with aphasia were provided in hospitals and rehabilitation environment, which followed the medical model. Under this model, individuals are viewed as a patient with an ailment that needs to be fixed by a professional. Chronic conditions such as aphasia, can present challenges to the medical model of healthcare because a cure is not often

possible. As a result, a social model of healthcare has evolved under which the individual and their caregiver are treated as part of a collaborative team alongside the healthcare professionals (Elman, 2007). Healthcare problems are seen as an interaction among personal, physical, environmental and societal factors. The healthcare goal in the social model is to create positive change, even when a cure is not possible.

Most aphasia centers encompass a philosophy of service delivery consistent with a social model of healthcare. It wasn't until the 1990s that a growing number of aphasia researchers began to focus their attention on social approaches to aphasia assessment and intervention. The Life Participation Aphasia Approach (LPAA) is an example of this revolution in approaches (Elman, 2007). The LPAA framework includes five core components, which are: 1) the explicit goal is enhancement of life participation, 2) all those affected by aphasia are entitled to services, 3) both personal and environmental factors are targets of assessment and intervention, 4) success is measured via documented life enhancement changes, and lastly, 5) emphasis is placed on availability of services as needed at all stages of life with aphasia. This contemporary approach also indicates that advocacy efforts should focus on components of speech-language pathology that are not yet available within the current healthcare system.

Elman (2007) described how the LPAA has been an important catalyst in transforming and refocusing clinical work, research and advocacy efforts in relation to aphasia. As a speech-language pathologist, an important professional responsibility is to help reconnect persons with aphasia to their family members, their friends, and their communities. By helping to rebuild interpersonal connections and community, as well as

establishing new relationships, speech-language pathologists can help all individuals who are affected by aphasia to live fuller and healthier lives at each stage of this chronic impairment.

In a chapter from the book *Aphasia Inside Out*, Aura Kagan (2003) discusses what ‘community’ means relative to the term aphasia. Kagan has been involved with the Toronto’s Aphasia Institute, which is the pioneer of aphasia centers. The author reflected on how services provided at this aphasia facility served as an informal acknowledgement of the community’s desire to move away from the idea that discharge from traditional speech-language treatment was the end of the line in terms of support and resources. She goes on to define community in terms of ‘little c’ and ‘big C.’ ‘Big C’ community consists of a patient’s use of different community facilities or the degree to which a patient takes on community roles. The ‘small c’ community refers to a person’s immediate family, extended family, work colleagues, and different friend groups all with their own, unique bonds (Kagan, 2003, p. 43).

A critical aspect of centers such as the Aphasia Institute is that community is accessible to anyone with aphasia, including those with very severe deficits. Another important component is that the physical setting and atmosphere of these centers needn’t feel like a hospital or institution, but rather an energetic adult community. The culture of the center emphasizes caring, equality and involvement rather than being cared for and cured. In this type of community intervention framework, group facilitators are encouraged to veer away from the role of the expert who chooses and manages activities with the goal of curing communication deficits. Within this framework, facilitators foster

social interaction among group members through their knowledge of the group process, and ability their ability to provide appropriate conversational supports.

Family education, communication skills training, and supportive counseling are programs that have also been reported in the literature as ways to complement the more frequently used traditional treatment model (Sorin-Peters, 2003). Communication skills training programs involve a shift from speech-language pathologists fixing linguistic or cognitive aspects of communication impairments to a professional who lends their expertise in providing clients with aphasia achieve mutually satisfying conversations with their primary communication partners. In offering communicatively supported conversational opportunities, the role of the speech-language pathologist expands to include deliberate attempts to reduce frustration, which allows participants to overlook their deficits to the greatest degree possible.

The implication of this approach is that, by improving communication between adults with aphasia and their family members, one may help improve social participant and psychological well being (Sorin-Peters, 2003). Communication training can help promote quality of life for couples living with aphasia by improving conversation. An adult learner approach to treating aphasia, which emphasizes that learning begins with the learner and not a treatment plan, includes all three components of education, communication skill training and counseling. The program is unique in its explicit incorporation of adult learner principles as part of the program procedures. Unlike in traditional medical model approaches, the client with aphasia is seen as an experienced and competent adult learner and learning proceeds from his or her needs. Through this

approach, clients gain awareness into their preferred style of learning and these preferences are taken into account throughout the sessions.

The program discussed in Sorin-Peters' (2003) study began with spouses sharing their experiences in living with aphasia and their previous knowledge about aphasia. Healthcare professionals involved in the program also acknowledged the spouses' use of communication techniques that work well. By using reflective learning questions, the program implementers helped spouses to systemically review their experiences with the communication impairment in order to increase their understanding of how aphasia impacts conversations. Spousal reflections served as the basis for enabling caregivers to collaborate in setting goals and designing the program agenda. The approach introduced in this research article differs from the traditional approach of having the speech-language pathologist predetermine appropriate treatment goals and then simply share them with the spouses.

By incorporating adult education principles into aphasia intervention, a new dimension of treatment emerged. When spouse's shared and reflected on their experiences with aphasia as well as conceptualized and applied what had been learned, emotions and marital issues that were impacting the couple's communication surfaced. Adult education principles appear to help bridge family education, communication strategies and counseling of intervention naturally, in a way that could not have been attained without their use. Placing the learner in a central position in intervention also prompted the development of a broad and holistic scope of intervention. More than one aspect of the spouse and partner learning capacities were utilized throughout the training.

These included emotional, relational, physical, intellectual, and intuitive capabilities. The holistic learning approach in this program involved looking at communication behaviors in the context of the couple and family system, and treating the structure as a whole. In general, the adult learner approach offers insights into promoting the quality of life of couples living with aphasia.

As stated previously, LPAA refers to a philosophy of service delivery that focuses on an individual's re-engagement back into the community. The model represents a shift away from the traditional approach that focuses solely on fixing the speech and language impairments (Elman, 2007). Conversely, this modern approach goes beyond compensatory instruction during which the client substitutes one skill for another; it involves focusing on the real-life goals of the extended network of individuals who are affected by aphasia. The LPAA recommends that speech-language pathologists consider the dual function of communication in successfully transmitting and receiving messages, as well as establishing and maintaining social connections.

Sorin-Peters' (2003) adult learner approach promoted communication changes consistent with the life participation approach while placing the learner in the central role and integrating adult learner strategies into working with couples living with aphasia. Outcomes from this research demonstrate that improving quality of life for couples living with aphasia can extend even further than just promoting increased participation in conversation. By introducing learning as the central component to treatment, the couple's intervention goals included emotional and marital issues, as well as communication goals.

Within the literature, four phases have been described in regards to the development of acceptance in chronic illness such as aphasia (Sorin-Peters, 2003). These phases are denial, resistance, affirmation and integration. By agreeing to participate in the caregiver and aphasia training, couples implicitly acknowledge that their partners have aphasia and that they are consenting to help. This acknowledgement puts them in the affirmation phase. This stage may be characterized by pain in that there is an acceptance of the notion that things will never be as they previously had been. This pain also implies that, even when couples are willing to accept assistance, it's important to support them emotionally. Even at the affirmation phase, a need for intervention is warranted in that it can possibly help couples move beyond this phase to gain new or modified way of communicating with one another. With this adult learner training, couples were able to move towards the integration stage where they could manage the aphasia and participate in other activities with improved quality of life.

Sorin-Peters (2003) emphasized that in order to promote quality of life for couples living with aphasia, speech-language pathologists must address emotional issues that may hinder the learning process. Allowing couples to express feelings can systemically help them to move forward and encourage acceptance of the consequences of aphasia. The author also stress the importance of addressing marital issues that are intertwined with communication as a means of promoting quality of life for couples with aphasia.

Research in marital therapy has outlined five types of relationship maintenance behaviors that function preserve ongoing relationship. These include positivity, openness, assurances, network and the sharing of tasks (Sorin-Peters, 2003). The present approach

demonstrated that learner-centered training could promote relationship maintenance behaviors for couples that are willing to commit to interventions such as the one being discussed.

Within the field of speech-language pathology, Sorin-Peters (2003) states that spousal caregivers should be seen either individually or with their partners in order to address the couple's specific needs and desires. Under the adult learner framework, emotional and marital issues may surface and need to be addressed. Additionally, follow-up is beneficial to monitor progress and to maintain or further improve the quality of communication between couples. The approach described demonstrated that the wider scope of a learner-centered program can promote a wider scope of communication changes for couples living with aphasia. These include, improvement in interaction and transaction of information within conversations as well as increased participation in conversation from the person with aphasia. Secondly, the cognitive competence of the partner with aphasia is revealed through the skill of the trained spouse during conversation. Communication changes using an adult learner approach also included more balanced topics, turns and response control in conversation. A hierarchy of different conversation genres also emerged; the couples moved from conversation that was more focused on the performance of the partner to conversation with greater topic elaboration. After intervention, communication developed to include reminiscences and discussions such as sharing a memories and experiences. As a result, these reminiscences changed the whole meaning of the conversations between couples living with aphasia.

The more recent expansion of aphasia community centers, coupled with the adoption of adult learner approaches, has broadened the role of speech-language pathologists in aphasia treatment. Speech-language pathologists are now helping individuals and their loved ones living with aphasia to derive their own meaning and create their own outcomes in managing the impairment. A wider scope of practice can foster a growing acceptance and ability to develop creative solutions to be applied outside of therapy and without the speech-language pathologist's direct involvement.

These two fundamental trends within the profession can also promote increased quality of life for couples living with aphasia. When therapists get to know the individual's living with aphasia, initiate intervention by listening to stories and experiences, acknowledge their feelings and challenges, and promote social interaction, the speech-language pathologists can facilitate reflection to help clients and their communication partners become critically aware of their perspectives and behaviors. In acknowledging these individual perspectives and behaviors, speech-language pathologists can offer options for dealing with personally imposed aphasia constraints and help to promote a new level of well being that was possibly considered out of reach by individuals with aphasia and their primary caregivers.

Aphasia community centers and the adult learner model suggest a healthcare relationship in which the speech-language pathologist and couple are active collaborators in the learning and recovery process. For speech-language pathologists to properly utilize these approaches, they must broaden their technical expertise to areas such as adult education principles, family systems and marital interaction and methods of dealing with

familial interactions in intervention programs. In doing so, speech-language pathologists may better understand some of the experiences of the clients and their families they work with as well as facilitate more appropriate, meaningful changes to promote improved quality of life.

In today's healthcare environment, the notion of entitlement to long-term and dynamic support for individuals with aphasia does not necessarily fit with the term 'rehabilitation' (Kagan, 2003). Many people think of rehabilitation as having a finite end point and involving solely the individual directly experiencing impairments. People with chronic medical conditions or illness such as diabetes receive ongoing treatment rather than rehabilitation; however, this is not the case in traditional aphasia therapy. Moreover, diabetes treatment consists of periodic check-ups to monitor health status and make adjustments to medications if necessary. Treatment of a chronic impairment, unlike rehabilitation, does not necessarily imply improvement in the condition. It may also include the goal of maintaining current functional status with the belief that, if such treatment were withdrawn, consequences might ensue.

Unfortunately, under today's healthcare system, the issue of extended and family-centered speech and language services is less about justification of these principles than about logistics and funding. The challenge is to find a way to provide this type of long-term support that offers a person with aphasia and their caregiver greater access to community in the sense that it becomes an intrinsic part of best practice in the continuum of care. Through acknowledging and harnessing the positive experiences offered by researchers, clinicians, and families living with aphasia, this information validates that

revolutionary approaches in aphasia treatment are considered effective and beneficial for individuals with aphasia and their families at all stages of the aphasia recovery process. Furthermore, these positive conclusions validate that these more modern approaches should continue to become an engrained and expected component in managing chronic aphasia post-stroke.

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