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CAREGIVER PERSPECTIVES: A PHENOMENOLOGICAL STUDY OF CAREGIVER  
GROUP EDUCATION DURING AN INTENSIVE COMPREHENSIVE APHASIA  
PROGRAM

By

MAGGIE ANN COLSTAD

Bachelor of Arts, University of Montana, Missoula, MT, 2015

Thesis

presented in partial fulfillment of the requirements  
for the degree of

Master of Science  
in Communicative Sciences and Disorders

The University of Montana  
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Caregiver Perspectives: A Phenomenological Study of Caregiver Group Education during an Intensive Comprehensive Aphasia Program

Chairperson: Catherine Off, Ph.D., CCC-SLP

The purpose of this study was to explore the benefits of a caregiver education, training, and wellness program to improve caregiver outcomes in the context of aphasia rehabilitation. Eight caregivers participated in one-hour group treatment sessions across four weeks as part of an intensive comprehensive aphasia program. Information about stroke and aphasia was provided in a didactic format, and facilitative communication strategies were discussed and practiced using Kolb's (1984) experiential learning cycle model. This qualitative study adhered to Moustakas' phenomenological approach. Participant post-treatment interviews were transcribed and coded for themes relating to their experiences throughout the treatment program. Caregivers described three major themes. The first theme related to information gained in both technical knowledge of stroke, aphasia, apraxia, neuroanatomy and physiology, and neuroplasticity in addition to applicable knowledge of facilitative communication techniques. The second theme entailed the benefits of a group service delivery model, particularly the psychosocial and educational support provided by peer group members. The final theme of "considering the future" for the caregivers included discussion of PWA progress, caregiver needs at different times, and recommended changes to the program. This study gives insight into the caregiver perspective of the benefits to participating in a caregiver group treatment program targeting educational and psychosocial outcomes.

*Keywords:* caregiver, aphasia, education, training, wellness, group treatment, phenomenological approach

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## **Chapter One: Introduction**

Cerebral vascular accidents, commonly known as “strokes,” cause damage to the brain that have effects extending far beyond the health of the survivor. Strokes can trigger a cascade of life-changing events that affect the individual, the family, and the community (Denby & Harvey, 2003). According to the National Aphasia Association, 25% to 40% of stroke survivors acquire aphasia (2016). The National Institute on Neurological Disorders and Stroke estimates that approximately one million individuals suffer from aphasia in the United States (2016).

Depression, social isolation, significant decreases in productivity and activities, and changes in family roles and functions are some of the documented effects of chronic aphasia (Astrom, Adolfsson, & Asplund, 1993; Gainotti, 1997; Hinckley & Packard, 2001). The World Health Organization Classification of Functioning, Disability, and Health (WHO-ICF) has shifted the focus of treatment for adults with aphasia to a psychosocial model of service delivery (World Health Organization, 2001). Relative to previous medical models, which solely focused on targeting the impairment, health care professionals including speech-language pathologists must consider how the impairment of aphasia impacts an individual’s ability to participate in activities and roles at home, at work, and in the community under the WHO-ICF model (Purdy & Hindenlang, 2005). Because facilitating communication and transition to the community often becomes the responsibility of family members, including them in the therapeutic process is vital.

Despite current trends in service provision that attempt to create strong links between primary care services and the community, family members of people with aphasia are often left to cope with substantial difficulties with few therapeutic supports (Riley, Hough, Meader, & Brennan, 2015). A caregiver (i.e., informal caregiver) is an unpaid individual (e.g., a spouse, partner, family member, friend, or neighbor) involved in assisting others with activities of daily living

and/or medical tasks (Family Caregiving Alliance, 2016). As reported in the National Alliance for Caregiving and the American Association of Retired Persons Public Policy Institute's "Caregiving in the U.S." 2015 Report, about 34.2 million Americans have provided unpaid care to an adult age 50 or older in the last 12 months. Although family members function as extensions to formal services, they are essentially de facto healthcare providers without formal training or support, and often without routine access to the healthcare systems that rely on their performance (Ramkumar & Elliott, 2010).

Several factors underscore the important role of caregivers. For example, change toward managed care in the United States means that more patients are expected to care for themselves at home, with the assistance of a formal or informal caregiver, in ways that would have required professional care in years past (Donohue, 2001; Redman, 2007). Legal and ethical mandates require that patients be informed of their health status and options so that they can be actively involved in developing and implementing treatment plans (Behar-Horenstein, Guin, Gamble, Hurlock, Leclair, Philipose, Shellnut, Ward, & Weldon, 2005). Caregivers of stroke patients with aphasia play a vital role in developing and supporting their loved ones' treatment interventions. Whether family caregivers are needed for 24-hour care or weekend visits, they provide support on behalf of the person with aphasia in a variety of ways including: (1) basic activities of daily living (e.g., feeding, dressing, bathing, toileting, mobility), (2) instrumental activities of daily living (e.g., transportation, shopping, housework, arranging services), (3) medical care (e.g., locating a medical specialist, physical therapy, administering medication), (4) administrative care (e.g., mediating, negotiating, scheduling, managing finances, legal affairs, and insurance issues) and (5) emotional care (e.g., maintaining systems of social support, providing encouragement, and attending to spiritual needs) (Horowitz, 1985). Although



caregivers serve a critical function as extensions of the healthcare system, they are not yet consistently addressed as a component of the rehabilitation process.

The current study assesses perspectives of caregivers receiving group treatment in a rural area. Five of the eight participants also lived in rural communities. Caregivers living in rural communities are likely to experience additional burdens compared to caregivers living in urban or suburban areas. Some of these burdens may include reduced program availability and acceptability, inadequate mental health support and an increased rate of changing needs over time (Talley, McCorkle, & Baile, 2012). Development of rural programs designed to assist caregivers may be impeded by caregivers' reluctance to seek help and to spend money on such services. In addition, caregivers who live in rural areas are often provided with "scaled down urban service models that fail to meet their needs or are insensitive to the real differences between urban and rural areas" (Van Hook, 1987, p. 13) often due to limited fiscal resources and infrastructure. Despite these barriers, evidence suggests that rural caregivers are highly motivated to undertake the difficult caregiving role, with some reporting a deep sense of personal satisfaction and growth from the experience (Buckwalter, Russell, & Hall, 1994).

### **The Psychosocial Impact of Stroke and Aphasia on Caregivers**

Taking on the role of a caregiver for someone who has had a stroke can have a considerable impact upon the caregiver's quality of life (McGurk & Kneebone, 2013). Research confirms declines in the physical and mental health, quality of life, and financial status of caregivers of persons with acquired neurologic injury (Donelan, Falik, & DesRoches, 2001; "Caregiving in the U.S.," 2015). Evidence also suggests that caregivers of stroke survivors experience a higher level of perceived strain and psychological morbidity compared to the

general population, which ultimately impacts the person receiving care (Schulz, Tompkins, & Rau, 1988).

The compassion that goes hand-in-hand with caring is defined as “feelings of deep sympathy and sorrow for another who is stricken by suffering or misfortune, accompanied by a strong desire to alleviate the pain or remove its cause” (Webster, 1989, p. 229). Caregivers are susceptible to compassion fatigue, a state of exhaustion and dysfunction (biologically, psychologically, and socially) resulting from prolonged exposure to emotionally draining experiences and people who are in pain or suffering (Aycock & Boyle, 2009). Compassion fatigue is considered a natural behavior and emotional response that results from helping another person suffering from trauma or pain. This condition can cause a caregiver’s pervasive decline in his/ her desire, ability, and energy to feel and care for others and loss of the ability to experience personal and professional satisfaction (Makic, 2015).

Considering the widespread psychosocial impact that aphasia can have on the well-being of caregivers of persons following the onset of disability, this area of need should be a priority in the healthcare system (Talley & Crews, 2007). A study by Visser-Meily, Post, van de Port, Maas, Forstberg-Warleby, and Lindeman (2009) suggests that among the factors that have an impact on caregivers' psychological well-being are the level of dependence of the stroke survivor, and the cognitive, behavioral, and communication impairments caused by the stroke. The prevalence of depression among caregivers of stroke survivors is estimated to be 30% (Hackett, Yapa, Parag, & Anderson, 2005). This statistic can be compared to the 7.6% of persons 12 years of age and older living with depression in any two-week period (Pratt & Brody, 2014). A study conducted by McGurk and Kneebone (2013) revealed caregivers of people with aphasia after stroke commonly experience problems in the following areas: role changes/new

responsibilities, difficulties with social and leisure activities, communication difficulties with the stroke survivor, employment and financial problems, problems in dealing with health professionals, relationship difficulties with the stroke survivor, difficulties in family relationships, lack of support or respite, managing difficult behaviors in the stroke survivor, physical health problems/fatigue, and emotional health problems. Physical, cognitive, emotional, and social challenges may combine with communication problems and impact upon virtually all aspects of life for stroke survivors and their families (Alaszewski, Alaszewski, Potter, Penhale, & Billings, 2003).

### **Education and Intervention Strategies to Reduce Caregiver Burden**

A fundamental part of the rehabilitation process is to provide education to address information about stroke rehabilitation, psychosocial aspects of recovery, and communicative strategies so that caregivers can improve their overall health and knowledge of stroke recovery. Unfortunately, researchers have yet to identify consistent psychosocial interventions that effectively benefit caregivers of persons following neurologic injury. Current interventions primarily focus on medical management while the psychosocial issues of family caregivers are left largely unaddressed (Ramkumar & Elliott, 2010). Thus, the demands of rehabilitation and impending discharge do not prepare family members for the full array of issues caregivers will face as the family tries to resume personal, social, and occupational roles outside of the healthcare system (Ramkumar & Elliott, 2010). Furthermore, caregiving in rural communities requires family members who often live at a distance to collaborate around care for a family member. Rural caregivers tend to be older than their urban counterparts, report more health issues associated with the demands of caregiving (Roberto, Blieszner, Reynolds, & Byrne, 2001), and consider themselves to be in worse health than people in the general population

(Sanford & Townsend-Rocchiccioli, 2004). Access to healthcare that supports both caregivers and their loved ones is also a critical component to effective services. Further empirical evidence is warranted to provide caregivers of stroke survivors effective treatment that addresses psychosocial aspects of recovery.

Although evidence-based interventions for caregivers have yet to be confirmed, psychosocial treatment for caregivers of persons who have aphasia has been shown to lower caregiver distress (and perhaps, depressive symptoms) and result in positive changes with respect to dealing with the aphasia in everyday situations (Howe, Davidson, Worrall, Hersh, Ferguson, Sherratt, & Gilbert, 2012). Caregiver interventions should focus on teaching caregivers active coping strategies, since these strategies appear to achieve greater strain reductions than passive ones (van den Heuvel, de Witte, Nooyen-Haazen, Sanderman, & Meyboom-de Jong, 2000).

Inconclusive findings from studies such as those from a 2008 study conducted by Franzen-Dahlin, Larson, Murray, Wredling, and Billing result in clinical messages such as, "Encouraging participation in the group meetings of a support program might have a positive effect on participants' psychological health" (p. 998). A study by van den Heuvel et al. (2000) found that caregivers reported increased confidence in [stroke rehabilitation] knowledge and increased use of active coping strategies in the span of a two-month education and training program. These findings corroborate previous studies, which showed a positive influence of active coping and knowledge on caregivers' well-being (Israel, Schulz, Parker, and Becker, 1998). These caregiver support programs seek to empower the active role of family caregivers in promoting their own health and well-being to maintain healthy relationships with their loved ones with disabilities.

Psychosocial intervention and education regarding stroke recovery are critical components of the WHO-ICF's intended social model of service delivery. Stroke survivors and

their caregivers report dissatisfaction with the quantity and quality of the information they receive such that their understanding of stroke, its consequences, and the available support is poor (Rodgers, Bond, & Curless, 2001). Patient education has been recognized as an integral component to ensuring that individuals are knowledgeable about treatment options and the management of their healthcare needs. In fact, over the past four decades, "patient and public education programs [have been] among the fastest growing component of health care in the United States, expanding from 50 hospital...program[s] in 1970 to the present when virtually every health institution has some type of patient education program" (Siminerio, 1999, p. 305). In comparison, caregiver education is lagging behind in both empirical research and implementation across healthcare systems.

A number of barriers currently exist in the relatively new clinical research area of caregiver education. A limited evidence base influences the effectiveness of caregiver educational materials that are currently available. Inconsistencies across education programs and written health care materials diminishes the benefits of caregiver education, hinders caregiver self-care, and compromises the quality of care (French & Larrabee, 1999). The short length of hospital stays may also reduce the effectiveness of patient and caregiver education (Begar-Horenstein et al., 2005). With a shortened length of stay, caregivers may not be ready to assimilate all of the information during the rehabilitative phase (i.e., the initial speech-language intervention). Avent, Glista, Wallace, Jackson, Nishioka, and Yip (2005) conducted a study to identify information needed by family members at the onset of aphasia (hospitalization), initial rehabilitation, and chronic phases of aphasia. Results indicated that family members would like information about general aspects of treatment, how to deal with co-existing behaviors, how to maximize communicative effectiveness, and how to access available resources during the initial

speech-language treatment phase. During the chronic phase of aphasia and return to home life, the families continued to discuss the need for general information about aphasia and resource information. Also, families reported that they needed more practical living-with-aphasia information, such as long-term planning and financial aid. Thus, although education should begin in a medical setting, it is essential that it continue in the community so that caregivers have ample opportunities to generalize learned material to real-life situations.

To reduce these barriers during caregiver education, Redman (2007) implemented an individualized approach to patient education. The following principles can also be applied to caregiver education. In conducting an individualized approach for caregivers, educators must initially assess the caregiver's needs, willingness or ability to learn, and their preferred learning styles. An assessment may include interviews, observations, and/or administration of questionnaires. After gaining the caregivers' cooperation, the educator can set learning goals and objectives collaboratively with the caregiver. After identifying intended outcomes, the caregiver educator can implement caregiver education by means of verbal communication supplemented by written materials, role play, demonstration, and visual media. Benefits to this approach include improved communication, caregiver satisfaction, and improved overall quality of life.

Group service delivery models targeting domains such as stroke rehabilitative education have proven to be a powerful learning mechanism for caregivers of persons with aphasia (Rayner & Marshall, 2003; Purdy & Hindenlang, 2005). In the broader realm, research has demonstrated that group therapy is a highly effective form of psychotherapy in that it utilizes group cohesiveness as a therapeutic tool to foster interpersonal learning (Yalom & Leszcz, 2005). The supportive atmosphere of caregiver education and training groups have been shown to foster bonding to help cope with the consequences of aphasia, and provide a means of social and

psychosocial support. A group service delivery model also allows for joint problem solving by promoting discussion of communication accomplishments and breakdowns. (Purdy & Hindenlang, 2005). Done and Thomas (2001) found that caregivers could be trained to structure questions for more successful communication with care recipients with Alzheimer's disease. Follow-up data from a two-day seminar style program designed for adults with chronic aphasia and their families demonstrated a significant improvement in functional activity level, improved knowledge of aphasia, and improved family relationships (Hinkley & Packard, 2001). Results from a randomized controlled trial evaluating the effect of a support and education program for spouses of people affected by stroke indicate that the spouses who participated more frequently (i.e., five or more times) in group education meetings gained more knowledge about stroke and reported stronger psychological health than participants who did not attend group meetings as frequently (Franzen-Dahlin et al., 2008). As the current literature suggests, implementation of group intervention into clinical practice can effectively provide psychosocial support, education, and training to caregivers.

### **The Impact of Caregiver Education on Caregiver and Patient Rehabilitation Outcomes**

A theme found throughout the rehabilitation literature is that caregiver education can lead to improved caregiver outcomes (Behar-Horenstein et al., 2005; Purdy & Hindenlang, 2005; Smith, Forster, & Young, 2004). Tringali (1986), who studied a group of caregivers of cancer patients, suggests that an increase in sense of control and a decrease in caregivers' anxiety can be reached by increasing caregivers' knowledge. Relating to caregivers of stroke survivors, by increasing the family members' understanding of aphasia, it is hoped that their interactions with the person with aphasia will become more satisfying; however, knowledge of the nature of aphasia alone does not necessarily improve communication or assist with coping with the

subsequent problems (Simmons-Mackie, & Damico, 2001; Purdy & Hindenlang, 2005). A study conducted by Hinkley, Packard, and Bardach (1995) showed that participants involved in an education program that provided information, resources, and social support and exchange to adults with aphasia and their families reported improvements in knowledge of aphasia and resources, independence at home, and communication with their partner. This approach is grounded in theory and research that suggests that caregiver programs addressing multiple domains such as education, psychosocial support, and facilitative communication strategies alleviate the multi-faceted challenges caregivers of people with aphasia face.

Caregivers need a variety of knowledge and skills to be effective, supportive communicators with their loved ones with aphasia. Studies such as those conducted by Simmons-Mackie and Damico (2001), Purdy and Hindenlang (2005), and Kagan, Black, Duchan, Simmons-Mackie, and Square (2001) found that specific communication skills training for communication partners in addition to caregiver education is necessary for techniques to be learned and incorporated into daily life situations. A controlled trial provided support for the efficacy of Supported Conversation for Adults with Aphasia (SCA) training in improving the skill of conversation partners (Kagan et al., 2001). On a fundamental level, this study lends support to the idea that clinicians should be looking beyond the impairment of the person with aphasia. A limitation of this study as it relates to caregiver training is that the conversation partners were highly experienced in delivering SCA training. It is possible that these factors balanced the relative lack of opportunity given the volunteers to practice and refine their skills (Kagan et al., 2001). Future research might examine SCA training or a more individualized training approach for other conversation partners such as family members. Improving skill through SCA training can increase access to opportunities for conversation by reducing barriers



for the person with aphasia. These results provide experimental support for a social approach that emphasizes a professional obligation to reduce communication barriers and to increase life participation opportunities for those affected by aphasia (Kagan et al., 2001).

In addition to an education and communication skills training program, Sorin-Peters (2003) and Purdy and Hindenlang (2005) developed a caregiver intervention approach that was conducted in a group environment that offered peer support through shared learning experiences and joint problem solving. Using the adult learning approach, which views the participant as a competent, experienced learner, the goals of the programs were developed with input from the person with aphasia and his or her partner (Purdy & Hindenlang, 2005). Communication skills training followed an experiential learning cycle, modeled by Kolb (1984). The basis of this model is that learning occurs through concrete experience, reflective observation, abstract conceptualization, and finally experimenting to apply what they have learned. After a group program in which stroke and aphasia education was provided and facilitative communication strategies were discussed and practiced, Purdy and Hindenlang's participants demonstrated increased communicative success, had a better understanding of aphasia, and were more confident using facilitative strategies (2005).

Clinical implications of group education and training programs such as those conducted by Purdy and Hindenlang (2005) suggest that direct education and training of caregivers is an ongoing development and should be included as part of the overall therapeutic process. This finding is consistent with the Life Participation Approach to Aphasia (LPAA; Chapey, Duchan, Elman, Garcia, Kagan, Lyon, Simmons-Mackie, & Damico, 2001), which emphasizes that services should be available to persons with aphasia and their caregivers through all stages of aphasia. The Life Participation Approach to Aphasia empowers individuals to participate in the

recovery process and to collaborate on the design of interventions that aim to reduce the consequences of disease and injury. The core values of LPAA include: a) enhancement of life participation; b) everyone affected by aphasia is entitled to healthcare services; c) success is measured in life enhancement changes; d) intervention targets include both personal and environmental factors; and e) availability of services is required at all stages of aphasia. Research advancements in group education and training programs could lead to improvements in reported caregiver mental, emotional, and physical health and lead to increased application of the LPAA.

Current research lacks the systematic exploration of the types of caregiver education approaches currently used by speech-language pathologists (SLPs) and the number of sessions required for significant clinical gains. Additional research could lead to more effective management of caregivers' perceived challenges. A gap in the current empirical evidence shows the success of communicative interactions and social participation in the context of intensive service delivery models and natural environments. Changes in quality of life as a result of participation in family education and training have also yet to be formally examined. The current phenomenological qualitative study explored the benefits of a caregiver education group designed to improve caregiver psychosocial health and to increase knowledge about stroke recovery, aphasia, and facilitative communication strategies in the context of an intensive comprehensive aphasia program (ICAP) service delivery model (Babbitt, Worrall, and Cherney, 2015). According to Rose, Cherney, and Worrall (2013) ICAPs provide a minimum of three hours of therapy per day for two weeks, with several programs providing as many as four to six hours a day over a period of four to five weeks. Within an ICAP, daily therapy typically includes individual sessions, group sessions, computer-based therapy delivery and community outings (Babbitt, Worrall, & Cherney, 2013). This service delivery model is different from the standard

therapy model of outpatient rehabilitation in which a person with aphasia receives two to three hours of therapy a week over a period of eight to 12 weeks (Rose et al., 2013).

The caregiver education group included a modified adult learning model and experiential learning cycle similar to that described by Sorin-Peters (2003) and implemented by Purdy and Hindenlang (2005). The program targeted education that addressed information about stroke rehabilitation and psychosocial aspects of recovery. Education addressing facilitative communicative strategies was provided so that caregivers of people with aphasia could be equipped with the skills required to improve daily communication with a person with aphasia. Caregiver education was conducted in a group setting to support peer learning and support as well as joint problem-solving opportunities (Purdy & Hindenlang, 2005). The research question for the current phenomenological study is stated as follows: What are caregivers' experiences during a caregiver education group designed to improve psychosocial health and to increase knowledge about stroke recovery, aphasia, and facilitative communication strategies?

## **Chapter Two: Methods**

### **Participants**

A total of eight caregivers of persons with aphasia participated in the caregiver education program. All participants spoke English as their primary language and all participants were Caucasian. Based upon the demographics reported in the U.S. Census for Missoula, Montana, 90-100% of people identify themselves as Caucasian (United States Census Bureau, 2015). See table 1.1 for participant characteristics. Each caregiver/person with aphasia (PWA) dyad was concurrently enrolled in the Summer 2016 Big Sky Aphasia Program's Intensive Comprehensive Aphasia Program (BSAP ICAP) for five hours per day, four days per week, for four weeks. As part of the BSAP ICAP, caregivers participated in a bi-weekly counseling group which targeted

self-care for well-being. Caregivers voluntarily consented to participate in the research protocol (University of Montana IRB# 116-14, see Appendix D for the caregiver consent document).

Participants were not compensated for their participation in this protocol.

**Table 1.1: Caregiver Participant Characteristics**

<b>Participant Alias</b>	<b>Gender</b>	<b>Age</b>	<b>Relationship to Person with Aphasia</b>	<b>Education</b>	<b>Employment History</b>
<b>CARE-001</b>	Female	71	Wife	Bachelor of Arts	Retired
<b>CARE-002</b>	Female	50	Wife	Master of Arts	Employed
<b>CARE-003</b>	Male	59	Husband	College Graduate	Retired
<b>CARE-004</b>	Female	72	Wife	Bachelor of Arts	Retired
<b>CARE-005</b>	Female	59	Wife	Vocational degree	Retired
<b>CARE-006</b>	Female	61	Sister	Bachelor of Arts	Employed
<b>CARE-007</b>	Female	53	Daughter	Bachelor of Science in Nursing	Employed
<b>CARE-008</b>	Female	73	Wife	Vocational degree	Retired

**CARE-001.** CARE-001 was a seventy-one-year-old female who lived in Seattle, Washington.

She had three adult children with her husband, a participant in the BSAP ICAP. She obtained a Bachelor of Arts degree and worked as a self-employed tax preparer until retirement in 2015.

CARE-001 was not in attendance for the third week of treatment.

**CARE-002.** CARE-002 was a fifty-year-old female who lived La Quinta, California. She had ten-year-old twins with her husband who participated in the BSAP ICAP. She was a first-grade teacher with a Master of Arts degree. CARE-002 attended all four treatment sessions.

**CARE-003.** CARE-003 was a 59-year-old male who lived in Baton Rouge, Louisiana with his wife, a participant in the BSAP ICAP. He was a college graduate who retired as a senior account executive in 2015. CARE-003 attended all four treatment sessions.

**CARE-004.** CARE-004 was a 72-year-old female from Boise, Idaho. She had two adult children with her husband who participated in the BSAP ICAP. She obtained a Bachelor of Arts degree and worked as a librarian in a public school system until she retired in 2004. CARE-004 attended all four treatment sessions.

**CARE-005.** CARE-005 was a 59-year-old female who resided in Missoula, Montana with her husband, a participant in the BSAP ICAP. She had three children. She retired from the U.S. Forest Service as a project manager in 2007. Although CARE-005 was not in attendance for content presented in week two, she did receive the information by watching the recorded session at a later date.

**CARE-006.** CARE-006 was a 61-year-old female who travelled from Maryville, Missouri to participate as a caregiver in the BSAP ICAP. She obtained a Bachelor of Arts degree and was a full-time para-educator at a middle school in Missouri at the time this study was conducted. CARE-006 attended all four treatment sessions.

**CARE-007.** CARE-007 was a 53-year-old female who lived in Plains, Montana with her husband and two children. She participated in the BSAP ICAP as a caregiver to her mother. She obtained a Bachelor of Science in nursing and worked as a part-time registered nurse, part-time bookkeeper at the time of this research study. CARE-007 attended all four treatment sessions.

**CARE-008.** CARE-008 was a 73-year-old female from Idaho Falls, Idaho. She had two children with her husband, a participant in the BSAP ICAP. She retired as a billing manager in 2008. CARE-008 attended all four treatment sessions.

## **Intervention Procedures**

Intensive Comprehensive Aphasia Programs (ICAPs) are a relatively new service delivery model for stroke rehabilitation (Babbitt et al., 2013; Rose et al., 2013). The number of ICAPs across the country is increasing as a result of a desire to approach aphasia rehabilitation from a holistic and bio-psychosocial background, while also implementing intensive treatment. Currently, the evidence suggests that intensive treatment yields the most effective treatment outcomes. The overarching goal of an ICAP is to maximize communication potential and improve life participation. In short, ICAPs are multi-faceted and take into consideration the many aspects of communication needs faced by those affected by aphasia. ICAPs provide a minimum of three hours of treatment per day for at least two weeks, with some programs providing as many as four to six hours per day over a period of four to five weeks. Daily treatment includes individual sessions, group sessions, and computer-based or technology-based treatment. Patient and family education should also be provided. Persons with aphasia and their caregivers who are enrolled in an ICAP may receive as many as 120 hours of focused language treatment over the span of one month, whereas a person who is enrolled in a standard treatment model will receive approximately eight to 12 hours of treatment in the same time frame. While research of the ICAP model is in its infancy, initial efficacy studies indicate positive patient outcomes across a variety of impairment-based and psychosocial domains.

The University of Montana's ICAP meets the criteria for an ICAP and has been intentionally designed with clearly defined intensity parameters, a concern for client, caregiver, and clinician perspectives, and a focus on comprehensive treatment that addresses multiple modalities using strategies and recreational opportunities that are individualized to those affected by aphasia. This ICAP provides four hours of treatment, four days a week, for four weeks for the

patients with aphasia. During the University of Montana's ICAP, caregivers of PWAs engage in education and counseling opportunities. During the Summer 2016 ICAP, caregivers attended weekly education groups and twice-weekly counseling groups in addition to having the opportunity to sit in on individual sessions, small group sessions, and large group sessions directed at the person with aphasia. The purpose of this study was to examine the caregivers' experience during the weekly education group.

Treatment procedures for the four-week education program consisted of six components. Following consent procedures, caregivers completed a demographic questionnaire before participating in a pre-treatment interview. Transactional communication samples (exchanges of specific information; see Appendix C for scenario prompts) were also elicited before and after the caregiver education group intervention. These language samples required the person with aphasia to communicate a short message (e.g., "Your daughter is moving to Colorado and you are sad because you will miss your grandchildren") to their caregiver using any means of communication (i.e., speaking, writing, gesturing, drawing). The researchers video recorded and transcribed these interactions to code for the presence or absence of caregiver behaviors including: verification, ensures comprehension, and facilitates responses (Purdy & Hindenlang, 2005). See Table 2 for examples of behaviors observed in caregivers. Participants also completed weekly self-report questionnaires. These questionnaires (see Appendix B) were completed by the caregiver at home, between each treatment week. These weekly probes were intended to evaluate the caregiver's perspective about the various components of the caregiver education group and the impact that the caregiver education group had on their communication. Following the four-week group treatment, all caregivers participated in a post-treatment interview. Although a large volume of data was collected through these six components of

treatment, the focus of this study is the qualitative experience of this education group. All of the other data will be presented in separate papers.

The caregiver education program was provided during a group setting for one 60-minute session per week for four consecutive weeks during the summer 2016 BSAP ICAP. The educational program for caregivers included both didactic and experiential training methods. All sessions were led by a graduate student researcher (the author) under the direct supervision of a board-certified speech-language pathologist (SLP).

*Didactic training.* A topic was introduced each week, addressing four sessions of different content determined by the caregivers, graduate student clinician, and supervisors collectively. Session one (week one) addressed the goals of the program, from the perspectives of the SLP and the caregivers. The graduate student clinician provided information to the group regarding stroke, stroke rehabilitation, neuroanatomy in relation to speech and language function, and aphasia during session two (week two). The graduate student researcher provided visual models of the brain to supplement the verbal presentation and distributed journal articles and reference sheets from reputable sources such as the American Speech-Language-Hearing Association website ([asha.org](http://asha.org)). Session three addressed various compensatory strategies and supportive techniques within the context of acknowledging the inherent competence of the person with aphasia and helping to reveal that competence (Kagan et al., 2001). Techniques for facilitating communication were demonstrated by the graduate student clinician, exemplified by videos, and embedded in the didactic training. For example, key concepts were written on a dry erase board, verbal pacing was slow, sentence structure was simplified, and gestures were used. Session four targeted psychosocial aspects of caregiver treatment including a discussion of the Caregiver Bill of Rights (Horne, n.d.; See Appendix E for Caregiver Bill of Rights) and



brainstorming ideas regarding extended family education and involvement (see Appendix F for summary of PowerPoint presentations that accompanied each of these educational modules).

*Experiential learning.* As first described by Kolb (1984), the learning cycle promotes a process of learning through critical self-reflection on experiences. To enhance caregivers' understanding of having difficulties communicating, a role-play/role-reversal activity was conducted in sessions three and four during which the caregivers were paired with each other and took turns acting out the role of a person with aphasia during a transactional communication activity (i.e., the caregiver "with aphasia" communicated a message without speaking or writing). For example, one scenario read: "I need to buy a birthday present for my sister." The caregiver simulating a person with aphasia was instructed to only use the word "wash" for all nouns and verbs to communicate the message.

*Reflective observation.* The next phase of the program addressed reflective observation of communication strategies used by the caregivers. From the transactional communication exercise, the group identified behaviors of caregivers that facilitated communication (e.g., encouraging the PWA, rephrasing the PWA's responses) or hindered communication (e.g., used a rapid speaking rate, abruptly changed topics). An explanation of why these behaviors help or hinder communication and the rationale for use of specific strategies was provided relative to the nature of aphasia in general and the skills of each person with aphasia specifically (Purdy & Hindenlang, 2005).

*Abstract conceptualization.* During this final stage, caregivers discussed communication successes and breakdowns that occurred at home during the previous week with their loved ones. Together they considered the facilitative strategies used, differentiated which transactions and interactions were successful and unsuccessful, and provided suggestions to one another regarding

strategies that may have better suited each exchange. Self-evaluating communicative strategies was intended to help monitor the caregivers' future interactions with their loved ones with aphasia, leading to continued learning and generalization of skills.

### **Phenomenological Approach**

A phenomenological approach to this study allowed for empathic exploration of the experiences of the caregivers who participated in the caregiver education group (Creswell, 2007; Wertz, 2005). Phenomenological research seeks to understand the intimate human experience that is captured and consolidated in the mind (Wertz, 2005), a phenomenon beyond the scope of natural scientific methods which collects only observable data. Phenomenological researchers co-construct reality with the participant, shaped by qualities within the individual person, by conducting extended interviews (Creswell, 2007).

By interviewing the participants, the researcher accessed the participants' reflective processes, thereby knowing their experience more accurately than if she were to observe the participants going through the phenomenon. The researcher's goal was to portray the "essence" of the participants' experience (Moustakas, 1994). The essence of an experience is comprised of both objective and subjective realities, including thoughts, perceptions, memories, judgments, and feelings. The researcher's "commitment to copresence" created a reciprocal understanding of the participants' experiences (Moustakas, 1994, p. 57).

The phenomenological method required the researcher to portray the essence of an experience after making efforts to set aside biases to meet the participant in a place of mutual understanding (Wertz, 2005). Within the interview setting, the researcher and participant co-created reality based on the participant's experience. The researcher then strived to accurately depict this reality through a rich and textural conceptualization of the experience. In this way, the

essence of the phenomenon came from a mutually created reality, and yet the depiction was derived from the researcher's perspective. Because of this unavoidable bias, feedback from the participant, in the form of a member check was requested after themes were developed from the interview transcripts to develop trustworthiness.

This study followed Moustakas' four-stage framework of phenomenological research. The four stages of phenomenological research are: 1) epoche, 2) phenomenological reduction, 3) imaginative variation, and 4) synthesis.

*Epoche.* Epoche is a Greek term, meaning "to abstain from." This is a process of bracketing bias and setting it aside. The researcher strived to eliminate bias and receive information that was understood and unfiltered through a previous set of expectations or stereotypes (Wertz, 2005) by reviewing transcripts multiple times to catch possible preconceptions that would influence the outcome data. Implementing inquiry auditing in which a researcher not involved in the research process examined the data collection and analysis processes also provided a means to minimize bias. Epoche is acknowledged as an ideal state that is not achieved, but a continued process for ameliorating bias.

*Phenomenological reduction.* This second stage of the process entails ridding distractions from previous knowledge and fully attending to the participant to receive a textured and detailed view of the phenomenon. The researcher encouraged each participant to reflect upon their group treatment experience in detail to extract layers of meaning and to experience the phenomenon fully. Semi-structured interviews allowed the researcher to deviate from delineated interview questions by pursuing relevant avenues introduced by the caregiver.

*Imaginative variation.* This next stage occurs after data collection during the analysis process. It requires intuition and reflection on the part of the researcher to establish themes or

underlying meanings from the collected textured information. The researcher explored multiple and conflicting perspectives between caregivers, which required reading, re-reading, and coding interviews.

*Synthesis.* For this final stage, the researcher took material after the data analysis and synthesized it through “textural and structural descriptions” (Moustakas, 1994, p. 100) to fully depict the phenomenon of the participant. This process illustrates the essence of the phenomenon, recreating the participants’ realities through rich, detailed descriptions.

### **Data Collection**

Prior to and following the four weeks of caregiver education group intervention, caregivers participated in a semi-structured interview. Written questions served as a guideline to help structure the interview, and the researcher ultimately responded to the direction of the participant. This entailed further questioning not previously indicated on the protocol and skipping questions that may have been answered in an earlier response.

Pre-treatment interviews for the caregiver education group included the following questions: (1) What are your most pressing issues related to aphasia as a caregiver?; and (2) What do you hope to gain from the caregiver education group? Data obtained from the pre-treatment interviews was used to guide the intervention.

Post-treatment interviews for the caregiver education group included the following four questions: (1) What are your most pressing issues related to aphasia as a caregiver?; (2) Tell me about your experience in the caregiver education group; (3) What did you gain from being a part of the caregiver education group?; and (4) What might you change about your experience in the caregiver education group? The first question was excluded from analysis as it did not contribute to understanding the caregivers’ experience in the education group. Interviews were videotaped

and subsequently transcribed by naïve reviewers who were uninvolved in the data collection process.

### **Data Analysis**

Qualitative data were organized for analysis using QSR International's NVivo 11 qualitative data analysis software (2015). NVivo's capabilities to code text-based data and analyze trends, themes, and patterns between data points supported this study's research goals and its approach to data analysis. NVivo enabled the researcher to examine coded segments of the data in context to explore coded passages without separating them from the interview transcripts. This software efficiently automated data management and analysis tasks.

The researcher first imported the eight participants' post-treatment interview transcripts as Word documents to a new project created in NVivo. The interview data was methodically reviewed by the researcher. Each transcript was read through three times to gain familiarity with the content. Next, the transcripts were coded to gather relevant information about each interview. In doing so, the researcher aimed to identify themes from the raw data that were relevant to the caregivers' experiences of the treatment program. As the researcher explored the transcripts, she selected direct quotes from the participants and coded them in storage containers called nodes. Nodes represent themes, topics, concepts, ideas, opinions, or experiences ("NVivo 11 Starter for Windows," 2017). Nodes established the "core themes of the experience" (Moustakas, 1994, p. 121). As part of the analytical process, the nodes were organized into a hierarchy to draw connections between themes. The researcher added sub-nodes under existing nodes to create a hierarchy. Upon opening a node, the researcher could view all the references to reflect on the data, compare attitudes, and discover patterns.

Throughout data analysis, the researcher added annotations to selected content, linked memos to sources or nodes, and added “see also” links to reflect on the data and establish themes or underlying meanings from the interviews. For example, the researcher often self-reflected on her justification of the structure of particular nodes. In doing so, the researcher adhered to the imaginative variation stage of phenomenological research which requires reflection on the part of the researcher to establish themes or underlying meanings from the collected textured information by exploring the participants’ multiple and conflicting perspectives.

Themes were identified using phenomenological methodology and NVivo Qualitative Software. These chosen themes were compared to the interview transcript to validate that they were relevant to the experiences in the transcript. If a theme was not relevant to the experience of participating in a caregiver education group, it was removed. The inquiry auditor was involved in this process of determining relevancy. These themes were shared with caregivers during a member check during which the caregivers confirmed meaning from the themes derived from the data analysis. The researcher requested feedback regarding these conclusions, checking for accuracy and completion of responses. The caregivers also had the opportunity to share thoughts or criticisms about the treatment, data collection, and analysis processes.

Finally, the researcher provided a thick description (i.e., detailed quotes from the interviews and analysis of the shared experiences) of the experience of participating in a caregiver education program. This was synthesized into a narrative description of the phenomenon to portray the essence of the experience.

### **Trustworthiness**

Trustworthiness is a quality that is integral to determine the worth of qualitative research (Carter, Bryant-Lukosius, DiCenso, Blythe, Neville, 2014). To establish trustworthiness, the

researcher implemented triangulation, inquiry auditing, a member check, and rich and thick description.

Triangulation is a method used by qualitative researchers to check and establish validity in their studies by analyzing a research question from multiple perspectives to determine consistent results across data sources or approaches (Carter et al., 2014). Incorporating this method of confirmability allowed for identification of frequently occurring experiences from multiple people, triangulating important aspects. The triangulation process included considering inconsistencies in coding and understanding differences in meanings.

Inquiry auditing included a researcher not involved in the research process examining both the process and product of the developed themes. This researcher evaluated whether or not the findings, interpretations, and conclusions were supported by the data. Important feedback provided by the caregivers led to additional data gathering and the development of more accurate findings. The inquiry auditor for this study was Dr. Catherine Off who mentored the author through this project.

Participants had the opportunity to redirect or corroborate the information that the researcher deemed to be important, clarify, and build on themes in the process of member checking. These member checks took place via teleconferencing during data analysis. After themes and subthemes were primarily developed from the raw data using NVivo, the researcher shared a graphical representation of the results with the caregivers and requested verification and expansion of themes during each member check. If a caregiver contradicted an idea depicted in a theme or subtheme, the researcher noted the direct quotation in Appendix A. In this way, the accuracy of each participant's experience was apparent in the outcome of the study. The narrative report contained rich, thick descriptions from caregivers from both post-treatment

interviews and member checks. A holistic synthesis with multiple perspectives provided a true sense of the caregiver education program experience.

### **Chapter Three: Results**

Caregivers described their experience of participating in a caregiver education group during post-treatment interviews. Themes that arose from these interviews involved both psychosocial and educational facets. Participants elaborated on three common themes in response to interview questions: (1) educational information gained throughout the four-week group treatment, (2) benefits of participating in a group program, and (3) considering the future following the caregiver education group. Interview questions guided the discussion and consequently the extracted themes, though oftentimes themes emerged through tangential lines of discussion. The results below describe the three main themes and subthemes that emerged from the following post-interview questions: (1) Tell me about your experience in the caregiver education group; (2) What did you gain from being a part of the caregiver education group?; and (3) What might you change about your experience in the caregiver education group? (see Figure 1). The three main themes included: (1) educational information gained, (2) benefits of a group model, and (3) considering the future.

#### **Educational Information Gained**

In exploring the caregiver's perspective of a caregiver education program, caregivers reported gaining valuable educational information throughout the four-week program. Seven subthemes were discussed that highlighted such gains. The opinion that there is *always more to learn* in regard to the latest evidence-based practice and sheer volume of information to learn about aphasia and its consequent communication challenges was an important subtheme. The



caregivers stated that medicine is always evolving and that one can never learn enough about aphasia (see Table A1).

A second subtheme was that caregivers appreciated learning communication tips to use with their loved ones with aphasia. Caregivers reported using the personalized cards, which provided ways to best communicate with a PWA to share with communication partners. The paired role-playing activity, which required one person to simulate a person with aphasia when given a scenario, was regarded as an “insightful” activity. Other terms used by caregivers to describe this activity were “hit home” and “valuable.” One caregiver mentioned that learning about communication tips enabled her to use those strategies in functional contexts such as writing down key words when eating out at a restaurant. The videos that provided a visual for communication tips being used by people with aphasia and their communication partners were also reportedly helpful for the caregivers.

Next, the caregivers noted that information gained in the caregiver education group was useful for teaching others about aphasia and communicating effectively with someone who has aphasia. This included disseminating weekly handouts, sharing videos, and distributing the resource handout containing recommendations of books, websites, and videos to reference. The resource handout was described as “helpful,” “convenient,” and “up-to-date.” Many caregivers shared that the information gained in the education group was a repetition of what they had learned from doing their own research and that the information was a great reinforcement of what they were already doing to help their loved ones communicate effectively.

Another subtheme was that most caregivers found the second week’s content to be the most informative of all the weekly sessions. As a whole, caregivers enjoyed learning about concomitant deficits of aphasia such as apraxia of speech, the ten principles of neuroplasticity,

and examining infographics provided of the neuroanatomy and physiology affected by a left-hemisphere stroke. Finally, caregivers appreciated the evidence-based aphasia intervention practices provided during the caregiver education group. One caregiver noted that good quality research with cited references provided credibility to the weekly lessons.

### **Benefits of a Group Model**

The caregivers reported that they experienced many benefits of participating in a group model. They used terms such as “hint-sharing,” “building relationships,” “closeness,” “support,” and “comradery” to describe their program experience with other caregivers (see Table A2). Subthemes to support the theme of benefits of a group model included: *psychosocial and educational support, Q&A session, and co-teaching method.*

Several caregivers identified the benefits of participating in a group model in terms of the psychosocial and educational support it provides. Caregivers relayed information about the sharing that often occurred between group members. Many spoke of the close-knit relationships that were built by bonding over the realities of day-to-day issues. One caregiver mentioned that she had recently found herself calling fellow caregivers for support. Another caregiver reported that developing such intimate relationships with fellow caregivers in such a short period of time was “indescribable.”

The question and answer session at the end of each session was also identified as a benefit of participating in a group model. Caregivers stated that they learned the most during this time because their specific needs were addressed. One participant reported that caregivers who had participated in the caregiver education group in previous years helped the new caregivers know what questions to ask during this time.

The third subtheme of the benefits of a group model, co-teaching method, was discussed by several caregivers. Some caregivers stated that they appreciated the dynamic of the different perspectives and expertise offered by the graduate student, supervisor, and caregivers at each weekly session. The context of the ICAP at the University of Montana is unique. The structure of this ICAP is developed minding the nature of training graduate student clinicians while simultaneously providing intervention for people with aphasia and their caregivers. This clinical model is also dynamic in that graduate students are learning to be clinicians from supervisors who are master clinicians in the area of aphasiology. One caregiver commented on the relaxed, informal feel of the group which encouraged participation from all members. Another caregiver valued the opportunity to co-create the program as the graduate student asked for input regarding the next week's content at the end of each session.

### **Considering the Future**

Caregivers discussed many topics that were categorized under the broad theme of "considering the future" (see Table A3). One subtheme was *not applicable information*. Two caregivers reported that the role-playing activity was not beneficial because they already knew how frustrating it is to have aphasia without having to simulate having aphasia. A few caregivers of people with non-fluent aphasia mentioned that information relevant to caregivers of people with fluent aphasia was not pertinent. Most caregivers, however, felt that all information presented in the program was useful. One caregiver remarked that it was good to see a variety of issues that other caregivers may be experiencing because "it's all the same boat."

Another subtheme described recommended changes to the program. Most caregivers talked about extending the hour-long sessions by fifteen to thirty minutes; however, a couple of caregivers warned against longer sessions for reasons such as taking away time from watching

their loved one in therapy and “jamming in too much information at once.” Some caregivers suggested to make the font size larger on the weekly handouts to make them easier to read. Two caregivers recommended spending more time on discussing tips for communication breakdowns that occur in common situations (e.g., ordering food at a restaurant). One caregiver suggested implementing a round-table discussion on the first day to provide caregivers an opportunity to share their stories of how they came to be a caregiver of a loved one with aphasia.

A third subtheme related to caregiver needs at different times along the care continuum for their loved ones. During her post-treatment interview, one caregiver reported that some of the information presented in the caregiver education group was repetition from healthcare providers soon after her sister’s stroke; however, she processed more information during the BSAP ICAP because “the shock was long gone.” During member checks, several caregivers supported this idea. They described their emotional state for the first few months after their loved one’s stroke and how technical information would have been too overwhelming at first in the hectic atmosphere of the hospital. On the contrary, one caregiver reported that she did most of her research right after her husband’s stroke. At the time of BSAP (i.e., a year and a half after her husband’s stroke), she felt less urgency in gaining new information because her family had settled into a routine that worked for them.

Several caregivers remarked that components of the caregiver education program stimulated thoughts about their loved ones’ language recovery progress. One caregiver explained that after watching videos in the group, she felt uncertain yet hopeful that her husband would regain his ability to verbally communicate in the future. Many caregivers referred to the lifelong nature of aphasia; one caregiver analogized it to moving walkways at an airport, “You’re always moving forward.” Two caregivers talked about the possibilities of how much progress

their loved ones could make by comparing them to other participants in the BSAP ICAP. One caregiver also mentioned that after her time in the BSAP ICAP and the caregiver education group, she learned that her husband did not need to be verbal to be an effective communicator. While the caregivers talked specifically about the language recovery process, underlying their comments seemed to be an inspired hope for change.

Finally, the caregivers described their ability to reference handouts provided in the caregiver education group. One caregiver reported that annotating the handouts was helpful for future reference because “there [was] a lot going on during [those] weeks.” Another caregiver mentioned that although some of the information presented on the handouts may not have been applicable at that time, it would likely come in handy to reference in the future. Some caregivers noted during member checks (approximately nine months after group treatment) that they had referenced the handouts multiple times since the BSAP ICAP had ended.

#### **Chapter Four: Discussion**

Post-treatment interviews provided insight into what eight participants of a four-week caregiver education group targeting psychosocial and educational outcomes experienced during such a program. Common themes arose from the interviews including that participating in a caregiver education program led to learning valuable educational information throughout the four group sessions, that there were numerous benefits of participating in a group service delivery model, and that the caregivers considered future ideas and events following the caregiver education group.

Caregivers enrolled in this study remarked on their knowledge acquired regarding their understanding of stroke and its consequences. These findings are similar to past studies by Israel et al. (2008), Hinkley et al. (1995), and van den Heuvel et al. (2000) in which caregivers reported

increased confidence in [stroke rehabilitation] knowledge, increased use of active coping strategies, and increased well-being following participation in education and training programs. Many caregivers in the current study mentioned that the hands-on training of facilitative communication tips (e.g., the role- playing activity) was helpful in providing the opportunity to practice strategies in a supportive environment. This outcome is supported by previous research on an individualized patient education program conducted by Redman (2007). Redman found that implementing demonstration, visuals, and role-play into an education program improved communication, participant satisfaction, and improved overall quality of life. Most caregiver participants in the BSAP ICAP indicated that they had learned a number of new strategies and were beginning to incorporate them into functional contexts more often. This new skillset answers a need commonly read throughout the literature that caregivers experience problems with communicating with their loved one during social and leisure activities (McGurk & Kneebone, 2013). Many participants in the current study noted that much of the evidence-based resources shared throughout the program reinforced what they had already known prior to the group treatment. This information (i.e., weekly handouts, printed resources, videos) was readily shared with friends and families to educate them about aphasia and how best to communicate with a person with aphasia, according to the group members.

Current literature suggests that social isolation is commonly experienced by caregivers of those with an acquired communication disorder (Astrom et al., 1993; Gainotti, 1997; Hinckley & Packard, 2001). The group setting can be a powerful, supportive learning avenue for caregivers of people with aphasia. Similar to results of studies such as those by van den Heuvel et al. (2000) and Purdy and Hindenlang (2005), the supportive atmosphere of the BSAP ICAP caregiver education group fostered bonding to help cope with the consequences of aphasia, and provided a

means of psychosocial and educational support. Many caregivers reported the benefit of gaining valuable knowledge from fellow caregivers, the graduate student clinician, and the supervising clinician. A few caregivers noted being grateful for the opportunity to set the learning goals collaboratively with the graduate student clinician, an outcome mirrored in studies by Redman (2007) and Purdy & Hindenlang (2005).

Many subthemes arose during post-treatment interviews that revolved around a larger theme: “Considering the Future.” One subtheme involved caregivers discussing information in the program that was not applicable to them. Although the consensus was that all of the material discussed was valuable, some caregivers mentioned that the role-playing activity, intended to gain perspective of a person with aphasia as well as to practice facilitative communication techniques, was not relevant to them. One caregiver whose loved one had non-fluent aphasia commented that she did not find the technical information about fluent aphasia helpful. Popular recommended changes to the group treatment included making the weekly sessions longer to cover more information and offering the printed handouts with larger font or in electronic form to increase readability and for ease of future reference. Most caregivers felt that components of the programs (e.g., videos, speaking with fellow caregivers) evoked thoughts of their PWA’s continual progress (e.g., “Will my husband ever be verbal again?). Most caregivers supported the idea that education and training to be a facilitative communicator is an ongoing process. This is consistent with the Life Participation Approach to Aphasia (Chapey et al., 2001), which promotes that services be available to persons with aphasia and their caregivers through the care continuum. One caregiver expressed that the needs of a caregiver change over time. According to Avent et al.’s (2005) research, this may be related to a particular stage of acceptance at which the caregiver is currently functioning. Another caregiver supported this idea by saying that

information about stroke, aphasia, strategies, and resources was likely provided in the hospital setting, yet she was not at a stage that was conducive to receiving and processing the information. As she moved toward acceptance of the stroke's effects, she was prepared to absorb and apply information that was provided by healthcare professionals. Studies such as those conducted by Lutz, Young, Cox, Martz, and Creasy (2011) and Palmer, Glass, Palmer, Loo, and Wegener (2004) also provide evidence to support the claim that when individuals are faced with crisis situations, their capacity to assimilate new information and make decisions is compromised.

The predominantly positive experience conveyed by participants of the caregiver education group reflects the positive outcomes for caregivers. Considering the growing number of ICAPs worldwide, it is likely that the number of caregiver education and support programs will also increase. This study suggests that caregivers who participate in these upcoming programs may also improve their wellness and increase their knowledge of aphasia and how to best communicate with their loved one.

### **Clinical Implications**

Direct education and training of caregivers should be included as a part of the overall therapeutic process. To reap the psychosocial benefits supported by this study, these services should be delivered in a group model. Caregiver group treatment targeting education and psychosocial wellbeing have the potential to address the widespread reported need of emotional strain reduction, healthcare education, and peer support. As a result of group caregiver treatment, caregivers may have a more positive outlook, have more confidence, and feel better informed.

Organizations may want to examine how typical, non-intensive therapy settings can recreate specific factors from caregiver education programs embedded in ICAPs to help



caregivers acquire knowledge and skills to maximize quality care (Given & Given, 2008). For example, in addition to the predominant mode of working with caregivers of persons with aphasia which provides information only, future research and clinical practice should address training of facilitative communication strategies.

Caregiving can be particularly challenging for healthcare providers in rural communities. “The high incidence of chronic illness, the progressive loss of functional independence, and the increasing need for assistance make caregiving an exemplar of challenging family caregiving” (Talley et al., 2012, p. 28). Given the significant contributions families make to healthcare, rural clinicians, investigators, and policy makers must develop more effective, accessible ways of supporting families as the primary caregivers in rural communities (Talley et al., 2012).

### **Limitations**

Although this study unveiled promising results that corroborate the current literature base, there are limitations. First, the development of the phenomenological approach did not allow for implementation of bracketing bias before data analysis. Data collection and analysis was already in progress when Moustakas’ phenomenological approach was deemed appropriate for this interview data. Closer adherence to Moustakas’ framework would have allowed the researcher to engage in reflective writing about her experiences and expectations of the program before the education group commenced. The intended purpose of noting emotional responses to the process would be to build awareness to potential biases and therefore make it easier to set them aside.

Another bias may have arisen through caregivers not revealing their true feelings because they were interviewed by a graduate student researcher/clinician who had a perceived investment in the program. Being interviewed by a clinician who did not lead the weekly education group may have resulted in a less biased portrayal of the caregiver experience.

## **Future Directions**

The results of this study provided valuable preliminary information regarding the benefit of caregiver education programs; however, it also stimulated further questions. Now considering the caregiver perspective, future research may examine the efficacy of these education programs. Effective management of such programs may benefit from studies systematically examining components of these programs such as the number and length of sessions required to show meaningful, sustained changes (Purdy & Hindenlang, 2005).

Future research studies may consider more objective methods to decrease bias. Participants' characteristics (e.g., PWA's severity and/or type of aphasia, lapse of time post-stroke) may impact their perception of the group treatment. For instance, caregivers whose loved one experienced a stroke years (versus months) ago may not glean as much new information from the program as someone whose loved one recently acquired a communication disorder. Also, some caregivers whose loved one had fluent aphasia reported that some of the communication tips and educational content relevant to non-fluent aphasia was not applicable.

## **Conclusion**

This study described what eight caregivers perceive as important elements in the composition of caregiver education and training programs in the context of aphasia rehabilitation. Caregivers reported that a group treatment targeting education and wellness imparts both technical knowledge of aphasia, apraxia, neuroanatomy and physiology, and neuroplasticity in addition to applicable knowledge of facilitative communication techniques. They also reported numerous benefits of a group service delivery model, particularly the psychosocial and educational support provided by peer group members. Caregivers' future considerations inspired by the program included their loved ones' progress as well as caregiver

needs at different times along the care continuum. Further research should include systematic exploration of caregiver education programs to determine their efficacy. Future studies should also examine research methodologies that inherently decrease bias. Lastly, the influence of improved caregiver education and wellness on the rehabilitation outcomes of persons with aphasia should also be investigated.

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## Appendices

### Appendix A. Caregiver Comments

**Table A1. Theme 1: Educational Information Gained: Caregiver Comments**

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*1. Always more to learn*

- “I love the feeling of learning more every single time, [...]that there is always more to learn.”
- “We can never learn enough about this...ever. There’s always something.”
- “I’m sure that the information, just like any other part of medicine, is evolving and learning new stuff all the time.”
- “There is always something more coming out. You can never know it all.”
- “Even with my healthcare background, I’m always wanting to understand more.”

*2. Communication tips*

- “I liked one of the handouts; the one that had the steps to follow.”
- “The tips for communicating were really helpful.”
- “I like that little laminated card where it says, “I have aphasia.” You had a link on it. It’s helpful for communicating in public with friends or in restaurants.”
- “The little role playing exercise you did the one day really hit home for me because it starts to make this a whole lot more real in terms of having to see what it’s like to have aphasia.”
- “It reminds me of using those devices more, which I hadn’t done. I would say something and try to see if he understood it. If he’s frustrated, I would get something out of the fridge, you know. So, now I’m going to have to use the whiteboard of get a boogie board or try to write the word to see if that helps.”
- “Yeah, and maybe he could write. We could go to dinner and I could narrow it down to three things off the menu. You know, just reminding me, or even teaching me to do those sorts of things.”
- “You know, I liked the videos.”
- “The communication book and Boogie Board are most helpful for him.”
- “The role playing activity was valuable because there’s no way to replicate the feeling unless the other person is a caregiver.”
- “I’ve learned to narrow a menu down to three things I know he likes.”
- “I’m looking at putting together a binder to help him. Other people in his aphasia group use them.”
- “The laminated card is a good refresher. It reminds me what to tell people.”
- “The role playing was insightful.”
- “If something happens to him when I’m not standing by, [the laminated card] is good to have.”
- “It’s great to talk about these things, but more so to see other people and what works for them.”

- “[The role playing activity] made you think. You’re so involved that you don’t think of what you’re projecting and contributing to the conversation as a caregiver.”
- “The videos were good, but working in special education, I know it’s not realistic to carry around a communication book or iPad...particularly for those with mobility issues.”
- “I liked the advice to be patient, talk slowly, and write things down.”

### 3. *Educating others*

- “Now I have more knowledge about everything and I’ll have some information to give to others. You know, go to this YouTube, y’all got to learn [...], or I want to say I’ve been to a school and let me tell you what I learned, and I really encourage you to learn about my wife. Read this, or look at this for two minutes.”
- “I’ll be able to tell more people now.”
- “I may print out business cards that say that my wife had a stroke and has aphasia. I like that statement about how aphasia has nothing to do with intelligence, so say your words careful and slowly and give her a chance to respond. At least they are aware.”
- “We might still go places and I could say, “Hey, look, I just want to hand you that. Read that when you have a second. I think it would be helpful in case there are communication problems. They’ll understand. If she mispronounces a word, why, then if they know upfront, I think they are going to handle it a little different.”
- “I’m probably going to copy the notes and dispense them to people.”
- “I would like to share them [notes] with my sister.”
- “I don’t have other people to educate.”
- “I shared the shorter video with family.”
- “Everyone we interact with on a daily basis has received some communication tips.”
- “When family or friends come over, I’ll give them some tips that work best.”
- “I gave some handouts to a local attorney who recently had a stroke.”
- “I gave a copy of the handouts to her therapist. He doesn’t know a lot about aphasia. He works in a high school.”

### 4. *Resources handout*

- “It helps to learn a few of the things that may help; some websites, books, visuals.”
- “The different resources are great, even though I haven’t had a chance to look them up yet.”
- “I think you did a good job in having the resources there. I mean, people have to be proactive, and research, and look at it on their own. “
- “I appreciate [the researcher’s] effort in putting all the resources together in one convenient spot to reference.”

- “We’d been given a similar resource handout in a previous BSAP, but this one is up-to-date.”

#### 5. *Verifying knowledge*

- “Some of it was repetition of what I had read and learned earlier, but if nothing else, verification that I’ve done some research and gotten some of it right.”
- “With the aphasia part, I kind of knew because it had been two years out [the stroke], so I feel like I knew about his aphasia.”
- “That was good to hear, the reinforcement. You know, we’ve had different therapists so, there was one speech path that said we don’t have to worry about her progress in one year or what she has in two years because in speech[...] There was an older lady, so I’m not sure what continuing education she’d had, but she said, “Oh no, 10, 20 years down the line you can still improve in speech.” As long as the brain is still there you can just keep improving. So it was good to hear that again.”
- “I got a lot of things that reinforced what I was already doing.”
- “When you hear it from someone else, it embeds the information more.”
- “It’s nice to get some professional judgement.”

#### 6. *Week #2 content*

- “I love information about aphasia. I know the general stuff I’ve been able to read. I liked learning about the different types of other speech problems and the way they interact.”
- “Being aware of some of the other characteristics. I didn’t know there was verbal apraxia.”
- “I didn’t know so much about the other types of aphasia and names for them. Paraphasias and I guess it’s anomia.”
- “Stepping outside of your own bubble of your specific loved one’s issues and seeing all the other aspects that you probably didn’t know. When I read things...eh, that doesn’t apply to him, you know? You of course look for things that are relevant to you but it’s interesting to see. Maybe not so much a personal gain as an intellectual gain.”
- “Well, first I liked understanding what aphasia is.”
- “I look to this group as, “I’m going to walk in that room and come out of there either with a better understanding of something related to aphasia or some aspect related to aphasia that I didn’t know something about.”
- “I loved hearing that neuroplasticity part.”
- “I think week two was my favorite.”
- “I enjoyed the more technical information, especially the one where we actually looked at the parts of the brain.”
- “I was most amazed when you went through aphasia and all these little groups. I could see why [the loved one] does the things that he does.”
- “The apraxia stuff was really enlightening.”

- “When it comes to the scientific stuff, you have to go to the knowledgeable people. You can always Google, but oftentimes it’s not in understandable language.”
- “I liked all the definitions...learning about dysarthria and all that.”
- “Learning about neuroplasticity gave me good hope.”
- “It was interesting to map out and see the pattern of the stroke on the brain images.”
- “Week two was very informative and helpful.”
- “My main takeaway from this group was that the brain is always changing and can always make progress.”
- “It’s good to give definitions and figure out what parts of the brain were affected by looking at the brain pictures.”

7. *Evidence-based practice*

- “When you Google this stuff, you get everything. We appreciate the good quality stuff.”
- “[The caregivers] appreciate that [the researcher] adheres to [evidence-based practice]. There was always research to back up what you were teaching, and you were transparent when there was no solid research to back up what you were saying.”

**Table A2. Theme 2: Benefits of a Group Model: Caregiver Comments**

1. *Psychosocial and educational support*

- “I like learning more about what other caregivers are going through; to see what similarities I have with them.”
- “The sharing...love it.”
- “I appreciate the handy hint-sharing that comes out between the caregivers.”
- “I would hear someone’s experience that will be an, “Ah, why didn’t I think of that?””.
- “As with any group, you expect to get to know everyone. That’s just part of this relationship that gets built between all these caregivers.”
- “Not only are we learning, but while you might present the same things year after year, the audience is different, the caregivers are different, so their input is different than previous years.”
- “Learning about the realities of day-to-day issues is indescribable.”
- “No one else knows as intimately...the closeness.”
- “The comradery was great. Having someone else in a similar situation. They know, “Oh, it’s so frustrating when...””.
- “I find myself calling people for support.”
- “It’s good to hear tidbits from everyone around you...what they did with this knowledge and how it applied.”
- “I’ve read so many articles, but so often it’s not applicable, every-day information that I can use. As a group, you can relate to others and share insights.”

- “We’re relying on others with the same experience to see what things can be done better. It’s theory versus practicality. “This worked, this didn’t work.”
  - “I knew after one week that if something happened, I had people to call for information and support.”
  - “It can be a lonely world as a caregiver. You can’t put a price on [the group’s support.]”
2. *Q&A session*
- “We jump in and that’s why you didn’t get your slides done. People need to jump in because that’s the way we are going to learn.”
  - “It’s a good time to ask your specific questions.”
  - “I learn the most during the Q&A.”
  - “The leftovers get answered. You’re addressing the different caregivers’ different needs.”
  - “The questions [the caregivers who had already participated in this group the previous year] came up with helped the new caregivers know what questions to ask.”
3. *Co-teaching method*
- “You were filling in gaps because everybody has a different role coming in. Of course the group does, too.”
  - “It was wonderful because if [the graduate student researcher] didn’t know an answer, one of the supervisors did.”
  - “It was our opportunity to say, “This is something that we haven’t discussed, but I really need.”
  - “I liked having more than one person in charge. Everyone has different ways of learning, different perspectives,...etc.”
  - “I liked the informal, relaxed feel of the group. It was better than classroom-style. You made it comfortable for us to participate and contribute.”

**Table A3. Theme 3: Considering the Future: Caregiver Comments**

- 
1. *Not applicable information*
- “Other than the fluent aphasia information, it was all relevant.”
  - “I can’t think of anything that wasn’t applicable to me in that group.”
  - “I didn’t get as much out of the...when we had to interact and pretend to have aphasia...because I think everybody knows how frustrating it is.”
  - “Although the role playing was fun, it wasn’t as beneficial because I already know how frustrating it can be.”
  - “I was never getting something that I didn’t need to know.”
  - “It’s good to see all types of problems, even if their problems aren’t the same as yours. We’re all in the same boat.”
2. *Recommended changes*
- “Throw in an extra fifteen minutes. The question and answer tend to take up a lot of time.”

- “If there could be video examples more than just the one in the final week about someone working with a board, someone working with pictures...etc. It would be interesting to see some of the practical stuff because that’s what we all need to take away. After we leave here, what are we going to do differently to improve our communication with our loved one.”
- “I think all of the survivors might like those cards that you gave us about caregiver rights, but with their rights instead.”
- “Make it a little longer.”
- “I liked that round table we did last year on the first day where we all share our story. Everybody and the family knows it and the friends know it, but there is something purifying about getting it out again with people around the table. That way, each one of us knows each other more than we ever would have. It’s very important.”
- “I would like the handout print size to be bigger. There are some links in there that I might use, but I have to read it with a magnifying glass.”
- “With the timing, we often had to cut the Q&A short. There needs to be more time...like a half an hour...to allow for more Q&A.”
- “More time. An hour flies by. I would say at a minimum we need an hour and a half with this because I felt bad a couple of times when you had more material. We appreciate that, and of course we still have our handouts. You had more material than we had time to talk about. That’s an indicator to me that we either need to have more than one education session.”
- “I wish our handouts were bigger...had bigger pictures because it was really hard to see all the little teeny writing.”
- “I wish we’d had a little bit more time. If we would have had an hour and a half, maybe instead of an hour. I think an hour and a half is probably the limit, though. I think people don’t want to be away from their loved ones any longer.”
- “Longer hours. I’d rather have longer hours than it broken apart into two days because that gives you a chance to see more of what your loved one is doing and follow them a little more closely.”
- “I would like a packet of all the handouts given at the beginning of the program for less-organized people like me.”
- “I would like to practice some communication tips specific to certain situations. For example, we could brainstorm some problems encountered frequently as a group, and then discuss what supports could be used in those scenarios.”
- “I recommend not jamming in too much information into one session.”
- “I don’t recommend making the sessions longer. I like watching the techniques that the therapist is using. As caregivers, we’re always going to go on and on. It’s always going to seem like there is not enough time.”

### 3. *Needs at different times*

- “Some of this information you hear before, but you hear it right away. Well, now we’re in a much more relaxed state, and it’s more likely to soak in because we’re not in that shock anymore. The shock is long gone. Now we can process it.”



- “The first six months post-stroke were emotional. Aphasia was my last concern with all his other medical issues.”
- “I wanted to learn all this information at first. Now, after a year and a half, we’ve settled into a routine and I feel less urgency.”
- “The technical information would have been too much right away. You need the more practical, how-are-you-going-to-cope” first.”
- “Although you can learn at all times, you can only absorb so much.”
- “It’s a different atmosphere than the hustle and bustle of the hospital. Here you can absorb more information.”

#### 4. PWA progress

- “As they make progress, that gives you something else to think about. “Okay, what’s the next step?””
- “That video got me to thinking about when he does get some of his speech back, is he going to have some of those other issues down the road. Something I never thought about. There’re so many parts to it. I think of the future and I don’t know if we’ll ever get to those points. I’m hoping that we move into the slightly medium levels where it opens up a whole new ball of yarn.”
- “That video was a good reminder that some people don’t progress to the speaking part.”
- “It makes you think about those sidewalks at airports...always moving forward. We will never step off that sidewalk.”
- “Looking ahead, I now know that you don’t need to be verbal to be an effective communicator.”
- “As a caregiver, you’re always thinking, “Is this as good as it’s going to get?”. It’s important to accept that this is how it is and to support her as best I can.”
- “In a group, you look at the other [PWAs] and compare them to your loved one. It makes you think of all the possibilities.”

#### 5. Referencing handouts

- “You gave me a handout that I could take notes on or I could refer back to. It’s a lot. I mean, there’s just so much going on during these weeks.”
- “Maybe something didn’t necessarily apply to me that day on that topic, but it might later. I have those [handouts] to go back to and say, “Oh yeah, I think we talked about that.”
- “I will go over the notes again.”
- “You gave the written handouts so we can go back and reference it.”
- “I have referenced [the handouts] several times so far.”

\*Comments extracted from participants’ member checks

**Table 2. Potential Observed Behaviors in Caregivers During Transactional Communication Samples**

Verification	<p><i>Positive</i></p> <ul style="list-style-type: none"><li>• Repeated and/or rephrased PWA’s responses</li><li>• Combined gesture or writing with verbal repetitions</li><li>• Provided written summary using key words</li></ul> <p><i>Negative</i></p> <ul style="list-style-type: none"><li>• Ignored inconsistent yes/no responses</li><li>• Abruptly dropped topic if not understood</li></ul>
Ensures comprehension	<p><i>Positive</i></p> <ul style="list-style-type: none"><li>• Combined modalities</li><li>• Provided written yes/no choices</li><li>• Slowed rate of speech</li><li>• Paced questions</li><li>• Got PWA’s attention</li></ul> <p><i>Negative</i></p> <ul style="list-style-type: none"><li>• Rapid firing of questions</li><li>• No techniques used</li><li>• Changed topic quickly</li></ul>
Facilitates response	<p><i>Positive</i></p> <ul style="list-style-type: none"><li>• Referred to communication book</li><li>• Asked questions while pointing to picture in communication book</li><li>• Presented written “wh” questions</li><li>• Provided written choices</li><li>• Provided cues to: expand utterance, slow down, use gestures, write response</li></ul> <p><i>Negative</i></p> <ul style="list-style-type: none"><li>• Did not allow time to formulate response</li><li>• Insisted PWA “say” response</li></ul>

(Purdy & Hindenlang, 2005)

## Appendix B. Weekly Probes

### Big Sky Aphasia Program Caregiver Education Group Weekly Probes

*Instructions: Please think about this week's Caregiver Education Group when you are answering the following questions. Circle your rating for each question. Please feel free to comment or provide feedback.*

1. How useful was the **Instruction/Lecture** component of the Caregiver Education Group?

1	2	3	4	5
Not Useful At All	Somewhat Useful	Moderately Useful	Mostly Useful	Very Useful

**Comments:**

2. How useful was the **Hands-On Activity** component of the Caregiver Education Group?

1	2	3	4	5
Not Useful At All	Somewhat Useful	Moderately Useful	Mostly Useful	Very Useful

**Comments:**

3. How useful was the **Demonstration** component of the Caregiver Education Group?

1	2	3	4	5
Not Useful At All	Somewhat Useful	Moderately Useful	Mostly Useful	Very Useful

**Comments:**

4. How useful was the open **Question and Answer** component of the Caregiver Education Group?

1	2	3	4	5
Not Useful At All	Somewhat Useful	Moderately Useful	Mostly Useful	Very Useful

**Comments:**

5. How useful were OTHER (please describe) components of the Caregiver Education Group?

1	2	3	4	5
Not Useful At All	Somewhat Useful	Moderately Useful	Mostly Useful	Very Useful

**Describe Component:**

**Comments:**

6. How successful is **daily communication** with the person with aphasia (PWA)?

1	2	3	4	5
Not Successful At All	Somewhat Successful	Moderately Successful	Mostly Successful	Always Successful

**Comments:**

7. How often do you have **communication breakdowns** each day with the PWA?

1	2	3	4	5
Less than 5 times per day	5-10 times per day	10-15 times per day	15-20 times per day	Greater than 20 times per day

**Comments:**

8. How knowledgeable do you currently feel about **aphasia**?

1	2	3	4	5
I feel like I know nothing	I feel like I know a little	I feel like I am moderately knowledgeable	I feel mostly knowledgeable	I feel confident about this topic

**Comments:**

9. How knowledgeable do you currently feel about **stroke** and **stroke rehabilitation/recovery**?

1	2	3	4	5
I feel like I know nothing	I feel like I know a little	I feel like I am moderately knowledgeable	I feel mostly knowledgeable	I feel confident about this topic

**Comments:**

10. How knowledgeable do your currently feel about **other symptoms of stroke** that relate to communication (e.g., apraxia of speech, cognitive impairments, etc.)?

1	2	3	4	5
I feel like I know nothing	I feel like I know a little	I feel like I am moderately knowledgeable	I feel mostly knowledgeable	I feel confident about this topic

**Comments:**

11. Please comment here about any other ideas or feedback you may have about the caregiver education group.

### **Appendix C. Transactional Communication Scenario Prompts**

1. Your grandson's birthday is coming up and you want to go to the store to buy a toy train set.
2. You need to schedule an appointment to get an oil change and to put on your snow tires next week.
3. You want to buy a new vacuum cleaner that you saw on sale at Target.
4. You want to invite your friends over for dinner and a game of cards on Friday.

(Purdy & Hindenlang, 2005)

## Appendix D. IRB #116-14 UM



### Department of Communicative Sciences and Disorders SUBJECT INFORMATION AND INFORMED CONSENT Caregivers

Title: The Big Sky Aphasia Program: Patient and Student Training Outcomes

Investigators	Title	Role	Department	Phone	Email
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#### RESEARCHER'S STATEMENT

We are asking you to be in a research study. The purpose of this consent form is to give you the information you will need to help you decide whether to be in the study or not. Please read the form carefully. You may ask questions about the purpose of the research, what we would ask you to do, the possible risks and benefits, your rights as a volunteer, and anything else about the research or this form that is not clear. When we have answered all of your questions, you can decide if you want to be in the study or not. This process is called "informed consent". We will give you a copy of this form for your records.

#### PURPOSE OF STUDY

We want to learn about people who have speech, language, and/or cognitive-communication problems because of having a stroke or traumatic brain injury. Many stroke or traumatic brain injury survivors have speech and/or language difficulties that reduce their ability to communicate during their daily activities. Speech-language pathologists work with people with aphasia to help them with their communication.

The purpose of this study is to learn more about how stroke survivors respond to treatment in an intensive comprehensive aphasia program and to determine caregivers' satisfaction with the intensive comprehensive aphasia program. We are hopeful that this knowledge will help speech-language pathologists provide the optimal amount and quality of practice for people with speech and language impairments following a brain injury.

## PROCEDURES

We would like to ask your permission to use information you provide about your satisfaction with the BSAP ICAP. You will participate as a caregiver in the BSAP ICAP. You may attend as many or as few caregiver sessions or large group sessions as you wish over the course of the five week period. On the last day of services at the BSAP ICAP, you will have the opportunity to complete a satisfaction survey. This will be a paper and pen task and should take approximately 10-15 minutes to complete. One month later, a second survey will be emailed to you through a survey software platform such as SurveyMonkey. You will have the opportunity to provide further feedback about the BSAP ICAP at that time. Both surveys will ask you questions about the quality of the program and your satisfaction with the BSAP ICAP.

The BSAP ICAP will take place in Missoula, MT at the University of Montana RiteCare Speech, Language, and Hearing Clinic, located in Curry Health Center on the Lower Level.

## RISKS/DISCOMFORT

Some people become upset because some of the questions ask about difficult times you have had as a caregiver. You do not have to answer any questions you do not want to answer.

Participation in a research study involves a risk to your confidentiality. This means it is possible other people may find out that you are in a study. We will make every effort to protect your confidentiality. For example, we assign your data an identification code that bears no resemblance to your name or other identifying information. All data will be stored on secure servers at the University of Montana.

## BENEFITS

We hope the results of this study will lead to important changes in how we provide treatment for persons with communication disorders stemming from stroke and traumatic brain injury and their caregivers. Although we hope the findings from this study will benefit society, you may not directly benefit from taking part in the study.

## CONFIDENTIALITY

Your records will be kept private and will not be released without your consent except as required by law.

**Only the researchers and authorized authorities will have access to the files.**

Your identity will be kept confidential. If the data from this study are written in a scientific journal or scientific meeting, your name will not be used. The data will be stored in a locked file cabinet; digital data will be password-protected and stored in the researcher's office/lab on a computer work-station. Your signed consent form will be stored in a locked cabinet separate from the data.

## COMPENSATION FOR INJURY

Although we do not foresee any risk in taking part in this study, the following liability statement is required in all University of Montana consent forms.

In the event that you are injured as a result of this research you should individually seek appropriate medical treatment. If the injury is caused by the negligence of The University of Montana or any of its employees, you may be entitled to reimbursement or compensation pursuant to the Comprehensive

State Insurance Plan established by the Department of Administration under the authority of M.C.A., Title 2, Chapter 9. In the event of a claim for such injury, further information may be obtained from the University's Risk Manager or Office of Legal Counsel. (Reviewed by University Legal Counsel, March 23, 2012).

### **VOLUNTARY PARTICIPATION/WITHDRAWAL**

Your decision to take part in this research study is entirely voluntary. You may refuse to take part in or you may withdraw from the study at any time without penalty or loss of benefits to which you are normally entitled. You may leave the study for any reason. You will be asked to leave the study for the following reasons:

- The study is terminated.

### **QUESTIONS**

You may wish to discuss this with others before you agree to participate in the study. If you have questions about the research now or during the study, contact: Catherine Off, (406) 243-2104. If you have any questions regarding your rights as a research subject, you may contact the Chair of the IRB through The University of Montana Research Office at 243-6672.

### **STATEMENT OF CONSENT**

I have read the above description of this research study, and this study has been explained to me. I have been informed of the risks and benefits involved. I have had a chance to ask questions; all my questions have been answered to my satisfaction. I have been assured that any future questions I may have will also be answered by a member of the research team. I volunteer to take part in this research. I understand I will receive a copy of this consent form.

\_\_\_\_\_  
Printed Name of Participant

\_\_\_\_\_  
Signature of Participant

\_\_\_\_\_  
Date



## Appendix E. Caregiver Bill of Rights

### A Caregiver's Bill of Rights

I have the right . . .

- To take care of myself. This is not an act of selfishness. It will give me the capacity of taking better care of my relative.
- To seek help from others even though my relative may object. I recognize the limits of my own endurance and strength.
- To maintain facets of my own life that do not include the person I care for, just as I would if he or she were healthy. I know that I do everything that I reasonably can for this person, and I have the right to do some things for myself.
- To get angry, be depressed and express other difficult feelings occasionally.
- To reject any attempt by my relative (either conscious or unconscious) to manipulate me through guilt, anger or depression.
- To receive consideration, affection, forgiveness and acceptance for what I do for my loved one for as long as I offer these qualities in return.
- To take pride in what I am accomplishing and to applaud the courage it has sometimes taken to meet the needs of my relative.
- To protect my individuality and my right to make a life for myself that will sustain me in the time when my relative no longer needs my full-time help.
- To expect and demand that as new strides are made in finding resources to aid physically and mentally impaired older persons in out country, similar strides will be made toward aiding and supporting caregivers.
- To \_\_\_\_\_ (Add you own statement of rights to this list. Read the list to yourself every day.)

— Jo Horne, author of *CareGiving: Helping an Aging Loved One*

## **Appendix F. Summary of PowerPoint Presentations that Accompanied Educational Modules**

### *Week 1*

Introductions  
Daily Overview: Caregiver Education Groups  
What to Expect  
Goals/Insights/Questions

### *Week 2*

Prevalence & Incidence of Stroke  
Speech & Language Regions of the Brain (visual provided)  
What is Aphasia?  
How is Aphasia Classified?  
Summary of Aphasia Types  
Paraphasias  
Anomia  
Alexia & Agraphia  
Apraxia  
Dysarthria  
Neuroplasticity  
10 Principles of Neuroplasticity

### *Week 3*

Aphasia Simulation Activity  
Simple Techniques to Improve Communication  
Create an “Enriched Communicative Environment”  
Get Involved in the Community  
Tips for Communicating in Social Settings  
Videos: Supporting Successful Conversation  
Tips to Support Conversation

### *Week 4*

Videos: Supporting Successful Conversation  
Aphasia Simulation Activity: Part 2  
Caregiver Bill of Rights  
Involving and Educating Family & Friends  
Evidence-Based Practice Resources

Figure 1.

