

# Interprofessional Caregiver Education, Training, and Wellness in the Context of a Cohort Model for Aphasia Rehabilitation

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Patient-centered care is extending the sphere of health care beyond the patient, focusing attention upon the family caregiver(s). In this context, patient-family relationships are at the center of consistent, well-developed interprofessional interventions that encompass caregiver education, training, and wellness. Cohort models of intervention include groups of patients who start and stop a program or intervention simultaneously. One such cohort-based service delivery model is an intensive comprehensive aphasia program (ICAP), which provides an ideal context in which to address holistic care for the person with aphasia and his or her family caregivers. The interprofessional family caregiver intervention program of the ICAP at the University of Montana is twofold: (1) speech-language pathologists and graduate student clinicians in speech-language pathology provide family caregiver education and resources, communication training, and psychosocial support and (2) a licensed professional counselor and counselor-in-training provide group counseling for family caregivers focusing on personal wellness, caregiving strategies, emotional health, and adaptation to significant life changes. The fusion of equitable interprofessional collaboration, along with the cohort model of the ICAP, allows for acquisition of knowledge, communication strategies, and coping skills along with the development of close, meaningful relationships with other caregivers and persons with aphasia. **Key words:** *aphasia, caregiver intervention, cohort model, counseling, intensive comprehensive aphasia program, interprofessional collaboration, psychosocial well-being*

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**P**ATIENT-CENTERED CARE and patient perspectives, including patient-reported outcomes, are extending the sphere of health care beyond the patient to include families and community systems, fostering commitments to innovative applications of the World Health Organization's model of International Classification of Functioning and Disability (WHO-ICF; Burns, Baylor, Dudgeon, Starks, & Yorkston, 2015; de Riesthal & Ross, 2015; Schifferdecker et al., 2018; WHO, 2001). In this context, attention to the family caregiver(s), patient-family relationships, and intervention supports beyond the traditional clinical setting come immediately into focus.

Treating the patient with parallel consideration for family caregiver education, training, and psychosocial support extends the treatment to the family and broader social networks that are critical to patient health. To ensure successful health care for both the patient and the patient–family caregiver unit, consistent, well-developed, interprofessional collaboration is essential. This interprofessional collaboration, with an emphasis on holistic care for the person with aphasia and their family caregiver(s), helps address impairment-based needs, as well as the activity limitations and participation restrictions that both members of the dyad (i.e., the person with aphasia and their family caregiver) experience. This article reviews the impact of aphasia on family caregivers and the advantages of treating family caregivers in a cohort model, and provides a description of an aphasia rehabilitation program that includes a focus on family caregiver education, training, and wellness within the context of an intensive comprehensive aphasia program (ICAP).

### **THE IMPACT OF APHASIA ON FAMILY CAREGIVERS**

Family caregiving for stroke survivors presents unique challenges and burdens. Family caregivers are those unpaid individuals such as spouses, partners, siblings, children, or friends, who assist the person with aphasia during activities of daily living and participation in life's roles (Han & Haley, 1999). Family caregivers function as extensions to formal services. These family caregivers often find themselves in the role of health care providers without the formal training or support that paid caregivers may have. Family caregivers may also not have routine access to health care systems either for the person with aphasia or for themselves (Ramkumar & Elliott, 2010), leading to both psychological and physical tolls on the caregiver. Both patients and health care providers have formed a critical reliance on family caregiver performance. Given these demands, family caregivers experience higher instances of depression, mar-

ital discord, family strife, social isolation, loneliness, medication use, higher levels of stress hormones, and lower level antibody responses (Vedhara, Shanks, Anderson, & Lightman, 2000; Vitaliano, Young, & Zhang, 2004).

Family caregivers of stroke survivors frequently experience third-party disability, which is defined as the disability experienced by others as a consequence of their family members' health condition (WHO, 2001). This third party disability experienced by family caregivers puts their psychological health at risk (Bookwala, Yee, & Schulz, 2000), increases their mortality rates (Schultz, Tompkins, & Rau, 1988), and prematurely ages their immune responses (Kiecolt-Glaser et al., 2003). Mental health factors of perceived stress, burden, and depression are prevalent in family caregivers (Ladner & Cuellar, 2002; Talley, McCorkle, & Baile, 2012) and health complications resulting from caregiver burden (e.g., chronic stress and depression) have high incidence and prevalence (Morthland & Scogin, 2011). The prevalence of depression among caregivers of stroke survivors is estimated to be 30% (Hackett, Yapa, Parag, & Anderson, 2005).

Caregiving for a stroke survivor with aphasia further worsens third party disability, relative to family caregivers of stroke survivors without aphasia (McGurk & Kneebone, 2013; Simmons-Mackie, 2018). Grawburg, Howe, Worrall, and Scarinci (2013) found that family members of persons with aphasia experience negative changes to their bodily functions (e.g., psychiatric disorders such as depression), as well as to the activity and participation components of the WHO-ICF (e.g., self-care, communication, and domestic life). According to Donelan, Falik, and DesRoches (2001), caregivers of persons with aphasia experience decreased quality of life compared to the general population, stemming from greater financial burden and declines in physical and mental health. Caregivers of stroke survivors with aphasia often experience (1) a change in the relationship with the person with aphasia; (2) a lower quality of life relative to caregivers of stroke survivors without

aphasia; (3) increased roles and responsibilities; (4) increased social isolation and loneliness; (5) increased depression; (6) increased negative physical health consequences; and (7) a lack of involvement in the rehabilitation process (Simmons-Mackie, 2018). Approximately 655,000 people in the United States survive a stroke each year (Mozzafarian et al., 2016) and approximately two million to four million stroke survivors in the United States are diagnosed with aphasia (Simmons-Mackie, 2018). Despite this high prevalence of disability, family caregivers are not consistently included as an essential element of rehabilitation for persons with aphasia. While family caregivers serve a critical function as extensions of the health care system, they inconsistently receive formal training or ongoing support. That is, translation of this research to widespread clinical settings has yet to be implemented.

Although the prevalence and incidence of complications related to caregiver burden are high, limited evidence suggests that caregiver intervention can lead to improved outcomes for the caregiving unit (Behar-Horenstein et al., 2005; Purdy & Hindenlang, 2005). For example, providing education and training can improve the communication between the caregiver and the person with aphasia, while also improving quality of life and psychosocial well-being for both members of the dyad (Simmons-Mackie, Raymer, Armstrong, Holland, & Cherney, 2010; Smith, Forster, & Young, 2004; Sorin-Peters, 2004). Despite evidence supporting the effectiveness of holistic treatment on quality-of-life outcomes for persons with aphasia, little research has been conducted to explore treatments that may benefit caregiver quality of life when caring for persons with aphasia.

Emerging evidence suggests that caregivers of persons with aphasia respond positively to education and wellness programs (Boles, 2011; Boles & Area, 2010; Boles & Lewis, 2003; Howe et al., 2012). Howe and colleagues (2012) found that caregiver education programs result in positive changes in dealing with the everyday communication prob-

lems and barriers that accompany aphasia and found that such education programs lower caregiver distress. The authors also found that education programs may even reduce the presence of depression in caregivers of persons with aphasia. Furthermore, caregivers have reported increased confidence in stroke rehabilitation knowledge and increased use of active coping strategies in the span of a 2-month education and training program (van den Heuvel, de Witte, Nooyen-Haazen, Sanderman, & Meyboom-de Jong, 2000). These findings corroborate previous studies, which showed a positive influence of active coping and knowledge on caregivers' well-being (Israel, Schulz, Parker, & 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. Finally, despite heightened prevalence of depression, isolation, and loneliness for caregivers with aphasia, no studies have examined the effectiveness of group counseling treatment to address such disorders. Though group counseling treatments have shown effectiveness when treating similar symptoms across other populations such as individuals with depression and dementia (e.g., McDermut, Miller, & Brown, 2001; Senanarong et al., 2004), a dearth of evidence remains when treating caregivers of persons with aphasia.

#### **ADVANTAGES OF TREATING FAMILY CAREGIVERS USING A COHORT MODEL**

Cohort models provide an ideal context for family caregiver interventions, as caregivers have the potential to understand and hold genuine compassion for one another, while empathizing and identifying with each other's circumstances and struggles. Cohorts are commonly defined as groups of individuals who are banded together, treated as a group, or who start and stop an experience at the same time. While evidence for cohort-based delivery of family caregiver intervention is scarce, research across health care domains

(e.g., cancer care) strongly indicates that group caregiver interventions positively impact caregiver well-being including improving caregiver knowledge, perceived competence, and quality of life (Pallier et al., 2015). Even brief group interventions that allow caregivers to share their experiences have the potential to reduce the isolation that stems from family caregiving (McGrath, 2000). Group training for caregivers of persons with aphasia that targets education, support, and improved communication skills has been found to be moderately successful in reducing caregiver stress and third party disability (Draper et al., 2007). Specifically, group service delivery models targeting domains such as stroke rehabilitation education have proved to be a powerful learning mechanism for family caregivers of persons with aphasia (Purdy & Hindenlang, 2005; Rayner & Marshall, 2003). Purdy and Hindenlang (2005) found that 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. Overall, this caregiver group intervention evidence base suggests that employing a cohort-based intervention will allow for rapport and empathic relationships to be built within the caregiver education and counseling groups. Furthermore, this cohort model of caregiver intervention has the potential to extend beyond the structured group setting by providing a foundation upon which caregivers can establish long-lasting, meaningful support and friendship networks.

Even for long-time family caregivers who are familiar with the effects and impact of aphasia, a group or cohort-based model of intervention serves to resettle a caregiver's knowledge base. Evidence shows that caregivers require multiple iterations of information to truly process and understand it (Avent et al., 2005; Purdy & Hindenlang, 2005). The group model can serve to remind caregivers of information they may have heard previ-

ously, while also giving them the opportunity to more deeply process and apply this knowledge to their current place in their rehabilitation journey. Furthermore, the cohort model provides the opportunity for more experienced family caregivers to take leadership and/or mentorship roles and to provide experience-based knowledge and support to newer group members. Finally, participation in a cohort model of caregiver intervention provides an opportunity for connection and group cohesion in the often-isolating and lonely roles of caregiving.

### **TREATING FAMILY CAREGIVERS IN THE CONTEXT OF INTENSIVE COMPREHENSIVE APHASIA PROGRAMS**

While considerable work needs to be done to continue to further specify the nature of “intensive treatment,” the emerging evidence base suggests that intensive aphasia treatment approaches can be more efficacious than the traditional standard of care (Brady, Kelly, Godwin, Enderby, & Campbell, 2016; Breitenstein et al., 2017). These intensive service delivery approaches are thought to capitalize on principles of neuroplasticity and to facilitate adaptive experience-dependent neuroplasticity and neuronal reorganization (Cramer et al., 2011; Kleim & Jones, 2008). Intensive comprehensive aphasia programs are an emerging intensive, holistic health care delivery model developed to improve communication impairments as well as psychosocial well-being for persons with aphasia and their family caregivers (Babbitt, Worrall, & Cherney, 2013, 2015; Rose, Cherney, & Worrall, 2013). ICAPs differ from traditional aphasia rehabilitation programs in that they target multiple speech, language, cognitive, and psychosocial domains through a variety of individualized, evidence-based treatment approaches using high treatment intensity and dosage. ICAPs operate within a prescribed time frame (e.g., 4 weeks) with a cohort of persons with aphasia and their family caregivers who enroll simultaneously (Rose et al., 2013), thus providing a sense of community and numerous opportunities to generalize trained skills

in natural, everyday social communication contexts.

Intensive Comprehensive Aphasia Programs provide a minimum of 3 hrs of therapy per day for 2 weeks, with some programs providing as many as 4–6 hrs per day over a period of 4–5 weeks (Rose et al., 2013). Daily therapy typically includes individual sessions, group sessions, technology-based therapy delivery, and community outings (Babbitt et al., 2015). Ideally, ICAPs also provide opportunities for caregiver intervention. This model of health care delivery is intended to treat all aspects of the WHO-ICF in a condensed period of time, with outcomes matching or exceeding those of traditional, weekly intervention that is implemented over a relatively long period of time (i.e., months). Initial efficacy studies of ICAPs indicate positive patient outcomes across a variety of impairment-based and psychosocial domains (e.g., Hoover & Carney, 2014; Persad, Wozniak, & Kostopoulos, 2013; Rodriguez et al., 2013; Wenke et al., 2014; Winans-Mitrik et al., 2014). No ICAP studies, to date, have reported about the inclusion of caregiver experiences, education, training, or psychosocial support.

The ICAP model also provides an optimal environment for formal, deliberate interprofessional collaboration, which ideally is extended to the patient-family caregiving unit. Thus far, ICAP researchers have described interprofessional collaboration including art and music therapy, recreational therapy, and physical therapy (Persad et al., 2013; Rodriguez et al., 2013). More recently, Hoover, Caplan, Waters, and Carney (2017) reviewed the extant ICAP literature through the lens of interprofessional collaboration and subsequently highlighted their prospective investigation of the ICAP at Boston University that includes collaboration with physical therapists, occupational therapists, and dieticians to work toward individualized patient participation goals (e.g., dining out independently). In their model, the team dedicated 5 hrs per week to group occupational therapy, 4.5 hrs per week to group physical therapy, and 5 hrs per week to group nutrition education, in addition to the 15.5 hrs of speech-

language therapy (i.e., 9.5 hrs of group treatment, 3 hrs of dyadic treatment, and 3 hrs of individual treatment) provided each week. The authors did not report upon interprofessional collaboration with a counselor or report upon caregiver intervention. While Hoover and colleagues did not align the relative contribution of each of these specialized interprofessional services to outcomes in their study, their overall results provide evidence of significantly improved linguistic, communicative, and quality-of-life outcomes in individuals with chronic aphasia who were treated in an interprofessional ICAP. In the context of an ICAP, these nonhierarchical, joint ventures have the potential to put the patient-caregiving unit at the heart of a highly focused and intensive experience that provides frequent access to numerous rehabilitation specialists.

Family caregivers of persons with aphasia should receive psychosocial support from experts in deliberate collaboration with speech-language pathologists. This interprofessional collaboration allows for health care professionals to have a shared goal with the patient's needs at the center (Yeager, 2005). To date, no ICAP researchers have described an interprofessional collaboration with a family counselor and no ICAP researchers have described a focus on interprofessional collaboration to treat family caregivers or the patient-family caregiving unit. Both synchronous (i.e., same time and space/place) and asynchronous collaborations with family counselors have the potential to offer caregivers the collaborative psychosocial support they need from both family counselors and speech-language pathologists while also allowing for privacy, confidentiality, and space in which they can share their most intimate feelings, struggles, hopes, and needs (DePompei & Williams, 1994).

#### **AN INTERPROFESSIONAL COHORT-BASED MODEL OF FAMILY CAREGIVING INTERVENTION**

The ICAP at the University of Montana, the Big Sky Aphasia Program ICAP (BSAP ICAP),

was initially implemented in the summer of 2011 and has continued to develop over the course of 7 years with interprofessional collaboration between speech–language pathologists, a family counselor, and physical therapists. The BSAP ICAP has clearly defined intensity parameters and patient and family caregiver perspectives. This ICAP implements comprehensive, evidence-based therapy to address multiple modalities using strategies, community experiences, and recreational opportunities individualized to each patient–family caregiver unit. A primary mission of the BSAP ICAP is to serve families in the Mountain West region and rural families who do not have regular, ongoing access to aphasia services, while providing training for graduate student clinicians in speech–language pathology and other health care professions (e.g., counselor education, physical therapy). Delivering the ICAP in the university clinic context allows us to keep program costs low to best serve families engaged in the rehabilitation process for a chronic condition like aphasia.

The participants of the BSAP ICAP include persons with aphasia and their family caregiver(s). To enroll in the BSAP ICAP, persons

with aphasia must be over the age of 18 years, medically stable, able to tolerate intensive therapy, and have minimal comorbid cognitive impairments (i.e., sufficient attention, memory, and executive function to engage in high-intensity therapies). No exclusions are made on the basis of aphasia type, severity, or time post-onset. Concomitant apraxia of speech is treated simultaneously with aphasia impairments. A maximum of eight and minimum of four families are enrolled in each ICAP session. The number of family caregivers per person with aphasia is not limited, but typically one to two family caregivers participate for the duration of the program. Optimally, we strive to have one consistent caregiver present for the duration of the ICAP; however, in some cases, multiple family caregivers will alternate care throughout the duration of the program to ease the time commitment for each. Family caregivers have included spouses, siblings, parents, and children of the persons with aphasia. Please refer to Table 1 for a brief description of the caregivers who have participated in these three ICAP sessions.

BSAP ICAP participants may apply for repeated ICAP experiences. While we do not

**Table 1.** ICAP caregiver participant descriptions

Caregiver ID	Age at ICAP, yr	Sex	Relationship to PWA	ICAP(s) Attended	Employment Status at the Time of ICAP
CARE-001	71, 72	F	Wife	2016, 2017	Retired
CARE-002	50	F	Wife	2016	Working F/T
CARE-003	59, 60	M	Husband	2016, 2017	Working F/T
CARE-004	71, 72, 73	F	Wife	2015, 2016, 2017	Retired
CARE-005	58, 59	F	Wife	2016, 2016	Retired
CARE-006	61	F	Sister	2016	Working F/T
CARE-007	53, 54	F	Daughter	2016, 2017	Working P/T
CARE-008	72, 73, 74	F	Wife	2015, 2016, 2017	Retired
CARE-009	56	F	Wife	2017	Retired career with P/T to F/T work for enjoyment
CARE-010	75	F	Wife	2017	Retired
CARE-011	76	M	Husband	2017	Working P/T

*Note.* F/T = full-time; P/T = part-time.

officially restrict the number of times a family may participate in the ICAP, our primary mission is to serve as many families in need as possible. Typically, we receive more applications than we have available spaces. These applications are reviewed prior to each ICAP session and decisions about enrollment into the program are based upon several factors including (1) current access to ongoing aphasia therapy and resources at home, (2) previous intensive aphasia therapy experience(s), (3) current rehabilitation needs, and (4) fit of persons with aphasia and their caregivers within the cohort model.

For the persons with aphasia, the ICAP includes pretreatment assessment (see Table 2), 4 weeks of treatment including daily individual, daily small conversation group (i.e., 2-3 individuals with aphasia and their clinicians), and weekly large group (i.e., entire cohort) treatment sessions, along with once weekly community outings. All assessment and treatment sessions are delivered by graduate student clinicians enrolled in the Department of Communicative Sciences and Disorders' Speech-Language Pathology program under direct supervision of certified and licensed speech-language pathologists. Treatment

**Table 2.** Big Sky Aphasia Program ICAP outcome measures for individuals with aphasia

Outcome Measure	Purpose
Western Aphasia Battery, Revised (WAB-R; Kertesz, 2006)	Impairment-based measure used to detect the presence/absence of aphasia, and to determine aphasia severity and classification
Boston Naming Test, second edition, standard form (BNT-2; Kaplan, Goodglass, & Weintraub, 2001)	Impairment-based measure used to assess verbal word retrieval through confrontation naming of black and white line drawings of decreasing word frequency
Screen for Language Rehabilitation (SLR; Milman, 2010)	Impairment-based screening tool used to assess spoken language across naming, sentence production, and discourse domains
Raven's Coloured Progressive Matrices (RCPM; Kertesz, 2006)	Impairment-based measure used to assess nonverbal problem solving
AphasiaBank Discourse Protocol (MacWhinney, 2000)	Impairment-based measure used to assess verbal discourse production across discourse genres (e.g., conversation, picture description, story retell)
Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986)	Impairment-based patient-reported outcome measure—15-item mood rating scale used to detect the presence of depression
Communicative Participation Item Bank (CPIB; Baylor et al., 2013)	Participation-based patient-reported outcome measure—10-item rating scale used to assess degree of communicative participation across communicative environments
Communicative Confidence Rating Scale for Aphasia (CCRSA; Cherney & Babbitt, 2011)	Participation-based patient-reported outcome measure—10-item rating scale used to assess communicative confidence across a variety of communicative environments
Assessment of Living with Aphasia (ALA; Kagan et al., 2010)	Participation-based patient-reported outcome measure used to assess aphasia-related quality of life across domains, including aphasia, participation, and environment
Communicative Effectiveness Index (CETI; Lomas et al., 1989)	Participation-based proxy self-report assessment of communicative participation (caregiver completes)

intensity parameters have varied across the ICAP sessions that took place over the past 4 years (see Table 3). Collaboration with the University of Montana's Physical Therapy Department and New Directions Wellness Center affords patients the opportunity to receive ongoing physical therapy, consultation appointments, low-cost daily access to a guided adaptive gymnasium, and/or no-charge loaned mobility supports (e.g., wheelchairs, walkers, canes) for the duration of the ICAP. Physical therapists also provide in-services and facilitate access to adaptive recreational equipment (e.g., adaptive bikes) for the ICAP participants as needed. No charge consultations with alternative and augmentative communication (AAC) experts are also arranged as needed. The ICAP culminates with post-treatment assessment (see Table 2) and a subsequent debriefing including an individualized discussion about progress, recommendations, a home program for continued rehabilitation, and referrals and resources.

The BSAP ICAP provides education, training, and psychosocial support for the family caregivers of the persons with aphasia. An essential component of this ICAP is a focus on the person with aphasia and family caregiving unit as a whole. All aspects of the program are individualized to the persons with aphasia and their family caregiver(s). The interprofessional team leaders (i.e., the certified and licensed speech-language patholo-

gists and the licensed family counselor) meet regularly (approximately once per month) for the 6–8 months preceding the ICAP to review scheduling details, develop content, and finalize all procedures for the upcoming ICAP. Once applicants have been enrolled into the ICAP, a brief case history of the participating families is discussed by the team leaders to brainstorm additional content. Once the ICAP begins, the interprofessional team leaders meet as needed to share information about the cohort and to develop, in real time, intervention procedures, activities, strategies, and materials to tailor support to each dyad. This ongoing, regular collaboration is essential to create cohesiveness across the various types of intervention sessions. Every effort is made to ensure that each dyad is treated as unique so that all interventions are personalized and meaningful, while also maintaining confidentiality and informed consent procedures between speech-language pathology and counseling treatment teams.

#### **A FOCUS ON FAMILY CAREGIVERS: ASSESSMENT AND INTERVENTION PROCEDURES**

Following consent and enrollment procedures, family caregivers complete a demographic questionnaire and pre- and post-intervention self-report assessments that focus on psychosocial well-being (see Table 4 for a complete list and brief description of

**Table 3.** Big Sky Aphasia Program ICAP intensity specifications

ICAP Session	Hours Per Day	Days Per Week	# of Weeks	Total Hours of Intervention	Treatment Intensity Ratio
Fall 2014	3	3	4	36	0.225
Summer 2015 <sup>a</sup>	4	4	4	64	0.40
Fall 2015	3	3	5	45	0.23
Summer 2016 <sup>a</sup>	4	4	4	64	0.40
Summer 2017 <sup>a</sup>	4.5	4	4	72	0.45

*Note.* Treatment intensity ratio = the number of total intervention hours per week divided by 40 hrs (the number of hours in a typical work week). From Babbitt et al. (2015).

<sup>a</sup>ICAP sessions that included the caregiver counseling component.



**Table 4.** Big Sky Aphasia Program ICAP outcome measures for family caregivers

Outcome Measure	Purpose
Bakas Caregiving Outcomes Scale (Bakas, Champion, Perkins, Farran, & Williams, 2006)	Self-report scale to measure life changes in family caregivers of stroke survivors
Perceived Stress Scale (Cohen, Kamarck, & Mermelstein, 1983)	Self-report scale to measure the degree to which one perceives life events as stressful
Family Crisis Oriented Personal Evaluation Scales (McCubbin, Larsen, & Olson, 1985)	Self-report scale that identifies the coping behaviors used by family in difficult situations
Beck Depression Inventory II (Beck, Steer, & Brown, 1996)	Self-report scale that detects symptoms of depression
Beck Hopelessness Scale (Beck & Steer, 1988)	Self-report scale that measures hopefulness and pessimism about the future
Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet, & Farley, 1988)	Self-report scale to determine the level (and source) of perceived social support
General Self-Efficacy Scale (Sherer et al., 1982)	Self-report scale to measure the degree of optimistic self-belief to accomplish difficult tasks and cope with adversity
Caregiver Reaction Scale (Given et al., 1992)	Self-report scale to measure one’s ability to understand difficulties faced in family caregiver roles

these measures). Caregivers also participate in individual, semi-structured interviews about their experience and process with the counseling group once the group has concluded. The interviews are transcribed and coded for qualitative analysis, and pre- and postself-report measures are scored and analyzed to inform the practice of future groups and research projects. A retrospective analysis of this data is currently under way, which will be reported in a separate paper.

The interprofessional family caregiver intervention program of the BSAP ICAP is twofold: (1) speech-language pathologists and graduate student clinicians in speech-language pathology provide family caregiver education and resources, communication training, and psychosocial support and; (2) a licensed professional counselor and counselor-in-training provide group counseling for family caregivers that focuses on personal wellness, caregiving strategies, emotional health, and adaptation to significant life changes. To date, three BSAP ICAP sessions (summer 2015, sum-

mer 2016, and summer 2017) have included this family caregiver group counseling intervention in conjunction with the family caregiver education group.

**THE SPEECH-LANGUAGE PATHOLOGIST: FAMILY CAREGIVER EDUCATION GROUP**

The family caregiver education group meets weekly for an hour and a half for the duration of the ICAP (for a total of five sessions and 7-8 hrs of intervention) to provide education and resources, communication training, and psychosocial support for the family caregivers. Caregiver education is conducted in a group setting to support peer learning and joint problem-solving opportunities (Purdy & Hindenlang, 2005). Each group session is coled by two graduate student clinicians in speech-language pathology and at least one licensed speech-language pathologist. The licensed professional counselor and counselor-in-training also attend these education sessions to build rapport and learn more details

about the experience of living with aphasia alongside the caregiver cohort. The licensed speech–language pathologists and graduate student clinicians meet daily to debrief and make adjustments to content as needed.

All caregivers are invited and strongly encouraged to attend the caregiver education group. We leave the caregiver opportunities optional for a variety of reasons: (1) some persons with aphasia are independent and do not enroll in the ICAP with a family caregiver, (2) some family caregivers do not have the ability to take time away from work and/or other responsibilities to attend caregiver sessions, (3) some persons with aphasia have multiple family caregivers and those caregivers do not feel comfortable “dropping in” intermittently for caregiver services, and (4) some family caregivers choose to use this time for self-care activities (e.g., grocery shopping, personal appointments, socialization with friends and family) to mitigate caregiver fatigue and burnout. Although attendance is not mandatory, the majority of caregivers have attended on a regular basis. The current ICAP literature base does not systematically report the nature of caregiver involvement; as such, a comparison of the BSAP ICAP caregiver programming to other ICAPs is currently outside the scope of this article.

The didactic content of this family caregiver education group varies depending on the needs of each family caregiver, but in general, topics include the following: the nature of aphasia and apraxia of speech, the nature of stroke, the stroke rehabilitation process and the nature of recovery, principles of neuroplasticity, communication strategies and tools, and resources. The educational program includes both didactic and experiential training methods (Kolb, 2014; Purdy & Hindenlang, 2005). General tenets of the caregiver education program have been established, but specific information and depth of information presented in each of the sessions are tailored to the needs of each cohort. The general content of each session is described below (see Table 5 for a summary of topics, materials, and activities for these

education sessions). At the closing of each educational session, caregivers are asked to complete a short open-ended questionnaire about the knowledge and skills they have been working on and feedback about knowledge and skills that they would like to target during the remaining sessions of the ICAP.

### **Education session 1**

During session 1, the group facilitators address the goals of the ICAP program and the goals that the family caregivers have for the duration of the ICAP. Participants are given a 40-page aphasia-friendly rehabilitation handbook that focuses on the nature of aphasia, the natural recovery process, treatment options, and local/national/global resources available for persons with aphasia and their family caregivers (Milman et al., 2014). This handbook is consistently referred to and explored throughout the education program (see Appendix A for a link to this resource and the table of contents).

### **Education session 2**

During session 2, group facilitators provide information regarding stroke, stroke recovery and rehabilitation, and neuroanatomy and neuroplasticity in relation to speech and language function, aphasia, and apraxia of speech. Participants are directed to the relevant sections of the aphasia handbook (see Appendix B for an example) and are given a variety of written and graphical materials to supplement their learning. Approximately 20–30 min of this session are dedicated to answering questions that caregivers may have about the specific nature of their loved one’s aphasia and apraxia of speech and the expected course of recovery and rehabilitation.

### **Education session 3**

During session 3, group facilitators address various compensatory strategies and supportive communication techniques, acknowledging the inherent competence of the person with aphasia and helping to reveal that competence (Kagan, 1995; Kagan, Black, Duchan, Simmons-Mackie, & Square, 2001). During

**Table 5.** ICAP caregiver education sessions

Session #	Topics Covered	Materials Provided	Demonstrations and Practice
1	Stroke stories; family caregiver goals	<i>Your Guide to Aphasia: Recovery, Treatment, &amp; Resources</i> PowerPoint notes	NA
2	The nature of stroke and aphasia and apraxia of speech, recovery and rehabilitation, neuroplasticity	PowerPoint notes Handout that differentiates aphasia symptoms from apraxia of speech symptoms Direct participants to relevant chapters of <i>Your Guide to Aphasia</i>	NA
3	Compensatory strategies, supportive communication techniques	PowerPoint notes	Live demonstration and video tutorial demonstrating strong vs. weak supportive communication techniques Practice strategies with each other Homework: review all materials and identify 2-3 personally relevant topics to be covered during the last session
4	Psychosocial well-being; planning for the future; individualized caregiver resources; additional topics of interest	<i>Caregiver Bill of Rights</i> PowerPoint notes	Demonstrate how aphasia guidebook can be used to access resources based on individual needs

this session, specific and individualized communication skills needed to improve daily communicative exchanges with the person with aphasia are discussed and practiced. Techniques for facilitating communication are demonstrated by the lead graduate student clinician, exemplified by videos, and embedded in didactic training. At the closing of this session, caregivers are asked to do homework in collaboration with their loved ones over the course of the week. They are asked to review materials from previous sessions, including the aphasia handbook, and to iden-

tify 2-3 personally relevant questions or needs that they would like to be covered during the final educational session. This homework is completed and turned in a few days prior to the last day of the ICAP.

**Education session 4**

During session 4, group facilitators target psychosocial aspects of caregiver well-being including a discussion of the Caregiver Bill of Rights (Horne, 1985) and extended family education and involvement. Caregivers are encouraged to share experiences and strategies

and to reflect upon their current knowledge, skills, and access to resources. Questions and/or concerns are fielded by the graduate student clinicians and team leaders.

### Wrap-up education session

On the last day of the ICAP, a final education session is provided that includes both the caregivers and the persons with aphasia. This final session focuses on individualized continuing education and resources that ICAP participants may need once the ICAP ends. During this last session, the graduate student clinicians summarize the specific questions and/or needs that the participants identified through their session three homework assignment. Clinicians then present a broad overview of resources that are available to participants once they leave the ICAP (e.g., published materials, national organizations, online resources, and tele-rehabilitation options). Clinicians then demonstrate how the aphasia handbook can be used to access information and/or resources specific to the participant-generated questions and/or needs that were summarized at the start of the session. At the end of the session, ICAP participants are asked to suggest topics that they would like to learn more about if they were

to have additional, future caregiver education opportunities. Figure 1 provides an example of one caregiver's experience with the Family Caregiver Education Group.

### THE LICENSED PROFESSIONAL COUNSELOR: FAMILY CAREGIVER COUNSELING GROUP

The family caregiver counseling group meets twice per week for hour-and-a-half sessions for the duration of the ICAP (for a total of 8 sessions and 12 hrs of treatment). The group is designed to serve approximately 8–10 members. As a process-oriented group, the focus is on the here-and-now experiences of group members. Counselors encourage relationships between caregivers while also building awareness of their needs, limitations, and strengths during new roles and phases of life after stroke (Gallagher & Hagen, 1996; Gan, Gargaro, Brandys, Gerber, & Boschen, 2010; Golden & Lund, 2009). The group takes place in a building separate from the ongoing intervention provided to the persons with aphasia, creating beneficial boundaries for space, privacy, and confidentiality. This separation of space provides an exclusive focus on the caregivers themselves. The group

An example of one family caregiver's experience in the Family Caregiver Education Group at the University of Montana's Intensive Comprehensive Aphasia Program (ICAP). Aliases are used to protect the privacy and confidentiality of our participants.

*During the summer 2017 ICAP, a family caregiver, "Sue\*," reluctantly joined the caregiver education group. Her husband, "Carl," is a 72-year-old male who presents with severe nonfluent aphasia and concomitant apraxia of speech. Sue's initial knowledge of aphasia was limited. For example, she reported that she did not understand why her husband was participating in group aphasia sessions, as he "couldn't talk." Both Sue and Carl experienced frequent communication breakdowns during the first days of the ICAP, resulting in observable frustration. Following participation in the 4 weeks of the caregiver education group, Sue reported that she felt significantly more knowledgeable about aphasia, and that she wanted to go home and educate other friends and family members about aphasia. During the ICAP, Sue effectively implemented several communication strategies, including using multiple language modalities, to better communicate with her husband.*

**Figure 1.** Vignette 1: Family caregiver education group.

is coled by a licensed professional counselor and a counselor-in-training. Speech-language pathology team members are deliberately not present to further promote privacy and confidentiality. Participation in the counseling group is voluntary and continuous attendance is encouraged. Since beginning the counseling group in 2016, every family caregiver attending the ICAP has been an active participant.

Counselors first focus on establishing initial cohesiveness around the homogeneity of caregiving for persons with aphasia. Themes of grief and loss, stressors of daily life, commitment to loved ones, roles as advocates, and tendencies to relegate personal needs and emotional responses are similarities drawn on to establish initial rapport. Joining on these universalities establishes relationships where group participants feel known and understood in the complexities of caring for persons with aphasia. Capitalizing on this cohesion and motivating group members to disclose differences is also necessary for authentic and meaningful group experiences. Coleaders emphasize the exploration of differences and help the group establish patterns of responsiveness in the context of diverse identities and experiences. Differences emerge in gender, age, familial role (i.e., spouse, child, sibling), degree of caregiving (i.e., how dependent the person with aphasia is on their caregiver), abilities of loved ones, health of the relationship with the person with aphasia, both before and after stroke, and access to resources and support. Drawing out these differences requires participants to risk disclosure and for group counselors to foster relationships in the context of differences. A focus on universality and unique personal experiences of members positions the group to both connect with one another and to be known; these two foci are critical for an authentic supportive experience. To achieve these goals, counselors enlist interventions and techniques that include (but are not limited to) the following: here-and-now process statements; linking members in content and affect; responding

to individual member's content and affect; drawing-out and cutting-off responses to hold, shift, or deepen the focus of the group; facilitating feedback loops; active listening; and scanning and verbalizing observations. In addition to the skills required to encourage disclosures and responsiveness between members, group leaders must also be attuned to opportunities for altruism, instillation of hope, corrective emotional experiences, and exchanges of helpful information and resources (Diefenbeck, Klemm, & Hayes, 2014; Jacobs, Masson, Harvill, & Schimmel, 2011; Yalom & Leszcz, 2008). The licensed professional counselor and counselor-in-training meet regularly for the duration of the ICAP to both hone skills and intentionally plan future interventions that maximize connection, growth, and learning. Figure 2 provides an example of one caregiver's experience in the Family Caregiver Counseling Group.

#### **ADDITIONAL ICAP-PROVIDED FAMILY CAREGIVER OPPORTUNITIES**

A number of other caregiver-centered opportunities are made available by the cohort-based nature of the ICAP including: (1) opening/closing group meetings; (2) lunch breaks; (3) weekly hosted lunches; (4) weekly community outings; and (5) an end of ICAP social. Collectively, these ICAP-provided caregiver experiences provide numerous opportunities for building relationships, increasing group cohesion, and encouraging social communication between all participants of the ICAP.

For each day of service, all participants attend opening and closing meetings. These short, 20–30 min, group meetings at the beginning and ending of each ICAP treatment day are led by the graduate student clinicians and speech-language pathologists to provide continuity across days and weeks of intervention. Topics include but are not limited to ice breaker activities, daily agendas, daily topics or themes, recaps, and weekly plans. All opening and closing meetings also provide the opportunity for participants to ask questions

An example of one family caregiver's experience in the Family Caregiver Counseling Group at University of Montana's Intensive Comprehensive Aphasia Program (ICAP). Aliases are used to protect the privacy and confidentiality of our participants.

*"Stacey" attended the first ICAP caregiver counseling group in 2015. She and her husband, "Peter," have now been active participants in the ICAP for 3 years. Stacey is a 72-year-old Caucasian female and Peter is a 76-year-old Caucasian male status-post left cerebral vascular accident in 2013. During the first group session, Stacey reluctantly reported that she was "just fine, but her daughter wanted her to try [the group] out." As sessions progressed, Stacey witnessed other group members effectively integrate their pain and loss with love and appreciation for their loved ones. Later, Stacey disclosed that she did not want anyone's pity or to have anyone mistake her struggles for a lack of love or support for her husband. She thanked the group for doing neither and proceeded to talk more openly about her difficulties and fears. Stacey has participated in the caregiver counseling group for 3 years now, and proceeds to joke upon arrival, "Remember when I told you I was 'just fine,'" as she laughs and puts her arm around one of the coleader's shoulders.*

**Figure 2.** Vignette 2: Family caregiver counseling group.

about the program or about living with aphasia, or to discuss aspects of their experience in the ICAP thus far. It is not uncommon for patients and their family caregivers to increasingly arrive earlier each day so that they can chat socially over coffee with each other before the formal ICAP program begins. Graduate student clinicians set up the meeting room and coffee bar 20–30 min prior to the start of the opening session to help families feel welcome to socialize and get settled before programming begins.

Three days of the week, participants are on their own for lunch. Frequently, family caregivers and persons with aphasia will use this time to meet up with each other. Once per week, the ICAP hosts a group lunch. All family caregivers are encouraged to join the persons with aphasia, graduate student clinicians, counselor-in-training, and the interprofessional team leaders for a large group lunch. Although optional, attendance from family caregivers is consistent. Periodically, interprofessional in-services are delivered during these hosted lunches (e.g., physical therapy tips, alternative and augmentative communication tips, family counselor tips for self-efficacy).

Once per week, the ICAP interprofessional team organizes a community outing in Missoula. These outings may include aphasia-friendly guided museum tours, outdoor excursions, recreational experiences, or movie-going experiences. Often, the outings include an aphasia-friendly demonstration or guided experience (e.g., MonTech, the State of Montana's resource for adaptive recreation and technology has collaborated with Missoula Parks and Recreation to provide adaptive fishing tutorials and experiences). The outings are attended by all participants, with communication facilitated by graduate student clinicians and speech-language pathologists. The family counselor and counselor-in-training do not typically attend these outings, although they are invited to do so.

At the conclusion of the ICAP, team leaders host an evening potluck social at an off-campus venue. All current ICAP participants, team leaders, collaborators, graduate student clinicians, the counselor-in-training, and previous ICAP participants (i.e., BSAP ICAP alumni) are invited to attend. This culminating event provides closure, allows ICAP participants to celebrate their accomplishments in a natural setting, and solidifies

relationships that have been formed between ICAP participants. Many ICAP participants arrange for additional family members and friends to attend, which adds to the sense of community and closure.

### **FAMILY CAREGIVER-INITIATED ACTIVITIES**

While the ICAP provides numerous structured opportunities for family caregiver interactions, education, counseling, and socialization, family caregivers also report that they arrange a number of experiences on their own while they are in Missoula for the ICAP. These experiences may include walks to the counseling group, coffee outings, breakfasts, lunches and dinners, lodging in proximity to one another, and shared recreational activities. For example, a family caregiver arranged for a local ice creamery to bring its ice cream truck to the ICAP facility as an end of the week celebration for all individuals with aphasia, family caregivers, graduate student clinicians, and ICAP team leaders. Collectively, these experiences create and sustain cohesiveness, foster a sense of unity and care, and allow family caregivers the opportunity to build on meaningful relationships that frequently persist once the ICAP concludes.

### **CASE STUDY: AN EXAMPLE OF THE COHORT-BASED MODEL OF CAREGIVER INTERVENTION**

To illustrate the process and meaningfulness of the BSAP ICAP interprofessional caregiver intervention, a single case is reflected here. Aliases are used to protect the privacy and confidentiality of our participants. William is an 81-year-old Caucasian male who is now 5 years status-post cerebrovascular accident, who presents with fluent aphasia, right hemiparesis, and who walks for short distances, but primarily ambulates using a wheelchair. As a result of his stroke, William retired from his profession of psychologist and professor of psychology. His specialty in psychology was focused on neurorehabilitation, giving him unique insight into

his acquired disorder and the recovery process. Williams's family caregiver is his spouse, Betty. Betty is a 74-year-old Caucasian female, a retired librarian, who provides full-time care for William. William and Betty hold advanced degrees, navigate from an upper-class socioeconomic status (affording them exceptional health care access), and have a well-cultivated and supportive family and friend support network. Their constellation of privilege (i.e., a white, cisgendered, heterosexual, educated, and financially secure couple) factor positively into their navigation of the difficult and oppressive factors that accompany disabilities following stroke. William and Betty first came to the BSAP ICAP during the summer of 2015. They also attended the program during the summers of 2016 and 2017. This continuum of care offers a unique opportunity to reflect upon their progress, relationships, and experiences within the ICAP and their influence on the program development across 3 years of service.

#### **Betty and the family caregiver education group**

Betty participated in the family caregiver education group for 3 years (2015–2017). In the group, Betty was immediately looked to as a leader and mentor in both knowledge about aphasia, as well as coping skills as a family caregiver. She asked insightful questions to other group members, helping to foster their awareness of their own knowledge of aphasia. An information-seeker at heart, Betty often asked questions of the group leaders and of the other family caregivers to encourage discussion and draw out the experiences of the other members. She was an active participant, often taking notes and asking for additional resources. Betty's strong interpersonal skills helped foster a warm, compassionate environment for discussion and engendered deep, somewhat vulnerable questions from less experienced caregivers.

#### **Betty and the family caregiver counseling group**

Betty joined the first family caregiver counseling group in 2015 highly motivated. Her

ability to be aware of her own process and emotion, make appropriate disclosures, and remain responsive to group members were on point and helped establish effective norms for the group. Over 3 years of participation, Betty took risks to be increasingly vulnerable with the group. Group leaders encouraged her expression of moments of regret, loss, anger, and exhaustion in authentic and congruent ways. Following such disclosure, group leaders intentionally connected her with responsive group members, often those who had similar experiences or those who were deeply touched by Betty's authenticity. As members came to know and understand her struggles, moments of celebration also came into more meaningful focus for the group. As she and her husband overcame obstacles (e.g., successfully managing a night out to dinner without a wheelchair), experimented with new behavior (e.g., scheduling home health assistance), and made advances in communication during the ICAP, the group recognized the significance of such events, celebrating and understanding these accomplishments as substantial and life changing.

### **Betty and other ICAP-provided caregiver opportunities and family caregiver-initiated activities**

During participation in all ICAP sessions, Betty was present and engaged with her husband and other group members. At the start of most days, Betty was observed "checking-in" on other caregivers and persons with aphasia. She was a dedicated, compassionate presence, frequently walking around the large meeting room before the ICAP began, taking coffee to other participants, and talking with other caregivers. Because of her natural leadership skills, Betty was invited to act as a liaison between the caregiver cohort and the interprofessional team leaders. Facilitating this mentorship role allowed the ICAP team leaders to disseminate and receive information to and from other caregivers or persons with aphasia. In this role, Betty was also often the orchestrator of logistics for the group outings; she frequently provided transporta-

tion for group members to the community outings and initiated after-hours activities or helped other participants think through potential after-hours activities. Betty initiated frequent interactions with ICAP participants and their families when therapy activities were done for the day. Activities that were reported to us included barbecues hosted at their vacation rental, informal gatherings following community outings (i.e., going to get ice cream), and weekend excursions with other families. Together with one other family caregiver, Betty helped organize a biweekly caregiver coffee group at a coffee shop close to campus. Finally, although not from Montana, Betty was identified as the "Missoula expert" and was often approached for ideas about how to optimize the ICAP experience and how to identify "stroke-friendly" recreational experiences, dining, Montana travel, and how to implement communication strategies learned during the ICAP upon return home.

### **Reflecting on Betty's experiences**

Over the course of three summer ICAPs, Betty not only supported the caregivers and persons with aphasia, but she also worked closely with the interprofessional team leaders to discuss issues that were of importance to the families. Team leaders engaged Betty in conversation several times per week to glean information or ideas about topics that were of interest to her or to other ICAP participants. Service delivery for Betty and William improved over the three ICAP sessions because team leaders gave her the space to feel comfortable to provide feedback and discuss elements of the program that team leaders may not have observed or were tuned into as clinical service providers.

This reciprocal teaching and learning relationship allowed for ongoing, real-time innovation and dynamic interventions that may not have spontaneously emerged from just the team leaders. In this sense, it is important to recognize that some caregivers have the potential to become a formal part of the interprofessional team. In clinical practice, it



is common for caregivers to be encouraged to become advocates for their loved ones after stroke (Le Dorze & Signori, 2010; Pierson, 2018). In the case of the BSAP ICAP, advocacy roles are welcomed and encouraged. During the caregiver counseling group, advocacy is a frequent topic of interest for caregivers. This role carries the weight of responsibility and aims to ease experiences after stroke. Though requiring active energy, our caregivers report that a significant burden of advocacy does not typically arise until the dyad is dismissed or ignored in the various systems they are navigating. We argue that welcoming and highlighting the advocacy role may provide relief for the caregiver and may lead to improvements during treatment. Like other caregivers, navigating treatment for William placed Betty in an immediate leadership role. Though this engaged advocacy role could potentially add to the burden of family caregivers, in the context of this ICAP caregivers have welcomed and embraced such a role and have experienced benefits from clinician responsiveness.

While Betty's case is unique in that she and her husband attended three consecutive ICAPs (thus leading to an increased mentorship/leadership role), and she exemplifies a privileged position, her ICAP experiences are not so different from the other caregivers who have participated in our ICAP. Over the years, the majority of our patients with aphasia attended the ICAP with a primary caregiver. All caregivers who have attended the ICAP thus far have made full use of the offered education and wellness opportunities. As reflected in Figure 2, even caregivers who were initially reluctant to join caregiver groups ultimately reported that they found the experiences to be positive and life-changing.

We suspect that the nature of the BSAP ICAP itself (i.e., an intensive 5-week program located in Montana) likely draws unique families. The majority of our ICAP participants relocate to Missoula for the duration of the ICAP. As a result of this relocation, caregivers may be predisposed to participate more actively in the caregiving components of the program than may be the case in more tradi-

tional health care settings. While Betty's experience cannot be broadly generalized to other caregivers, her participation and insight have provided a strong foundation about how to include caregivers, how to provide education and wellness for caregivers, and how to implement interventions that cohesively treat the patient-family caregiver dyad.

## DISCUSSION

Family caregivers of persons with aphasia may not have the necessary skills and knowledge to successfully communicate with their loved ones, they may lack confidence and experience in caregiving roles, and they may express a general sense of unpreparedness to meet the needs of their loved ones (Ramkumar & Elliott, 2010). Family caregivers often report that they receive little guidance from inpatient health care providers (Behar-Horenstein et al., 2005), resulting in limited knowledge when they access and use rehabilitative resources. Therefore, they may not know how to competently assume the caregiver role or know how to access and use rehabilitative resources. Family caregivers of persons with aphasia seek tangible information about stroke and aphasia symptoms, treatment and condition progression, and strategies to facilitate communication with their loved ones. Resource handouts, comradery, and education addressing the nature of aphasia and facilitative communication techniques support therapeutic gains across family caregivers. Family caregivers also seek psychosocial services and express the desire to have a network of other caregivers with whom they can explore caregiving strategies.

Family caregivers of persons with aphasia often experience dramatic shifts in family roles, relationship expectations, and increased responsibilities, while also experiencing removed involvement from the rehabilitative process. Increased symptoms of depression, social isolation, and loneliness further complicate adaptation to these new challenges. Attending to caregiver psychosocial needs in the context of a process-oriented

counseling support group facilitates opportunities for connection among caregivers, cathartic expression, celebration of accomplishments, and shared strategies for caregiving. Supporting the relational and mental health of family caregivers fosters the ultimate health of the caregiver–patient dyad, supporting the holistic rehabilitative process.

Although the focus on family caregiver intervention is in its infancy in the BSAP ICAP, it is clear that the caregiver intervention program provides significant and meaningful impact on the family caregivers, the persons with aphasia, the graduate students in training, and the interprofessional team. Increased knowledge and skills competency, psychosocial well-being, and caregiving confidence emerge. Lifelong relationships develop over the course of 4 weeks. These relationships between caregivers and persons with aphasia are authentic, meaningful, and create lasting changes in the lives of all parties. This type of family caregiver intervention program, in the context of an ICAP, is likely to have a profound and measurable impact upon the caregiver–patient dyad that will ultimately lead to improved outcomes across WHO-ICF domains and to improve third-party functioning for both the person with aphasia and their family caregiver(s).

Many factors are likely to contribute to the success of this type of caregiver intervention program. Interprofessional collaboration is essential and mutually rewarding for the interprofessional team members and for the participants of the ICAP. Ongoing collaboration between interprofessional team members provides cohesion in service delivery and results in personal satisfaction at the professional level. Working collaboratively builds appreciation and understanding for the work and expertise of other professionals. Ongoing collaboration between the interprofessional team and the caregivers allows for reciprocal knowledge-building and learning, resulting in high-quality and dynamic clinical care.

The fusion of equitable interprofessional collaboration (i.e., equal investment from all

parties), with the cohort model of this closed system (i.e., the ICAP) is also likely to contribute to program success. Planning for a constrained amount of time and a constrained number of participants (i.e., one cohort at a time) protects the interprofessional team from a logistical perspective, while simultaneously allowing the interprofessional team members to remain flexible in terms of their roles and responsibilities. All participants (i.e., individuals with aphasia, family caregivers, clinicians, related professionals, and program directors) are highly invested in the process, which fosters collective motivation.

The nature of a cohort model provides numerous advantages compared with traditional models of intervention. Shared learning and shared psychosocial experiences during this immersive ICAP allow for family caregivers to bond quickly and to hold a focus on themselves as caregivers and individuals. The cohort model also promotes a collectivism among the family caregivers. Caregivers begin to rely on each other and to allow themselves the opportunity to share some of the caregiving “duties” with each other. This cohort becomes a family of sorts, with many participants maintaining relationships far beyond the end of the program.

While the cohort model is likely to have advantages for many participants, some cohort-based experiences may negatively impact the potential for positive patient and/or caregiver outcomes. In the cohort model, caregivers are treated in group contexts. For some individuals, this group setting may not be a comfortable genre for learning or for relying on psychosocial support. Some participants may not be receptive to the group format and may not perceive a value in interacting with other caregivers in such a context. Additionally, if the person with aphasia does not attend the ICAP with a family caregiver, both parties miss the opportunity to have focused sessions that target communication and conversation with a familiar communication partner. Such limitations need to be considered when referring patients to cohort model programs.

### Future directions

Looking to the future, interprofessional collaboration should be further developed to include planned interprofessional practice. Ideally, the speech-language pathologists/graduate student clinicians and family counselors/counselors-in-training should deliver interprofessional sessions to caregiver-patient dyads to target both communication strategies and psychosocial support.

Additionally, once caregiver outcomes have been retrospectively analyzed for these first few years of intervention, prospective research will need to be conducted to systematically assess the influence that this caregiver intervention has on the caregivers, the persons with aphasia, and the caregiver-patient units. While both patient and caregiver outcomes are currently being retrospectively analyzed, further assessment methods and techniques need to be developed to evaluate the impact that the ICAP has on the patient-caregiver unit. Future, prospective studies should address the impact of the ICAP on the patient-caregiver unit including impairment-based and participation-based outcomes and psychosocial well-being for all participants. One possible approach to evaluating these more holistic outcomes could be to develop a tool that is completed by the caregiver-patient dyad together. Such a tool should evaluate the impact of the ICAP on impairment, participation, interdyad communication strategies, and psychosocial well-being of both members of the dyad individually and collectively.

### Clinical recommendations

Family caregivers of persons with aphasia should receive clinical services that augment and/or complement those received by individuals with chronic conditions and should have access to ongoing intervention throughout the aphasia rehabilitation process. Providing these services would mitigate third-party disability and promote third-party functioning. More low-cost, high-quality

programs need to be developed to increase access for less privileged individuals to promote ongoing education, communication skill training, and psychosocial well-being. Overall, the caregiver-person with aphasia dyad must be treated simultaneously and holistically to maximize outcomes.

### Specific recommendations include the following:

- Consider the “patient” or “participant” to be a unit; that is, the person with aphasia and their family caregiver.
- Include a family caregiver intervention program that focuses on education, communicative training, and psychosocial well-being across all aphasia service delivery models and settings.
- Provide caregivers with continuous access to other caregivers, professionals, and resources throughout the rehabilitation process. This ongoing access could include online resources (e.g., [https://comdde.usu.edu/services/research/lanr/2\\_aphasia\\_online\\_handbook.pdf](https://comdde.usu.edu/services/research/lanr/2_aphasia_online_handbook.pdf)), telegroups, or online social media groups.
- Increase low-cost, high-quality cohort-based models of family caregiver intervention programs to reduce health disparities. Universities are poised to deliver such programs as graduate student clinicians across health professions can provide services to reduce costs.
- Use an interprofessional model to deliver services to family caregivers. Interprofessional teams should consist minimally of the speech-language pathologists, physical therapists, family counselors, or psychologists. Additional team members to be considered are occupational therapists, recreational therapists, dieticians, and music/art therapists.
- Invite experienced family caregivers to be a formal part of the interprofessional team and/or to act as a liaison between the caregiver cohort and the interprofessional team.

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**APPENDIX A**  
**Aphasia Education Handbook: Table of Contents**

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From *Aphasia Recovery, Treatment, & Resources Handbook* by L. Milman, M. Tumeo, D. Clendenen, L. Schnaible, E. Anderson, C. Johnson, et al., 2014. Logan: Utah State University, Language and Aphasia NeuroRehabilitation Lab. Reproduced with permission.

**APPENDIX B**

**Aphasia Education Handbook: Example of Educational Content**

<p><b>RECOVERY IS AFFECTED BY:</b></p>	 <p>HEALTH</p>
 <p><b>BRAIN INJURY</b></p> <ul style="list-style-type: none"> <li>• Size</li> <li>• Location</li> </ul>	 <p>AGE</p>
 <p><b>LANGUAGE IMPAIRMENT</b></p> <ul style="list-style-type: none"> <li>• Type</li> <li>• Severity</li> </ul>	 <p>MOTIVATION</p>
	
<p><b>Recovery from aphasia can occur as a result of natural healing and treatment.</b></p>	

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