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Patient Perspectives of an Intensive Comprehensive Aphasia Program for Stroke Survivors

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PATIENT PERSPECTIVES OF AN INTENSIVE COMPREHENSIVE APHASIA PROGRAM

FOR STROKE SURVIVORS

By

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Patient Perspectives of An Intensive Comprehensive Aphasia Program for Stroke Survivors

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Introduction: Persons with aphasia (PWA) who participate in intensive comprehensive post-stroke language rehabilitation programs make a variety of significant investments. While intensive aphasia programs and intensive comprehensive aphasia programs (ICAPs) are becoming increasingly prevalent across health care settings, patient perspectives of ICAPs have not been explored. The purpose of this qualitative study was to examine patient perspectives about the experience of participating in an ICAP at the University of Montana. The primary research question of this study was: "what is it like to be a PWA in an ICAP?" Methods: Researchers used an interpretive phenomenological approach to conduct nine structured interviews from PWAs who described their lived experiences in the ICAP. All interviews were audiovisually recorded and transcribed from the video recordings. Analysis involved an iterative and collaborative coding process. Transcripts were coded and themes were developed from the PWAs' shared perspectives. Results: Three primary themes emerged from patient perspectives including: (1) experience with each of the ICAP components is generally positive, (2) we notice the impact of the ICAP on our communication, and (3) relationships with people in the ICAP are important. Discussion: Results support emerging evidence that ICAPs can be a positive experience for PWA due to the perceptible impact on communication improvement and frequent and varied opportunities to interact with others. ICAPs may be a worthwhile investment for PWA, thereby contributing to the cost-benefit utility and implementation feasibility of the service delivery model.

Keywords: patient perspectives, persons with aphasia (PWA), intensive comprehensive aphasia program (ICAP), intensity, cohort model

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Patient Perspectives of an Intensive Comprehensive Aphasia Program for Stroke Survivors

Background and Significance

Individuals with aphasia who participate in intensive and comprehensive post-stroke language rehabilitation programs make a variety of significant investments. Investments involve commitment across many domains including time, finance, family, temporary relocation, as well as cognitive, physical, and emotional exertion. While intensive comprehensive aphasia programs (ICAPs) are becoming increasingly prevalent across health care settings (Rodriguez et al., 2017; Rose, Cherney, & Worrall, 2013), and language-based and psychosocial outcomes are beginning to be reported in the literature (e.g. Babbitt, Worrall, & Cherney, 2015; Hoover Caplan, Waters, & Carney, 2017), patient perspectives of ICAPs have yet to be explored from a qualitative approach. As health care moves towards patient centered care (Robinson & Krol, 2014), persons with aphasia (PWA)'s perspectives of their rehabilitation experience should inform current ICAP research and intervention approaches (Barrett, 2010; Hinckley et al., 2014).

Stroke is a leading cause of disability worldwide (CDC, 2018). In the United States alone there are about 650,000 new stroke cases annually. Approximately two to four million stroke survivors in the United States live with aphasia (Aphasia Access, 2018; Simmons-Mackie, 2018). Evidence-based practice supports intervention that generalizes beyond improving decontextualized language skills in the therapy room by adopting the World Health Organization's International Classification of Functioning, Disability, and Health (WHO-ICF) model (World Health Organization [WHO], 2001). The WHO-ICF model provides a framework for maximizing person-centered care and impairment-based goals simultaneously (Hoover, Caplan, Waters, & Carney, 2017; Lanyon, Rose, & Worrall, 2013).

Historically, impairments of body structures and function were prioritized in aphasia treatment over activity and participation restrictions (Tippett, 2012). PWA experience

restrictions of activities of daily living and participation in roles they held prior to stroke due to language deficits. As such, particularly relevant goals for PWA are based on activity and participation limitations (Worrall, et al., 2011). Worrall and colleagues (2011) reported that while PWA want their language skills to improve, activity and participation limitations are a priority to target in speech language therapy. The WHO-ICF model provides a framework to ensure that clinicians treat the whole person by balancing impairment-based therapy approaches with those that target activity, participation, environmental, and personal restrictions. As the body of research evolves and suggests new intervention models, continuing investigation is warranted to increase person-centered approaches to assessment, diagnosis, and intervention that addresses what PWAs want.

To optimize the WHO-ICF model for PWAs, aphasia treatment approaches must harness principles of neuroplasticity (Kleim & Jones, 2008; Kurland et al., 2012; Raymer et al., 2008). Best practice in aphasia treatment is holistic (i.e., implements the WHO-ICF model) and maximizes amount of opportunities for practice. Aphasia rehabilitation capitalizes on the brain's capacity of experience-dependent functional reorganization to be more effective than spontaneous recovery (i.e., in the absence of language therapy; e.g., Meinzer et al., 2004). Intervention that applies principles of neuroplasticity maximizes opportunities for repeated practice within a short amount of time. Recently, clinical researchers have begun to investigate the principles of intensity and dosage in the context of aphasia intervention (Bhogal, Teasall, & Speechley, 2003; Brady et al., 2012, 2016; Brietenstein et al., 2017, Cherney, Patterson, & Raymer, 2011; Kleim & Jones, 2008; Meinzer et al., 2004; Pulvermuller et al., 2001; Raymer et al., 2008; Off, Griffin, Spencer, & Rogers, 2015).

High intensity treatment is at least as effective, if not more effective, than the current standard of care (i.e., less therapy distributed over more time) (Brady et al., 2016; Brietenstein et

al., 2017; Harnish et al., 2014; Pulvermuller et al., 2001). While the majority of the research on intensive aphasia treatments have manipulated the frequency of impairment-based (i.e., naming/lexical retrieval) treatment approaches (e.g., Beeson, 2013), a new model of health care is emerging that is inherently intensive and designed to treat all levels of the WHO-ICF (Rose et al., 2013; Babbitt, Worrall, & Cherney, 2016). An intensive comprehensive aphasia program (ICAP) is an intensive—involves at least three hours of therapy a day—and comprehensive— involves a wide range of goals through numerous treatment approaches—intervention model (Rose et al., 2013). This relatively new paradigm in health care requires a significant individual and familial investment for PWA. To date, researchers have not explored the patient experience of participating in an ICAP.

Defining the ICAP Service Delivery Model

Intensive Comprehensive Aphasia Programs (ICAPs) seek to deliver holistic treatment for PWA that maximizes both the WHO-ICF model and principles of neuroplasticity (Rose, Cherney, & Worrall, 2013). ICAPs deliver intense dosages of holistic treatment through individual and group therapy that target all aspects of the WHO-ICF framework including communication impairments, activity restrictions, and participation limitations. ICAPs also provide PWAs and their caregivers with interprofessional practice services including psychosocial support, physical therapy, occupational therapy, music therapy, and recreational therapy (Hoover et al., 2017).

While there is considerable variety in programmatic structure across ICAPs (Winans-Mitrik, et al., 2014), programs that meet the minimum definition of an ICAP must include the following features: (1) a minimum of at least three hours of treatment per day over a period of at least two weeks, (2) patient and family education, (3) a clear start and end date, (4) a cohort of participants who participate over the same period between the start and end dates, and (5) a

variety of treatment (i.e., group and individual therapy; Rose et al, 2013). ICAPs are often centered on university campuses due to cost-benefit constraints associated with the treatment intensity and number of enrolled participants. (Rose, Cherney, & Worrall, 2013).

Treatment Related Outcomes Following Participation in an ICAP

Evidence indicates that neural changes after ICAP participation are associated with language improvements (Baliki, Babbitt, & Cherney, 2018). A research base is emerging that shows ICAPs improve linguistic impairments, functional communication, and aphasia-related quality of life (e.g., Babbitt, Worrall & Cherney, 2015, 2016; Hoover, Caplan, Waters, & Carney, 2017; Hoover & Carney, 2014; Lanyon, Rose, & Worrall, 2013; Rodriguez et al., 2013, 2017; Winans-Mitrik et al., 2014). Although most of the research investigating outcomes of ICAPs has been published since 2011, initial patterns regarding the efficacy of ICAPs are developing. Specifically, patterns of findings reveal that ICAPs are successful across multiple domains of the WHO-ICF model of communication (Worrall, et al., 2010). That is, the majority of evidence indicates that ICAP intervention is efficacious across linguistic impairment, functional communication, and psychosocial outcomes (Babbitt, Worrall, & Cherney, 2015, 2016; Hoover et al., 2017; Lanyon, Rose, & Worrall, 2013; Rodriguez et al., 2013, 2017; Persad et al., 2013; Winans-Mitrik et al, 2014).

A number of studies demonstrated improved linguistic outcomes following participation in an ICAP (Babbitt, Worrall & Cherney, 2015, 2016; Hoover, Caplan, Waters, & Carney, 2017; Hoover & Carney, 2014; Rodriguez et al., 2013, 2017; Winans-Mitrik et al., 2014). For example, the Program for Intensive Residential Aphasia Treatment and Education (PIRATE) ICAP yielded improvements on two standardized language assessments. PIRATE participants scores improved significantly on an aphasia battery called *Comprehensive Aphasia Test* (CAT; Swinburn, Porter, & Howard, 2004) and a verbal discourse task called the *Story Retell Procedure*

4

(SRT; McNeil, Doyle, Fossett, Park, & Goda, 2001). These studies supply phase II evidence for efficacious treatment for linguistic outcomes (Robey, 2004).

Some studies (Hoover, Caplan, Waters, & Carney, 2017; Rodriguez, 2017), report observable change in functional communication outcomes (i.e., contextualized communication of basic and social needs), in addition to linguistic outcomes, thus achieving the original goal of the ICAP model as a holistic service delivery model (Lanyon et al., 2013). For example, Hoover et al. (2017) reported significant improvement on narrative production based on the *American Speech-Language and Hearing Association's Assessment of Functional Communication* (ASHA FACS; Frattali, Thomspon, Holland, Wohl, & Ferketic, 1995), a functional communication assessment. These studies supply phase II evidence showing ICAPs effectively treat functional communication (Robey, 2004).

A few studies have examined psychosocial outcomes of ICAPs (e.g., Rodriguez et al., 2017). Using the *Assessment for Living with Aphasia* (ALA; Kagan et al., 2010), Rodriguez and colleagues measured the impact of communication-related quality of life (QoL) across the following domains: socialization and activities, confidence and self-concept, and roles and responsibilities. The researchers found a statistically significant increase on communication-related QoL, although there was some individual participant rating variability. The significant improvement of ALA outcomes put forth phase II evidence to suggest ICAPs may be effective for improving communication-related QoL.

Collectively, researchers concur that ICAPs have a positive effect on language, functional communication, and psychosocial outcomes (e.g., Babbit, Worrall, & Cherney, 2015; Hoover, Caplan, Waters, & Carney, 2017; Rodriguez et al., 2013; Persad, Wozniak, & Kostopoulos, 2013; Winans-Mitrik et al., 2014). However, this early phase of research does not yet reveal a consistent pattern of results across outcome measures. The most consistent result is that strong

effect sizes are reported in relation to increases in functional communication and communication-related quality of life outcomes (Hoover et al., 2017; Lanyon, Rose, & Worrall, 2013). Efficacious results in the participation domain instill confidence that ICAPs might be able to address what people with aphasia want (Worrall et al., 2011). Some of these goals include: (1) communicating basic needs and opinions, (2) receiving educational information about stoke and aphasia, (3) receiving more speech therapy, (4) having more autonomy, dignity, and respect, and (4) having opportunities to engage socially and to help others. Emerging ICAP evidence suggests that the holistic, high dose nature of the model addresses the pillars of effective aphasia rehabilitation.

Current Limitations of ICAP Research

Rose, Cherney, and Worrall (2013) conducted an international survey to establish how many active ICAPs exist. Hula, Cherney, and Worrall (2013) set forth a research agenda to inform ICAP research goals and facilitate more rapid translation of research findings into clinical practice. These two studies address the emerging evidence addressing ICAP efficacy, effectiveness, cost-benefit utility, and potential to be implemented broadly. Due to the intensive nature of the programs and variability in health care coverage of the treatment, logistical limitations remain a significant barrier to widespread implementation of ICAPs as does the limited amount of publications on the ICAP model setting precedence for potential implementation (Trebilcock et al., 2019). Hula and colleagues describe a research agenda to explore the implementation and feasibility of the ICAP model. Patient perspectives of the ICAP model could reveal the potential for ICAPs to affect a large amount of change in a short amount of time.

Research examining the efficacy and effectiveness of the ICAP delivery model is in the beginning phases (Hula, Cherney, & Worrall, 2017) and thus is limited in a number of ways.

While each of the ICAP studies mentioned thus far reports generally positive outcomes, comparing outcomes and findings between these studies is challenging. These studies examine heterogenous PWA populations (e.g., severity of aphasia, level of education). Heterogeneity of PWA demographics threaten validity when comparing outcomes across ICAP participants, complicating the process of drawing generalizable conclusions that could eventually inform clinical decision making (Attard et al., 2015).

ICAP studies discussed above generally do not employ consistent experimental design, nor do they discuss comparable treatment outcomes. Thus, effect sizes cannot yet be compared across studies because the effect sizes do not measure comparable outcomes. For example, Rodriguez et al. (2017) assessed functional communication with the *Communicative Effectiveness Index* (CETI; Lomas et al., 1989), while Hoover et al. (2017) assessed functional communication with ASHA FACS. Studies such as these examine the same outcome, (e.g., functional communication) yet incongruence in experimental design prevents comparison that could yield a more powerful claim about effectiveness of ICAPs. Most of the studies lack a comparison group. For an exception see Dingam et al., 2015, a phase II non-randomized, parallel group pre-post follow-up study. Comparison groups are seldom used because of the heterogeneity of participants with aphasia.

Heterogeneity of ICAP structure also decreases explanatory power both within and across studies. Factors that might differ between programs include: location, funding, philosophy, values, number of participants, duration, distribution of hours (e.g., 4.5 hours spent in individual treatment versus 4.5 hours distributed between group format, individual therapy, and computer-based intervention) staffing, family involvement, admission criteria, and outcome measures (Rose, Cherney, & Worrall, 2013).

As such, the methodology used to examine ICAPs are not equivalent enough to make strong generalizations about the efficacy of ICAPs. Eliminating confounding elements, such as self-selecting participants, could move ICAP research forward into further phases of experimental design. Logistical concerns like cost, travel, and lack of awareness about ICAPs are paramount to tackling the issue of self-selection in ICAP studies (Rose, Cherney, & Worrall, 2013; Trebilcock et al., 2019). Further experiments should incorporate control groups. While the heterogeneity across PWA poses a challenge to designing a quasi-experimental study, researchers can turn to Babbitt, Worrall, and Cherney (2016) who found age is the only predictive factor contributing to response to treatment. While a minimal amount of variability across participants is unavoidable, future ICAP researchers should consider controlling for age as a variable that could be correlated with outcome, especially if it is similar to the ICAP explored by Babbitt, Worrall, and Cherney.

Patient Perspectives of ICAPs

While there is a foundation of emerging evidence addressing impairment-based outcomes associated with ICAPs (e.g., Babbitt, Worrall & Cherney, 2015, 2016; Code, Torney, Gildea-Howardine, & Wilmes, 2010; Hoover, Caplan, Waters, & Carney, 2017; Hoover & Carney, 2014; Lanyon, Rose, & Worrall, 2013; Rodriguez et al., 2013, 2017; Winans-Mitrik et al., 2014), quantitative patient-reported outcomes associated with ICAPs (i.e., psychosocial outcomes; e.g., Babbitt, Worrall, & Cherney, 2015), and clinician and caregiver perspectives of ICAPs (e.g., Babbitt, Worrall, & Cherney, 2013; Off, Griffin, Murray, & Milman, 2019), no qualitative evidence has been reported about the perspectives of individuals with aphasia who participate in ICAPs.

While researchers have focused on PWAs' experience (e.g., Barrett, 2010; Hinckley, Hasselkus, & Ganzfried, 2013; Luck & Rose, 2007; Palmer, Enderby, & Paterson, 2013; Strong

2018; Turner et al., 2018; Worrall et al., 2010), and PWA "consumer perspectives" of healthcare experiences specifically (e.g., Burns, Baylor, Dudgeon, Starks, & Yorkston, 2015), they have not done so in the context of an ICAP (Worrall et al., 2011). To date, there are no publications that have focused on qualitative participant perspectives of their experience in an ICAP. Refer to Appendix A for a summary of ICAP studies categorized by the focus of each study.

Lack of research that focuses on participant perspectives of ICAPs may be due to the fact that this service delivery model is a relatively rare and novel treatment option for PWA (Hula et al., 2013). Additionally, the difficulty inherent in collecting first-hand accounts from a population with language impairments may also contribute to the limited amount of resources addressing patient reported outcomes of ICAPs (Burns, 2013).

The purpose of the present study is twofold: 1) to learn about experiences of ICAP participants and, 2) to understand the cost-benefit utility of ICAPs from PWA's perspectives. This exploratory investigation aims to understand what it is like for a PWA to participate in an ICAP to explore the worthwhileness of the intensive comprehensive aphasia program treatment model. The primary research question of this phenomenological investigation is: *what is it like to be a PWA in an ICAP?*

Methods

Research Purpose and Design

The purpose of this study is to understand the lived experience of persons with aphasia who participated in the University of Montana's Intensive Comprehensive Aphasia Program (ICAP), the Big Sky Aphasia Program (BSAP). Applying a phenomenological approach, investigators conducted interviews to collect narrative data from PWA participating in the ICAP. Interviews were analyzed to understand themes of the participants' experiences.

Phenomenology is a theoretical approach based in describing a lived experience (Creswell & Poth, 2018; Moustakas, 1994). Phenomenological studies describe common meaning for several individuals with a shared experience. A more recent iteration of phenomenology, interpretive phenomenology, was applied to inform methods of this study (Smith, Flower, & Larkin, 2009). Interpretive phenomenology integrates the essence of the participants' experience while acknowledging the influence of the researchers' interpretation of their lived experience. In this study, the phenomenon is the ICAP, which was the participants' shared experience.

Participants

Eight individuals with aphasia and their families enrolled in the Big Sky Aphasia Program's Intensive Comprehensive Aphasia Program (BSAP ICAP) during the summer 2018 session. All participants were provided information about the current study. The first, second, and fourth authors of this manuscript collaborated to recruit participants during the first week of treatment. Eligibility was determined by the following inclusionary criteria determined during the pre-treatment assessment battery: (1) presence of fluent or non-fluent aphasia, (2) language production of at least the short phrase level, (3) capability of responding to questions through spoken production or message construction through an augmentative or alternative communication (AAC) device with multi-modal support from a speech-language pathologist (SLP), and (4) capability of comprehending questions with multi-modal support from an SLP. Five eligible PWA of the eight participants were recruited, forming the convenience sample for this study. The participants voluntarily agreed to partake in the study. No compensation was offered. The other three summer 2018 BSAP ICAP participants did not meet criteria of capability of phrase level language production and capability of responding to questions.

The second and fourth authors (experts in multi-modal communication) presented their patients and the patients' caregivers (if present) with the topic and goals of the research project using an aphasia-friendly consent form (see Appendix B). While explaining the informed consent documents, the researchers facilitated comprehension by talking slowly, pausing to check for understanding, writing keywords, and using gesture. The researchers asked if the participants had any questions about the study or the consent form. No participants had questions at the time. Each participant signed the consent form prior to the start of the first interview (University of Montana IRB# 116-14).

Participants' individual characteristics varied across language profile (i.e., severity and type of aphasia), age, employment history, levels of education, and rural or urban background. Homogenous demographics included race and ethnicity (all participants were caucasian), and gender (four of five participants were male). See Table 1 for a summary of participant characteristics.

Table 1

Participant Characteristics

Participant Alias	Gender	Age	pre- treatment WAB-AQ	WAB Language Profile	Date of Stroke	Education	Occupational History
PWA 1	Male	63	70.10	moderate Broca's	6/2015	college graduate	Military
PWA 2	Male	76	31.50	severe Wernicke's aphasia	2/2017	vocational, some college	Mechanical Parts
PWA 3	Female	65	89.40	mild Anomic aphasia	11/2015	college graduate, master's	Psychologist
PWA 4	Male	76	41.50	severe Broca's	1/2013	college graduate, master's	Physicist
PWA 5	Male	72	23.70	Severe Broca's	7/2014	vocational, some college	Military

Note. Western Aphasia Battery Aphasia Quotient (WAB-AQ; Kertesz, 2006)

The BSAP ICAP

Assessment. Prior to and immediately following treatment (i.e., the BSAP ICAP), individuals with aphasia underwent an extensive assessment battery used to document current level of functioning that included both cognitive-linguistic outcome measures and quantitative patient reported measures of psychosocial well-being. See Appendix C for a description of these measures.

Treatment. Individuals with aphasia who enrolled in this qualitative study participated in the summer 2018 Big Sky Aphasia Program's Intensive Comprehensive Aphasia Program (BSAP ICAP). This ICAP takes place at the University of Montana (UM) in Missoula, Montana in the DeWit RiteCare Speech, Language, and Hearing Clinic which is housed in the Department of Speech, Language, and Hearing Sciences (SLHS) in the lower level of the Curry Health Center. All assessment and treatment services were delivered by graduate student clinicians enrolled in UM's speech-language pathology master's program. The BSAP ICAP is directed by two nationally-certified and Montana-state licensed speech-language pathologists (the second and third authors of this manuscript). These two directors provide supervision of all assessment and treatment sessions.

The ICAP consisted of four and a half hours of intervention per day, four days per week, for four weeks, resulting in a total of 72 hours of focused treatment. Treatment consisted of a variety of individual (i.e., clinician and PWA), small conversation group (i.e., 2-3 PWA and their clinicians), and large group (i.e., all eight PWA and their clinicians) sessions designed to target individually tailored impairment and activity/participation-based goals. Wednesday's schedule was a unique day of programming including choice-based small group activities or "clubs," PWA education sessions on stroke and aphasia, a hosted lunch for all ICAP patients, caregivers, and staff, and an afternoon outing. Once per week, individuals with aphasia, their caregivers, and

clinicians were provided a community-based, recreational experience (e.g., trip to the movies, adaptive fishing excursion, show at a planetarium). During the ICAP, caregivers had the opportunity to participate in a once per week caregiver education group and a biweekly caregiver counseling group.

Data Collection

  Interviews. The five participants with aphasia were interviewed twice, once within the first 14 days of treatment (initial interview) and once within one week of completing treatment (post-treatment interview). One participant opted out of the post-treatment interview due to a scheduling conflict, fatigue after the post-treatment assessment battery, and lack of understanding of the purpose of the interview. A total of nine face-to-face interviews were led by the first author (a graduate student researcher) under the direct supervision of a nationally-certified and state-licensed SLP (the second and fourth authors). Two researchers and one participant were present during each interview. Interviews were conducted in the DeWit Rite Care Speech, Language, and Hearing Clinic, where the ICAP treatment was held. Each interview lasted 15-55 minutes. The wide range in interview durations reflects the participants' variable language impairment and stamina, which was expected in the context of interviewing PWA (Luck & Rose, 2007).

  The first author conducted all nine interviews and managed equipment. All interviews were video recorded through Zoom (Zoom Video Communications, 2011), cameras fixed to the walls for clinical purposes, and audio recorded through a high-fidelity Yeti microphone (Blue 1967 Yeti Pro USB Condenser Microphone, Multipattern) to increase accuracy of transcription and interpretation of verbal and non-verbal communication. The second or fourth authors co-conducted interviews with the first author to support the participants while sharing their intended messages. The SLPs' role was to facilitate communication during breakdowns, which was

expected in the context of the participants' language disorders. During the interviews, participants were asked to join without caregivers, who were guided to take some time for themselves until the interview was over.

Since receptive and expressive communication difficulties were expected, interviews were structured to elicit discussion. Interviewers encouraged and pursued dialogue of participant-generated ideas. During each interview, the interviewer first described the purpose of the interview and then presented the open-ended questions. These open-ended questions were delivered in the same order for each participant. Participants were asked if they had any additional thoughts to share at the end of each interview.

Before each interview, the first author explained expectations to distinguish the purpose of the researchers' and participants' roles during the interview context from treatment-based roles as clinicians, directors, and patients. The following information was provided: (1) the researchers would like to learn about the participants' experience from their perspective; (2) interviews are not a test and not like treatment; (3) researchers hope to learn about all aspects of the program and will not take critiques personally; (4) communication is expected to be hard and will be supported by the researchers.

The structured interviews were based on a series of increasingly specific questions designed to elicit narrative responses (see Appendix D). If the initial questions did not elicit a narrative response, researchers asked more specific questions like, "how was individual treatment yesterday?" Interview questions were designed to have high semantic lexical representations. For example, when comparing "what was yesterday like?" with "how have things been in the past couple days?", "yesterday" has a specific semantic lexical representation, whereas the lexical representation for "past couple of days" is more ambiguous. Interview questions were printed one question per page with aphasia-friendly visual supports (see

Appendix E). These questions were provided to each participant before the interview began. The

first author reviewed each question with the participants, checked for basic understanding, and

allowed time for questions from the participants. While the same open-ended interview questions

were posed to each of the participants in the same order, participants were encouraged to share

stories and salient experiences that came to mind at any time throughout the conversation.

Researchers asked relevant follow-up questions spontaneously to learn more about the

participant-generated thoughts.

Multi-modal Communication Facilitation. Researchers set the expectation that

communication may be difficult and implemented multi-modal communication to facilitate

participants' comprehension and expression as needed. Researchers planned the communication

support protocol based on prior qualitative research with PWA (Burns, et al., 2015; Luck &

Rose, 2007), restating or paraphrasing interpretations of verbal and non-verbal communication

so as to provide an opportunity for PWA to correct or confirm researchers' understandings in the

moment. Triadic seating arrangements facilitated open, non-confrontational communication and

considered any needs to compensate for visual or hearing acuity and neglect. For example, the

researchers sat in the left visual field of a participant with right visuo-spatial neglect.

Participants were encouraged to use any and all techniques that improved communication

including their own alternative augmentative communication (AAC) devices. Communication

was facilitated through gesture, body language, slow, simple spoken production, and written

keywords or simple drawings. Ample time was given for responses. Researchers also used light-

tech and high-tech AAC tools. Light-tech communication facilitation tools included blank paper

and a black permanent marker, a whiteboard, and a dry erase marker. Messages written on paper

and pen could be saved and referenced to, while ease of correcting messages on dry-erase boards

16

decreased participants' frustration with written production deficits. High-tech AAC included an iPad used to search for relevant images as they came up during conversation.

The researchers also provided a communication support notebook with images of relevant people (i.e., ICAP participants, clinicians, clinical educators, researchers, counselors), environments (i.e., therapy rooms, outing destinations), and images of high frequency situations (i.e., two people engaging in individual therapy, a group of people engaging in therapy, faces with varying emotions, a person taking a break) to encourage expressive communication. The purpose of the notebook was to facilitate the efficiency of PWA comprehension and expression. Providing concepts in visual form eliminates linguistic elements, reducing cognitive exertion during verbal production (Rose, Worrall, Hickson, & Hoffmann, 2011). For example, if a participant wanted to talk about a fishing excursion, but had difficulty retrieving the word "fishing," they could find the picture of the pond where the excursion took place so that the researchers could verify that fishing was the intended topic.

Fieldnotes. The research protocol included *laminating* (i.e., developing layers of interpretation) through the use of fieldnotes (Saladaña, 2015). During each interview, researchers recorded impressions on worksheets (Appendix G) with the following categories, including: "thoughts and quotes," "facilitative methods," "affect," and "themes." The categories facilitated quick, in-the-moment note-taking and created the opportunity for researchers to compare impressions across similar domains, bracket notes on personal bias, and explicitly discuss moments in which bias was introduced.

After each initial pre-treatment interview, researchers debriefed about the following: (1) general impressions and themes that arose from the interview, (2) interview techniques that worked well and should be used again, (3) interview techniques that should be revised for post-treatment interviews, and (4) questions to ask during subsequent post-treatment interviews. The

themes observed during initial interviews were reviewed during post-treatment interviews to

provide the participants with opportunities to clarify any misinterpretations and to build on

salient participant themes. Reintroducing topics from initial interviews facilitated expansion

upon ideas generated by participants, striving to maximize authenticity of PWA expression and

reduce bias of co-constructed messages.

Data Analysis

       Transcription. Interviews were transcribed verbatim from the audiovisual recordings of

each participant. Transcription conventions (see Appendix F) were designed by the first, second,

and third authors, referencing previous studies that have collected PWA perspectives (Burns et

al., 2015; Luck & Rose, 2007). All meaningful speech sounds and non-speech expressions (i.e.,

gesture, expression, body language) were transcribed by the first author. Interpretations of non-

verbal communication were included based on the interviewer's understanding of the intended

message in-the-moment.

       To maximize authenticity of transcribed text, trained undergraduate researchers familiar

with aphasia, but unfamiliar with the data and participants, performed an inquiry audit

(researchers unfamiliar with data confirmed accuracy of interpretation) by transcribing 20% of

the data (Saladaña, 2015). Of the 20%, 10% was selected at random, and 10% was selected based

on the subjectively most incomprehensible speech production. The undergraduate researchers

received training from the first author about transcription conventions to maximize consistency.

The first author and undergraduate researchers discussed discrepancies between their transcripts

while watching the videos of the interviews and came to consensus about how to most

authentically describe participants' communication.

       Coding. To derive meaning from the collective experience of the ICAP participants,

significant statements from the transcripts were identified. During the process of

horizontalization (i.e., the act of highlighting significant statements that illustrate how the participants experienced the phenomena; Moustakas, 1994), the researchers developed keywords or phrases called "codes" that represented the topics that the participants discussed (Creswell & Poth, 2018; Moustakas, 1994). A code dictionary—or codebook—was established through five rounds of collaborative analysis by the coding team (i.e., first, second, and third authors). The third author served as an external auditor, unfamiliar with the data and the participants. The codebook includes definitions of each code that includes details about when to apply a specific code as well as a reference to an example of how the code was applied appropriately (see Appendix H).

During round one of coding, each member of the coding team reviewed a transcript and assigned keyword phrases to significant participant concepts. The team members met to discuss phrases they chose, consider discrepancies of how they assigned phrases throughout the transcript, and select keyword phrases that merited preliminary codes. Finally, the first author developed a pilot codebook based on consensus of preliminary codes. During rounds two and three of coding, the authors repeated the iterative process set forth during round one with two other transcripts using the pilot codebook. At this time, preliminary codes were assigned where appropriate, new codes were added when necessary, and definitions were modified to capture multiple PWA perspectives. The transcripts reviewed during rounds one, two, and three were chosen based on the variety of the PWA's experiences, difficulty communicating, and whether they attended the ICAP for the first time or attended the ICAP as a returning participant to ensure the coding team was exposed to the heterogeneity of the participants while developing codes.

During round four of coding, the first author coded two transcripts from participants that the team had not yet reviewed. The second author reviewed the two transcripts, reaching consistency with application of the codebook. During round five of coding, the first author coded

the remaining four interviews with the established codebook. After examining the coded data,

the first author generated themes that reflected a shared lived experience during the ICAP.

Ensuring Data Authenticity

To bracket researcher bias during co-constructed PWA messages, the authors strive to

ensure data authenticity through maintaining trustworthiness that the experiences shared are

representative of PWA perspectives. Trustworthiness can be demonstrated through

confirmability, credibility, and transferability (Burns et al., 2015; Lincoln & Gulba, 1985; Luck

& Rose, 2007; Portney & Watkins, 2015). In qualitative research, reliability is reflected through

confirmability, which is the extent to which the findings reflect participant perspectives.

Credibility is the level of confidence for the authenticity of findings. During this project,

researchers incorporated the following procedures to maximize conformability and credibility:

(1) explicitly introducing the purpose and agenda of the project to highlight the partnership

between participants and researchers to understand the ICAP experience; (2) restating or

summarizing researcher impressions of PWA perspective throughout interviews to provide

opportunity for verification or correction; (3) summarizing themes of initial interviews during

second interviews to verify correct understanding; (4) triangulating data collection across audio

and video recordings and fieldnotes; and (5) member-checking in the form of post-treatment

interview theme discussions, transcription, and coding verification. Each of these procedures

increases confidence that PWA messages accurately reflect their perspectives.

Transferability, the extent to which experience and perspective can extend to others in

similar situation, is to qualitative research as generalizability is to quantitative research (Portney

& Watkins, 2000). Since PWA experience is not universal and there is diversity among ICAP

patient characteristics (i.e., differences in age, gender, aphasia profiles, socioeconomic and

professional backgrounds), the research must acknowledge how the findings will be applicable

and to whom. The diversity among the ICAP participants reflects diversity of general PWA

populations, increasing opportunities to transfer the implications this research to other PWA.

Results

Three primary themes emerged from BSAP ICAP summer 2018 participants'

perspectives: (1) experience with each of the ICAP components is generally positive, (2) we

notice the impact of the ICAP on communication skills, and (3) relationships with people in the

ICAP are important. Table 3 summarizes themes and subthemes from the patients' experiences.

Table 3

Summary of Themes and Subthemes

Theme	Subtheme
1. Experience with each of the ICAP components is generally positive	1.1 Overall, the ICAP is a positive experience 1.2 Group treatment is challenging and rewarding 1.3 Outings are fun 1.4 Individual treatment is hard work
2. We notice the impact of the ICAP on our communication skills	2.1 We notice changes in our communication 2.2 Change happens in different ways for different people
3. Relationships with people in the ICAP are important	3.1 Relationships with cohort peers are important 3.2 Relationships extend beyond the ICAP 3.3 We celebrate our peers' successes 3.4 The ICAP staff are a positive part of the experience

Theme 1: Experience with the Components of the ICAP is Generally Positive

Participants described generally positive experiences about the program as a whole, and

also elaborated on specific features or components of the ICAP (i.e., individual treatment, group

treatment, recreational outings). One of the five participants described the ICAP as a generally

negative experience, expressing frustration with lack of attention from clinicians and lack of

challenge in treatment activities. Participants commented most frequently about group therapy.

Several participants also shared their perspectives about general impressions of the recreational outings and experiences during individual therapy sessions.

      Subtheme 1.1. Overall, the ICAP is a positive experience. When thinking what the ICAP experience was like as a whole, most participants commented that they enjoyed the program. PWA1 described the experience as "interesting, warm, compelling." He reported that he liked "everything" about the ICAP. When asked about his feelings and thoughts while attending the program, he commented "home," confirming that a feeling of familiarity made him feel comfortable in the ICAP setting.

      PWA2 also described enjoyment of his ICAP experience as a whole:

Interviewer 1: In general (circles whole calendar month of BSAP with finger), what was it like to do the program?
PWA2: Splendid we got it and everything. You know. XX I was in it everything. I decided enjoy myself (shrugged).
Interviewer 1: You enjoyed yourself?
PWA2: Yeah.
Interviewer 1: What did you enjoy about it?
PWA2: Just about all of it (laughs).

When prompted to consider his experience during various components of the ICAP treatment, PWA2 replied with reference to his experience globally, "I had a good shim [sounded like paraphasia of time] the whole thing. I can't complain." PWA2 summarized his experience in each of the components of the ICAP as a positive one.

      Regardless of the positivity of their experiences in the ICAP, both PWA2 and PWA5 communicated a feeling of relief in reaction to completing the program: "Oh in a way it would good XXX and everything (shrugs). It's good to end and everything…I enjoy it (chuckles)" (PWA2). PWA5 made a gesture showing hard work and then sighed, expressing relief about the hard work coming to a close.

While most participants expressed that they enjoyed the program, one participant described her experience as generally negative and poorly matched with her needs. PWA3 faced barriers to treatment in a number of ways throughout the ICAP. Anosognosia (lack of awareness of one's own deficits) prevented her from understanding her areas of potential cognitive-linguistic deficit (i.e., ICAP clinicians and directors reported her challenges to be more severe than her explanation of her abilities due to anosognosia and concomitant cognitive-linguistic difficulties involving confabulation and suspected psychological denial). PWA3 described a burst of self-reported spontaneous recovery—and ensuing independence—approximately one month before the ICAP as "really big," saying, "it all came together in a whole bunch. But then I come here it seems like third grade. I'm sorry but it does." When asked how the program has been going, PWA3 explained:

> PWA3: It's a little bit drowsy. It's a little bit under the weather. I don't like it very well but I'm trying to be a good sport about it.
> Interviewer 1: Yeah, I heard you say drowsy? Is that right?
> PWA3: It's a little bit… I feel like it's a below me. But maybe I don't know better (shrugs).
> Interviewer 1: But if that's your feeling, that's your feeling. How does it feel below you?
> PWA3: The words are very commonplace. But maybe I'm wrong (nods). Maybe I'm wrong.

PWA3 opted not to participate in the post-ICAP interview, citing her reasoning as "I don't need it." Following multiple explanations that interviews do not serve the purpose of treatment, but rather a platform to share her ICAP experience, she demonstrated lack of understanding of the purpose of the interview. This lack of understanding illustrates her deficits in awareness which posed a barrier to her engagement in the ICAP.

Subtheme 1.2. Group treatment is challenging and rewarding. All participants discussed their experience in group therapy, often initiating the topic themselves. They discussed both small group therapy (i.e., two PWA, two clinicians) and large group therapy (i.e., all PWA

and clinicians). Participants agreed that the group therapy is challenging for various reasons including that they are not always understood and it is emotional to see each other's struggles. Participants recognized the difficulty as an inherent element of group therapy, which they accepted as part of the experience, and agreed that group was also rewarding. PWA4 pointed to a picture in the communication support notebook representing small group therapy and described it as "busy," with accompanying facial expression and gesture that conveyed tolerance of the demanding nature of small group treatment.

When PWA2 was asked if he was challenged by the ICAP, he referenced group therapy, "I think so XXX my friends always XXX I XXXX we get together all the time. That's one thing," implying challenge of interactivity in group treatment sessions. He elaborated, comparing experiences in small and large group therapy, "I probably liked it XXX even, well I liked them both but I think probably more out of the small group. Be XX [honest]." PWA2 shared his perspective on small and large group therapy, stating small group therapy feels more productive.

PWA4 compared small and large group therapy as well. He pointed to an image of small group therapy sessions initiating the topic and implied that neither format is better than the other, rather, they are different:

> Interviewer 2: Did you like the one-on-one [i.e., small group] or the big group sessions more?
> PWA4: Well, I (pointing back and forth between written words on communication support notebook for big and one-on-one, draws a line with finger connecting the two)
> Interviewer 2: (laughs) uh huh!
> PWA4: Right. Big, big uh…one two three (holds up hand putting an end to that perseverative phrase, appearing to show he is going to restart intended message), big little fine.
> Interviewer 1: Mhmm. So am I seeing this right that one is not better than the other? They're different?
> PWA4: Yes.

While participants unanimously reported group work is difficult in some way, they also shared that it can be fun and helps improve communication skills.

PWA5 mentioned that being with everyone (i.e., cohort members, clinicians, directors, and caregivers) makes groups enjoyable and the challenge provides opportunity to improve communication skills. While he expressed a generally positive experience during groups, PWA5 said that group therapy can be hard because he is not always understood:

> Interviewer 3: Let me see if I'm understanding. What I think you might be saying (starts to write)—so you have fun in groups, but in groups people don't always understand you?
> PWA5: Yes. Yes (says with deep confirmatory tone).
> Interviewer 3: Is that what you were trying to say?
> PWA5: Yes (nods).
> Interviewer 3: Ok.
> PWA5: Eechoo. (puts arms out again and makes a mildly confused expression, also perhaps showing some resign/acceptance/understanding to not being understood in group treatment). Yeah (raises eyebrows and says with frustrated tone, chuckles). Yeah.
> Interviewer 1: Yeah, it's part of the experience in a group especially. Yes yes.
> PWA5: Yyyyes (makes a big nod). (Puts hands up and lets them fall).
> Interviewer 1: I'm guessing this (imitates hands up and letting them fall gesture) it's part of how it is going to be.
> PWA5: Yes (nods emphatically). Yes yes.
> Interviewer 1: It's part of the understanding that we all know it will be that way.
> PWA5: Yes. Yes (nods).
> Interviewer 1: That was what you were wanting to say?
> PWA5: Yes yes yes (nods).

Participants conveyed that while group sessions are challenging because intended messages may be misconstrued, they accepted that the challenge is intrinsic to group therapy. PWA1 agreed that he enjoys being with the people, but group treatment is difficult. He emphasized group therapy is hard "emotionally," seeing others' struggles in a group of people with aphasia.

For PWA3, small group treatment felt "aggravating." She voiced frustration at the imbalance of attention to each of the PWA during the small group sessions, especially when waiting at length for her peers to produce a message. PWA3 commented on small group sessions in which she worked with PWA with severe to profound aphasia, who require highly scaffolded clinician support and extensive periods of time to produce intended messages:

> PWA3: They work with him the whole time and I'm sitting there like ok. And I like this person a lot. I like him a lot. But, but come on (makes sideways glance at Interviewer

> 1)…I feel like they get ninety five percent of the attention…I just want attention to me and attention to [PWA5] and it hasn't been because [PWA5]'s got thirty minutes and he (uses index finger to mime tapping on an AAC device slowly four times). Yeah (looks at Interviewer 1 and raises eyebrows, emphasizing her point with a sweep of the hand).

PWA3 distinguished between her feelings towards her peer, reinforcing that her aggravation was not based in dislike of a peer; rather, she felt as though the consequence of working with a peer with more severe aphasia was a reduction in her opportunities to practice communication skills. For example, PWA3 reported, "I don't think I'm getting the amount of exposure that the other— cause I sit, and I just sit and sit (makes bored face) …all the time that that other person is getting to talk about how." She also said she requested not be placed with certain cohort members in small group treatment because they speak quietly and are difficult to hear or take a long time to produce a message. PWA3 said she could not be paired with these peers for an entire week, "I'll never make it. I'll never make. Cause I sit there for half an hour while they're trying to get one word out of him." She discussed feeling different than her peers: "They think like everybody as far as those people but there's none for me. I'm a little bit different and I can talk. And I can think and I say well what about that (points to page on table)?" PWA3 voiced that the small group sessions felt designed for her peers' needs and were not paced to her needs.

While group treatment was often viewed as difficult, most participants expressed understanding that the difficulty is the nature of group therapy, and part of what makes it productive and rewarding.

Subtheme 1.3. Outings are fun. Participants' commented on the outings broadly, with mostly neutral opinions. Many enjoyed the variety of the unique agenda on Wednesdays including choice-based club activities, catered community lunches, and afternoon recreational outings, "I think a lot of things have been really good. Your wacky Wednesdays are really good.

The night and days out are good" (PWA3). For others, "it was a lot of fun" (PWA2) to go on the outings.

PWA4, who has attended the BSAP ICAP four times, described outings overall as "so-so," confirming some activities were more preferred than others. He preferred visits to a local organization that promotes wildlife and a historical fort, while he confirmed that the planetarium show, art museum, stadium visit, and adaptive fishing excursion were "not up [his] alley." While the adaptive fishing excursion was not a preferred activity for PWA4, he mentioned enjoyment of having his dog accompany the group at the outing and appreciation for the walking aspect of the tour at the fort. Through facial expression and gesture (e.g., a hand sweep that conveyed brushing it off), PWA4 expressed expectation that while his individual interests were considered, it was not feasible for each of the outings to have been personalized to his preferences.

Subtheme 1.4. Individual treatment is hard work. When reflecting on the first couple weeks of the ICAP, participants discussed various aspects of individual therapy, highlighting their clinicians' involvement and the rigor of the sessions sometimes citing specific treatment protocols. PWA1 and PWA4 specifically mentioned they worked well with their clinicians during individual therapy. PWA4 shared about working hard with his clinician:

> Interviewer 2: So you've been working with her a lot.
> PWA4: Right, uh…voices? No. Uh, words, words.
> Interviewer 2: Oh the v. I know what you're heading towards.
> PWA4: Well (writes)…
> Interviewer 2: So all sorts of subjects, people.
> PWA4: Yes (writes daughter's name).
> Interviewer 1: That one's a [letter] if you're going for [your daughter's name].
> PWA4: Yes. Uh well, [my daughter] and [her husband]

When thinking about what treatment days were like in the first half of the program, most participants emphasized working on salient targets (e.g., family member's names) during individual sessions with his clinician. Some participants considered specific treatment approaches,

including Semantic Feature Analysis (SFA; Boyle, 2010) and Verb Network Strengthening

Treatment (V-NeST; Edmonds, 2016) which were implemented with those salient targets in mind.

When asked about his feeling about SFA, PWA4 responded with meaningful gesture, "Well (uses

high tone, raises eyebrows, and shrugs, as if expressing it has some merit)." Participants expressed

neither approval nor disapproval of their individual treatment plans.

During the initial interview after the first week of therapy, PWA5 explained his experience

by first referencing individual therapy as hard work:

> PWA5: …oh man (while looking at the picture of individual sessions, gestures with fists out, pushing away from him).
> Interviewer 3: So this (imitates fist pushing motion) makes me think of a lot of work.
> PWA5: Yes yes. (sighs). Yes (says resolutely with eyebrows raised and lips tightly closed and stretched and nods)
> Interviewer 3: Is it tiring?
> PWA5: Ooooh (laughs). Oh man (points to head and says in a tired voice). Uh… XXX. Oh man (appears as if he is acting out having confusion by looking around with exaggerated expression then points to head with a frowning facial expression).
> Interviewer 3: Are you thinking of when you guys [PWA5 and clinician] do sounds and things like that?
> PWA5: Yes (nods). Oh man (sighs as if out of breath) yes! It oh man yeah (nods). Eetoo (puts hand up and shrugs, then pumps a fist again appearing to show persisting hard work, and nods).

PWA3 demonstrated a lack of understanding of the purpose of the procedures in SFA as

well as specific communication strategies to improve her comprehension (i.e., talking slower,

pacing activities, and pausing to listen) during these activities. When her clinician wanted her to

"listen and just be quiet," she felt like her clinician was not advocating for her. PWA3 saw

communication with her clinician as a barrier to treatment:

> PWA3: and the way she's using, she's using (gestures hand in circles towards her body making a motion indicating trying to get something out or encourage something to continue and makes a strained noise, imitating clinician speaking slowly) what are you trying to say for Christ's sake. Say it!
> Interviewer 1: Who?
> PWA3: Uuuh [my clinician] (says in frustrated tone).
> Interviewer 1: Mhmm. So are you talking about the speed of delivery?

> PWA3: Yeah, well she they going she gets saying what she wants to hear. I have to go I guh guh guh guh (lowers torso and looks sideways into Interviewer 1's eyes showing effortful communication). I have to look all over her and she's not very composed about the way she wants to say it.
> Interviewer 1: mhmm, how does that make you feel?
> PWA3: Well (makes non-word verbalizations that sound like pushing through something, similar to a roar).

PWA3 also mentioned that although the program felt "below me" because "the words are commonplace," she works hard for her clinician and to "fill out the boxes there" during Semantic Feature Analysis or Phonologic Components Analysis (PCA; Leonard, Rochon, & Laird, 2008).

The majority of participants reported clinician involvement and the rigor of individual treatment as a necessary component of the ICAP that also contributed to the productivity of therapy.

Theme 2: We notice the impact of the ICAP on our communication skills

Participants talked about perceptible changes in communication skills attributed to the ICAP, noting general changes, changes in specific skill areas, and the manner in which they felt the change.

Subtheme 2.1 We notice changes in our communication. All ICAP participants reported changes in communication skills attributed to the ICAP. Some spoke of the overall effect and some described specific differences in language skills. Many shared that at some point during or at the conclusion of the four-week program something shifted, and they felt different. PWA2 explained how the program has affected speaking, listening, reading, and writing:

> PWA2: (looks at Interviewer 1) Yes (nods).
> Interviewer 1: It did affect it?
> PWA2: (closes eyes briefly, still nodding, and sincerely says) Yes.
> Interviewer 1: How so?
> PWA2: Well it was quite a, quite a bit more from what I for what I came XXX and everything.
> Interviewer 2: Mhmm.
> PWA2: XXX 'n stuff.
> Interviewer 1: Sounds like you're saying you can do more than when you came in?

> PWA2: I hope so (chuckles).

While PWA2 remarked about feeling like he had more communicative capability by the end of the ICAP, PWA1 discussed that he felt more comfortable communicating because "I listen and learn so much things…and better and better," attributing the improvement to high amount of practice while attending therapy four days per week.

Not only did PWA1 report feeling more comfortable with communicating, he felt the comfortable atmosphere he described like "home" helped him talk "more, more, more!" When explaining something that seemed different approximately halfway through the program, PWA1 said, "everything…. (smiles) Oh well I can speak aloud. Uh I can listen aloud. Family, uh friends aloud. Um. Everything aloud. Priceless (nods)." He described something feeling different in his head before he produced words, confirming that the change may be attributable to increased awareness of skills that are lacking and skills that are improving. PWA1 explained the final two weeks of treatment:

> PWA1: Uh…it it uh. Interesting. I can (looks up, thinking) listen. I my uh… my things. (Finger spells on table) um.
> Interviewer 2: So you wrote "a" (writes letter on whiteboard).
> PWA1: Aphasia! I think that I can't understand, but listen good (emphasizes with higher tone, nodding, smiling, and hand raising).
> Interviewer 1: Alright. Yeah.
> PWA1: Yeah (opens eyes wide in agreement).
> Interviewer 1: Specifically in the last two weeks?
> PWA1: Yeah (smiles and nods)
> Interviewer 1: Wow! Huh. How did you notice or what did you notice?
> PWA1: All kinds of things. Um my speech is amazing (smiles and chuckles).
> Interviewer 2: Seriously, right (laughs)?
> Interviewer 2 and PWA1: (shake hands)
> PWA1: All kinds of things.

PWA1 demonstrated his increased awareness of his communication strengths and deficits.

PWA2, who began the program with very low awareness of his jargon-heavy speech, also demonstrated increased awareness of generally improved communication skills when talking about how the program went during his post-treatment interview:

> Interviewer 1: I heard you say gettin' going.
> PWA2: Right.
> Interviewer 1: Something was getting going. What was getting going?
> PWA2: Just cleanin' the XX there so you can find out what's going on.
> Interviewer 1: Find out what's goin' on?
> PWA2: Right.
> Interviewer 1: Clean some things up?
> PWA2: Right.
> Interviewer 1: Cleaning things up. Are you thinking about making improvements?
> PWA2: I (nods) hope so. Yes.
> Interviewer 1: Yeah, with what?
> PWA2: Well just cleanin' up everything you know (chuckles). And maybe you that use this stuff especially make changes XX and everything.

Participants also indicated improvement of specific language domain skills. PWA2 pointed to an image depicting the act of listening and said, "so we had to learn that you know 'n learn over there. Yup she took something about that," confirming he learned to listen in a new way. He also pointed to his visual cue card that signaled jargon-filled speech, chuckled, and said, "right," confirming he understood the purpose of the cue and his goal to increase the ratio of meaningful content in his expressive communication. PWA2 continued to explain improvement in his skills saying he was "reading a lot better" and felt like he could more readily get ideas from his brain to his mouth to engage in conversation. Participants felt positive about the program's impact on communication, "there's a few things spelled. You know, which made things feel a lot very good," (PWA2) commenting on the feeling of success with a high quantity of opportunities to practice. When thinking about being done with the program, PWA2 said it will be good for him, "Stay a little stronger 'n everything and this—you know more people with stuff right there you know. Is being all full. It's good to have it takes again and too," while pointing to a picture of ideas going through head to speech.

31

PWA5, who has attended the BSAP ICAP two times including summer 2018, mentioned

that the first day of the program felt different coming back his second year because he could say

more. PWA1 also talked about the progress they've made during the ICAP in conjunction with

potential for continued improvement as motivation to attend the ICAP and persist through the

program.

> PWA1: Uh I think that. Uh I think that better and better. I think uh. Words have better and better.
> Interviewer 1: Mhmm. So it sounds like words are getting better and better.
> PWA1: Yeah (nods).
> Interviewer 1: Now?
> PWA1: Yeah (nods) and who knows. I think uh, the thkies the limit.
> Interviewer 1: The sky's the limit. Yeah, yeah.
> PWA1: Yeah
> Interviewer 1: Yeah mhmm. And this program?
> PWA1: Oh huge! Huge. And thank you (puts palm face-up towards Interviewer 2).

PWA1 and PWA5 commented on change in themselves as well as cohort peers' communication

improvements. PWA5 initiated the topic of peers' improvement by pointing to pictures of cohort

peers, comparing their skills from last year to this year illustrating an increase in skill across all

with whom he was familiar.

> PWA3 felt her speech was improving attributing a portion of the progress to spontaneous

recovery and some to the program:

> Interviewer 3: So I just want to make sure I'm understanding correctly because I think you said earlier that you aren't seeing a lot of change in the program, but then I heard you say that speech is getting easier?
> PWA3: Well that was going on before you guys got hold of me I'm afraid to say. I had a peak in April or May, where I just started to go brrrrrrr (draws up table with a flat, upright hand showing a steep line of progress) like that. And I can't help it. And I came here and some of it occurred here. Some of it's just gonna occur anyway.

Participants remarked on the perceptible changes they felt during the ICAP as well as the manner

in which they felt the change.

2.2 Change happens in different ways for different people. Several participants

explained the change they felt in increments, in comparison to another point in time, or in bursts.

PWA4 said during his post-treatment interview that he felt different from how he felt the year

before, as well as different from four weeks prior at the beginning of treatment. When PWA5

explained that it felt good to return to the BSAP ICAP this summer because, **"**Oh (laughs and

smiles). Uh… (acts out looking around suspiciously) yes and oh man (puts hand up showing a

flat line and then lifts it to show a higher line, then lifts it again to show an even higher line).

And yes (points emphatically and does high direction gesture again)."

PWA5 gestured with his arm moving upwards to illustrate improvement in his current level

of functioning as a marker of progress. He talked about how it felt easier to participate in the ICAP

the second time because talking was easier, "Yeah. Too eechoo (gestures hands up and together

placing one firmly and then the next about a foot away appearing to show an interval). Yeah." He

elaborated on the positive feeling he experienced in relation to being in a "different place," with

improved skills:

> PWA5: (laughs and looks into the distance) yes. Uh…eechoooooo (says with slow,
> relieved satisfied tone). Yes (holds arms wide and shakes them once). Eeechoo yeah
> (says in celebratory tone and bends arm makes a fist appearing to be cheering, then nods).
> Eechoo (says quickly and holds hands close together) baaaaeechoo (holds hands far apart
> and elongates sound).
> Interviewer 3: So you had just a couple things you could say and now you feel like you
> have much more.
> PWA5: Yeah yes.
> Interviewer 3: How does that feel to have so much more speech?
> PWA5: (sighs) Yes. Oh man (shakes head). Eechooo.
> Interviewer 3: Does it feel (thumbs up) good?
> PWA5: Yes yes (shakes a strong thumbs up and laughs).

As PWA5 felt different over intervals of time, PWA1 felt different after communicating

with friends over the weekend and returning to treatment on a Tuesday, demonstrating

generalization of skills over the weekend. He also described a bursting feeling that his skills

generalized to all parts of his thinking and interacting after about two weeks of the ICAP treatment

during the summer of 2018:

> PWA1: And then XXX suddenly boom.
> Interviewer 2: Something.
> PWA1: There we go.
> Interviewer 2: There we go.
> Interviewer 1: Have you felt a boom like this before?
> PWA1: No.
> CO: Probably more like slow like kinda this
> PWA1: yeah (nods and makes a low angle of progression with forearm and adjusts it to be steeper)
> Interviewer 2: And now this is like (makes a quick noise that sounds like something changing fast).
> PWA1: (smiles and puts head down appearing to show satisfaction)
> ...
> Interviewer 1: When you're thinking about that boom feeling, do you feel it all the time?
> PWA1: No, yeah yeah (says with affirmative tone)!
> Interviewer 1: Or is it in certain moments?
> PWA1: Yeah, no. Moments (nods), but uh I think yes!
> Interviewer 1: So even if you're not working on speech and language you're still feeling it?
> PWA1: (nods) yeah.

PWA1 expressed the "boom" he experienced not only changed quickly but changed across a

variety of domains beyond structured speech and language activities. Overall, participants

emphasized their excitement—and astonishment—about the perceptible nature of the progress

they made.

Theme 3: Relationships with People in the ICAP are Important

Participants shared about the personal nature of the relationships they developed with

their peers and the ICAP staff. They emphasized the meaningful connections based in empathy

for experiences struggling with communication, emphasizing that the bonds that extended

beyond the programmatic level.

Subtheme 3.1 Relationships with cohort peers are important. As perceptible changes

in communication skills motivated participants to attend and persist during the ICAP, all

participants talked about working with other PWAs as a significant part of their ICAP experience. Relationships with cohort peers enriched the experience by fostering comfort and excitement, helping them improve their skills, motivating them to work hard, creating a platform for shared experience, and establishing friendship.

BSAP ICAP summer 2018 participants talked about how gaining familiarity with peers strengthened personal connections. Returners with established cohort peer relationships and first time BSAP ICAP participants both agreed familiarity with peers strengthened relationships. During his pre-treatment interview, PWA2—a first-time BSAP ICAP participant—answered how he liked working with and being with the other PWAs, "I think so (nods)...I haven't XX have" confirming he had not gotten to know his peers yet. PWA2 expressed lack of familiarity with his peers when answering how he felt about being around them.

PWA5, a returner BSAP patient, also shared apprehension about participants with whom he was not familiar:

> PWA5: Hmm (shakes head, says with skeptical tone and points to [a first time BSAP-er]).
> Interviewer 3: You don't know him.
> PWA5: Yes (puts one hand up and doesn't change his face, perhaps conveying lack of connection)
> Interviewer 3: He's new to you?
> PWA5: Yeah. And (points to a cohort peer) oh man too too too (moving hands side to side).
> Interviewer 3: Yeah he talks.
> PWA5: Yeah yeah (says loudly and in confirming tone, laughs)
> Interviewer 3: Chatty?
> PWA5: Yeah yeah. And (points to another cohort member and acts out flat affect and not saying anything, makes confused look and then) eechoo (intonation in vocalization rises like a question conveying curiosity).
> Interviewer 3: Mhmm, maybe she's more quiet?
> PWA5: Yes yes.

PWA5, who exhibited an outgoing personality pre-morbidly and post-stroke, often conveyed excitement about personal connections with cohort members, citing his interactions with them as

a hallmark of his ICAP experience. As he got to know new peers better, between initial and post-

treatment interviews, he expressed more fondness for them and discovered relatability between

their experiences. PWA5 pointed to a picture of a peer with profound global aphasia, "yes yes

(puts fists together and moves them toward and away from his body conveying a sense of

connection between him and others)," verifying that he wished to express a connection between

them and their shared experience of living with aphasia and working hard in treatment.

Participants used gesture to express closeness to each other and confirmed that being with them

was a reason to apply themselves to working during the ICAP:

> PWA5: Hoochoo and oh man (smiles, laughs, and throws hand down appearing to show appreciation for his cohort member)!
> Interviewer 3: Yeah!
> PWA5: Yes yes. And... (points to a cohort member and makes a gesture pulling fists into chest and titling head to side implying sweetness of or appreciation for a cohort member) oh man!
> Interviewer 1: So there's something about [her].
> PWA5: Yeah yes (nods).
> Interviewer 1: And I heard aw man. I'm wondering there's something different about [her]?
> PWA5: (gestures that are difficult to interpret, points back to her, taps her picture, laughs and smiles). Yes oh man (taps PWA1's picture) oh man! (taps another cohort member's picture, makes a gesture showing small with his fingers) too too.
> Interviewer 3: Yeah. Yes. [She's] kind of quiet. She talks a little bit but she's sweet.
> PWA5: Yes yes. Yeah (nods). And too (laughs and nods). (points back and forth between two more cohort members) Oh man yes
> Interviewer 1: Important people to you?
> PWA5: Yeah yeah. Eechoo. (puts arms out tensely with fists and flexes them) Eetoo.
> Interviewer 1: You have strong feelings for them?
> PWA5: (says loudly and nods emphatically) Yeah yes yes.

Friendships with cohort peers in the ICAP were motivating and contributed to PWAs'

positive experiences during the ICAP. Returning participants remarked on their connections from

past years and said that these relationships contributed to their desire to participate in the BSAP

ICAP. The friendships added excitement. During the post-treatment interview, PWA2 looked at

the pictures of the cohort members and spontaneously said, "oh my, all friends isn't it." He

continued to attribute his communication progress to being around other people:

> Interviewer 1: How did it go for you?
> PWA2: (answers quickly) [quicker than usual] I think they did, yes (nods). Mhmm.
> Interviewer 1: Mhmm. What parts of it?
> PWA2: I think it XX XX speak and with people are wanting stuff and everything and doin it. You know more. I think it helps there.
> Interviewer 1: Mhmm. So I heard you say "with people" right? Being with people?
> PWA2: Yeah (says in understanding tone and rising intonation) [as if asking, yeah and what about it?].
> Interviewer 1: Mhmm what about being with people?
> PWA2: Well a lot of people and stuff things help clean me a little bit. XXX Stuff….getting going… colors and stuff….stuff. I like.

PWA1 also spoke of his relationships as an important part of his ICAP experience. He declared

the ICAP is worthwhile partly due to the people in the program:

> Interviewer 1: Mhmm. And another thing you mentioned is the people.
> PWA1: oh the people, I loves people. Oh um. [My BSAP ICAP cohort member] (points to pictures of cohort members).
> Interviewer 2: (shows pictures) Yeah, yeah, our group here. Yeah, yeah.
> PWA1: Yeah, worse it. [paraphasic/articulation error—based on context in the moment and clarification in the interviewer's restatement in the next line—interviewers understood "worth it."]
> Interviewer 1: Yeah, it's worth it.

As PWA2 made an association between communication improvement and being surrounded by

peers, so did PWA1. When saying it was "priceless" to be able to "speak aloud" and "listen

aloud. Family, friends aloud. Um. Everything aloud," PWA1 continued by making a connection

between improved communication and being with others, "good friends. Excellent friends."

PWA1 said he would want "friends" to be in the same ICAP. The interviewer asked if he would

come back to the BSAP ICAP if the cohort peers were all new people, to which he responded

"Uh yyyyeah! (in jokingly sure manner with tone implying obviously)." Existing friendships

with cohort peers during the ICAP are motivating and contribute to PWAs' positive experiences

during the ICAP. However, established relationships are not exclusively motivating to make the

ICAP worthwhile.

> PWA3, another first-timer, voiced she experienced frustration during the ICAP, but she

persisted through the entirety of the program partially due to the relationships she built:

> Interviewer 1: So what keeps you coming back to clinic everyday?
> PWA3: Well to meet the people I met here, [another PWA], um, [PWA5] and uh… doing things. It's a lot better than it used to be. Well no that's not accurXX.
> Interviewer 3: It's not what?
> PWA3: It's not accurate…It's better than not. You understand (looks at and leans towards JG)?
> Interviewer 3: It's better to come than not to come?
> PWA3: (nods) to come than not to come. And I mentioned today, not to put some people in the room with me

While PWA3 felt aggravated about being paired with certain cohort members who she believed

took time away from her therapeutic experience, she made connections with other peers who

contributed to her persistence in the program.

> **Subtheme 3.2 Relationships extend beyond the ICAP.** Participants discussed

relationships that they made during the ICAP that extended beyond the program sustaining into

personal connections. PWA4, who was attending the BSAP ICAP for the fourth time during the

summer of 2018, had contacted a friend he made in prior years of the ICAP. He and his wife

decided to attend regardless of their close friend's absence this year. He expressed that although

he missed his presence, the ICAP was still a worthwhile experience with a different cohort of

peers.

> During the summer 2018 BSAP ICAP, the group of PWA and their caregivers

independently organized two social events outside the program. PWA4 reported on his weekend

and initiated discussion of the group rendezvous saying,

> PWA4: Uh. Boys are…boys, girls are…um.
> …

Interviewer 2: Got together for (writes "dinner")— Is this right? (points to "Sunday dinner" written on whiteboard) for dinner? Right? You guys got together for dinner?
PWA4: Yes.
…
Interviewer 2: Did you like it?
PWA: Uh yes (makes a so-so face).
Interviewer 2: It's kinda pubby food.
PWA4: Yes, but fine (makes an accepting face).
Interviewer 1: But you go for the company anyways right? Not for the gourmet food?
PWA4: (smiles and nods) Right.

PWA4 expressed enjoyment about the development of cohort member-planned social events, which he said was a new aspect of his ICAP experience compared to other years.

When answering what he thought about being around other PWA, PWA1 remarked on the social get-togethers:

PWA1: (laughs) Hard but, uh. Oh [the restaurant we went to].
Interviewer 2: I know! You guys all went out!
PWA1: Yeah (smiles).
Interviewer 1: The dinner [last weekend] is that what you're talking about?
PWA1: Yeah (nods)!
Interviewer 2: I know! Two times this session you guys all got together.
PWA1: Yeah.
Interviewer 2: That's pretty cool that you are comfortable enough with each other to go out.
Interviewer 1: Yeah, how was it?
PWA1: Amaaaaazing!
…
Interviewer 2: So, some comfort with each other, which was cool. So you had said that it's also kinda hard.
PWA1: Oh yeah.

Although PWA1 identified it is "hard" to be surrounded by other PWA, he also expressed some comfort and excitement that the relationships became more personal than programmatic. PWA1 also discussed missing his clinician from the prior summer, noting appreciation for a personal connection with her.

PWA1: Yeah. Oh and they ree me.
Interviewer 2: They reached you?
PWA1: Yeah.
Interviewer 2: Oh good! They reached out. Did you get to see them or just talk to them?

39

> PWA1: yeah. Talk to em.
> Interviewer 2: Just talked to them on the phone? (PWA1 nods affirmatively) That's
> nice…So coming back this year kinda is making you
> PWA1: oh yeah (raises hand to emphasize agreement)
> Interviewer 2: think about being here last year a bit?...Yeah so some familiar faces.
> …
> Interviewer 1: What do you like about seeing familiar people?
> PWA1: Home… home.

Making personal connections contributed to PWA1's positive experience during the ICAP. He

elaborated on his relationship with a peer with whom he shares an intellectual connection. Both

the PWA were involved in intellectually demanding careers. During the post-treatment

interview, PWA1 was asked if he was still thinking about the people he's met in the ICAP, to

which he replied that this peer is "marvelous," commenting they share commonalities and will

stay in touch. He remarked "Ooooh" (in agreeing tone) that she made noticeable improvements

during the ICAP, to which he showed shared enjoyment.

      Subtheme 3.3 We celebrate our peers' successes. Some PWA talked about celebrating

communicative successes and progress of peers**.** PWA5 and PWA1 talked about feeling shared

enjoyment, that it was touching and exciting when someone effectively conveys an intended

message. PWA5 commented on his excitement for personal connections and shared experiences

of joy with the advancement of communication skills. He described a moment when a peer

accurately told her caregiver "I love you":

> PWA5: Yeah. (sits up and resets expression as if acting something out) I. love. You.
> (says with hand tapping each syllable). Awwww (smiles and makes a gesture like he's
> hugging himself, laughs).
> …
> PWA5: Yes yes. And XX…uh..I. Love. You. (makes a celebratory fist pump, appears to
> be sharing his affinity for her and excitement when cohort member has successes).
> Interviewer 1: (points to a cohort member) to [her]?
> PWA5: Yes yes (smiles).

PWA5 showed joy regarding his friend's success, recognizing the substantial achievement of her

meaningful utterance. He shared PWA1's noticeable progress in communication, acted out a

person sitting with their head down and then gestures a celebratory moment with a first pump

and a laugh. He delighted in the moments when they celebrated a friend's accomplishments.

PWA1 incorporated his identity as a teacher, confirming that he cheered his peers on when they

"had good moments:"

> PWA1: [PWA5].
> Interviewer 2: He was working hard.
> PWA1: Yes. Oh my god.
> Interviewer 2: What do you remember about him from last year?
> PWA1: Three words.
> Interviewer 2: Three SOUNDS!
> PWA1: Yeah and oh my god (looks up and gestures hand up, appears to be implying progress was impressive)! Wow.
> Interviewer 2: So some, some mentoring there too, right? Like I think [the two of you] kind of boost each other up?
> PWA1: Oh yeah and (points to another cohort member).
> …
> Interviewer 1: So I'm hearing you talk about a lot of people's progress? Right?
> PWA1: Yeah.
> Interviewer 1: Yours of course because you're feeling it. But also the other people's progress, too.
> PWA1: Oh oh (opens communication support notebook and gestures with hand across all photos, looks back at AL).
> Interviewer 1: Everybody's.
> PWA1: Yeah (nods).

Participants not only felt excitement during moments that revealed progression of each other's'

communication skills, they related to the effortful moments they experienced:

> PWA5: And choo (points to his friend's picture again). No yes et et et et too yes (sounds like he is referring to pace of continuous work sometimes getting things right, and sometimes getting them incorrect). Echo (gestures with pointer finger out and shakes it like someone is telling someone what to do or getting told what to do, then looks at JG and repeats a fist pump gesture looking like hard work continues).
> Interviewer 3: So he [your friend] has a hard time.
> PWA5: Yes yes (nods emphatically). And yes (puts hands together firmly and shakes them, showing a close connection).
> Interviewer 3: Is that maybe friendship?
> PWA5: Yes yes. And…(points at his friend's picture again repeats the close friend gesture) yeah.

Participants expressed comradery towards other PWA who invested in the ICAP, sometimes

succeeding, other times failing, always focused on their common goal to stay motivated to work

diligently.

Subtheme 3.4 The ICAP staff are a positive part of the experience. Participants

commented on the relationships they developed with BSAP ICAP clinicians and directors as

related to therapeutic and non-therapeutic contexts. Some participants claimed being near their

clinician helped them to be understood during naturalistic interactive moments outside of

structured group therapy. Others talked about the general positive association they developed

with the ICAP staff.

PWA5 began an interview saying his day was better because he had the opportunity to

talk with the interviewers, "Oh (says in happy tone while smiling, brings arms out and twists

back and forth gesturing between JG to AL) too too too," confirming he was happy to have the

extra time with us. Both PWA2 and PWA5 developed joking relationships with their clinicians.

PWA5 began his pre-treatment interview by sharing he was looking forward to joking with his

clinician:

> Interviewer 3: So how is Thursday morning, today?
> PWA5: Uh (hums a tune and puts elbow akimbo, moving it forward and back) eetoo.
> Interviewer 3: I didn't quite catch that.
> PWA5: I… (opens communication notebook, independently navigates to and points to picture of his clinician)
> Interviewer 1: [your clinician]
> PWA5: Yes! Oh eetoo eeetoo (smiles and laughs with arm gesturing again)
> Interviewer 3: Yeah, so you are maybe looking forward
> PWA5: Yes yes yes.
> Interviewer 3: to seeing [your clinician] (points to her picture).
> PWA5: Yes yes.
> Interviewer 3: That's great!
> Interviewer 1: Yeah. This part (imitates arm gesture) makes me think you like to joke with her? Is that right?
> PWA5: (laughs and nods)
> Interviewer 3: Yeah, you do a pretty good job of it (smiling).
> All: (laughing).

When starting his day, participants expressed looking forward to the personal and playful connections that sustained some levity throughout the intensity of the ICAP. PWA2 also joked with his clinician about enjoying working with her.

PWA3, who faced challenges understanding the purpose of the ICAP staff's aphasia-friendly communication strategies on a level that prevented development of personal relationships, found enjoyment in getting to know the clinicians and directors, "all the women are so wonderful. They are wonderful they are. Every one of them (nods). Like you (points to AL) and like you (points to JG) are wonderful."

PWA1 also commented on his positive association with the ICAP staff with whom he had gotten to know as a hallmark of his ICAP experience:

> Interviewer 1: …in thinking about the program as a whole, if you had to sum it up, what was it like to participate this year?
> PWA1: Uh, magical.
> Interviewer 1: Magical?
> PWA1: Yeah. I think…I know, but um.
> Interviewer 2: Do you have any sense of why?
> PWA1: No, no. I didn't.
> Interviewer 2: Yeah, cause neither do I. I mean (laughs) I know we do some stuff here
> PWA1: Yeah (smiles)
> Interviewer 2: but, but I don't know like what about—is it being here? Is it the time?
> PWA1: I think (says with sure tone in agreement). I think it's time and you people.
> Interviewer 2: Right.
> PWA1: You are good (smiles and nods).

PWA4's closing thoughts during his post-treatment interview, when asked if he had anything else to share about his experience during the ICAP, summarized his appreciation for his professional and personal relationship with a director:

> PWA4: Well (writes "Off").
> Interviewer 2: Me? (laughs) I always like having time with you here [PWA4].
> PWA4: Right (cry like pseudobulbar affect response).
> Interviewer 1: It seems like it's mutual.
> PWA4: Right.

Discussion

The findings of this study support the emerging efficacy research base for the ICAP service delivery model (e.g., Hoover, Caplan, Waters, & Carney, 2017; Rodriguez et al., 2017). The findings from this study also expand the knowledge base regarding how PWA experience an ICAP. The ICAP addressed what PWA want (Worrall et al., 2011): to communicate basic wants, needs, and opinions, education about stroke and aphasia, more speech therapy, more autonomy, dignity and respect, and opportunities to engage socially and help others. PWA's goals encompassed all the ICF components with a prioritization of activity and participation components. By definition, ICAPs incorporate a large quantity of opportunities to address activity and participation goals in both structured and naturalistic contexts.

The ICAP creates a "cohort effect" in which participants were provided a high quantity of opportunities to interact across contexts, share common experiences, and support each other in their aphasia rehabilitation journeys. Participants enrolled in the ICAP discussed the immense amount of structured and unstructured opportunities during which they could practice interacting with others. They also described the diversity of contexts in which they were challenged to interact. The intensive and varied structure of the program (i.e., variety in programmatic structure throughout the days and weeks) provided many contexts for opportunities to challenge the PWA to practice skills.

Participants also discussed the manner in which treatment, especially group treatment and unstructured interaction with other PWA, PWA caregivers, and ICAP staff throughout the day, contributed to awareness of their communication skills. Worrall and colleagues (2011) found that PWA's benefit from positive relationships with and their healthcare providers, especially speech therapists, as a focus of treatment. They recommend strong relationship-centered therapy as is

implemented in an ICAP service delivery model. The participants described that the increased

awareness of their strengths and difficulties contributed to a noticeable feeling of improvement

in communication skills in themselves. They also noted improvement in their ICAP cohort peers

progress as a contributor to awareness of their own current level of functioning. As they

celebrated momentary successes and continuing progress of their peers, participants reported

increased motivation and hope for their own recovery.

Many participants expressed enthusiasm for noticing improved ability to apply

communication skills beyond the context of treatment. Regardless of their repeated mention of

hard work required during the ICAP, participants' general satisfaction with the program suggests

that the level of difficulty contributes to the productivity of the treatment and the worthwhileness

of their investment. Participants' perspectives about the ICAP suggest that the service delivery

model may have worthwhile cost-benefit utility.

Clinical Implications

Based on patient perspectives of the ICAP service delivery model as implemented in this

study, the model is worthwhile. ICAP patients' communication profiles may be important to

determine candidacy for an ICAP. Prioritized consideration of candidates' awareness of their

skills and deficits may prevent attrition, increase patients' participation, improve outcomes, and

increase worthwhileness of the ICAP for the PWA. For example, PWA1, who began the program

with a relatively high level of awareness, reported that he benefited immensely from the program

and also increased awareness further throughout the duration of the ICAP. PWA3, however,

conveyed a generally negative experience in the ICAP potentially due to her lack of awareness of

deficits, resulting in lack of understanding of the purpose of treatment activities and frustration

with communication support she did not feel she needed. PWA3's investment in the ICAP may

have outweighed the benefits she reported. Nonetheless, clinicians using the ICAP model may

find it appropriate to engage PWA with lack of awareness considering prognosis for improved of awareness and could target awareness in treatment.

Several aspects of PWA3's experience highlight potential challenges in implementation of the ICAP model: (1) group treatment must appropriately meet the needs of different PWA's levels of severity (i.e., PWA3 did not think group treatment impacted her communication skills), (2) concomitant psycholinguistic and cognitive-linguistic challenges may pose a barrier to the comradery of the cohort effect (i.e., PWA3 viewed her deficits as less severe than her peers' and saw herself as "different"), and (3) PWA3's caregivers did not consistently attend the program. These elements of PWA3's experience in the ICAP can contribute to the clinical relevance of future ICAP researchers' questions. While PWA3's experience contrasts the majority experience, it does not invalidate it. Rather it may assist ICAP organizers in considering ICAP candidates with concomitant issues and decide if the ICAP is suitable for the PWA.

PWA may benefit from increased direct education about the therapeutic purpose of practicing skills in a naturalistic environment for generalization purposes. The weekly outings were described generally as "fun." Few participants elaborated. Most reported a neutral attitude towards the outings, suggesting they may benefit more from direct instruction of the therapeutic purpose to view the outings in the context of communication skill development.

To maintain engagement of PWA with differing levels of severity in both small and large group treatment contexts, PWA with milder aphasia could be trained in a mentorship role to assist those with more severe aphasia. Participants with more severe aphasia emphasized the challenge of small group (two PWA and two clinicians) therapy, and PWA with milder aphasia expressed the challenge of large group therapy (all PWA and clinicians). The commonly held belief that group and individual therapy posed a challenge was consistently accompanied with

46

acceptance of the difficulty, illustrating the worthwhileness of challenge in group contexts and one-on-one therapy.

Limitations

The dual role of researchers as clinicians and clinical educators (i.e., the first author also served as an ICAP clinician, and the second and fourth authors also served as ICAP directors) is a primary limitation of this study. The dual roles introduced bias throughout stages of research planning, data collection, and data analysis. The first, second, and fourth researchers may have unintentionally designed part of the research protocol based on preconceived notions of the worthwhileness of the ICAP model. Participants may not have felt comfortable expressing negative experiences to the ICAP staff while in their researcher roles. While the dual roles introduced bias, efforts were made to maximize authenticity of PWA perspectives through external auditing by collaborating researchers unfamiliar with participants during transcription and data analysis. Before submission for publication of this study, 20% of the data will be coded by one of the other authors and compared to resolve inconsistencies. The themes derived from the codes will be crosschecked as well.

A benefit of the dual roles of the researchers is their familiarity with communication styles of the participants. Several of the participants exhibited difficulties with verbal communication but maintained a relative strength in non-verbal communication which was more easily interpretable in-the-moment by the familiar listeners. These interpretations were recorded as part of the received message in the parenthetical, non-verbal portions of the transcriptions to represent the PWAs' full expression to those unfamiliar with the data and participants.

Future Directions

Further experiments should endeavor to incorporate a larger number of participants and implement member checking (i.e., verify with the participants that their experience is captured in

the themes) to increase trustworthiness. Eliminating confounding elements, such as self-selecting participants, could move ICAP research forward into further phases of experimental design. Logistical concerns like cost, travel, and lack of awareness about ICAPs are paramount to tackling the issue of self-selection in ICAP studies. While the heterogeneity across PWAs poses a challenge to designing a quasi-experimental design, researchers can capitalize on the natural diversity characteristic of ICAP patients to infer transferability to the general population of PWA. Future research should also consider the effect of number of times a patient had participated in the (i.e., compare first time ICAP patients' experiences with returning ICAP patients' experiences).

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Appendix A. ICAP Studies Organized by Outcome Measure Explored

ICAP Study	Neural Change re: Language	Impairment-based outcomes	Functional communication outcomes	Quantitative Psychosocial outcomes	Caregiver/SLP perspectives	Patient perspectives
Babbitt, Worrall, & Cherney (2013)					x	
Babbitt, Worrall, & Cherney (2015)		x	x	x		
Baliki, Babbitt, & Cherny (2018)	x					
Code, Torney, Gildea-Howardine, & Wilmes (2010)		x				
Off, Griffin, Murray, & Milman (2018)					x	
Dingam, et al. (2015)		x	x	x		
Hinckley & Craig (1998)		x				
Hoover & Carney (2014)		x	x	x		
Persad, Wozniak, & Kostopolos (2013)		x	x			
Rodriguez et al. (2017)		x	x	x		
Rodriguez et al. (2013)		x				
Rose, Cherney, & Worrall (2013)		x				
Trebilcock et al. (2019)					x	
Winans-Mitrik et al. (2014)		x				

Aphasia-Friendly

Consent Form Summary

participant
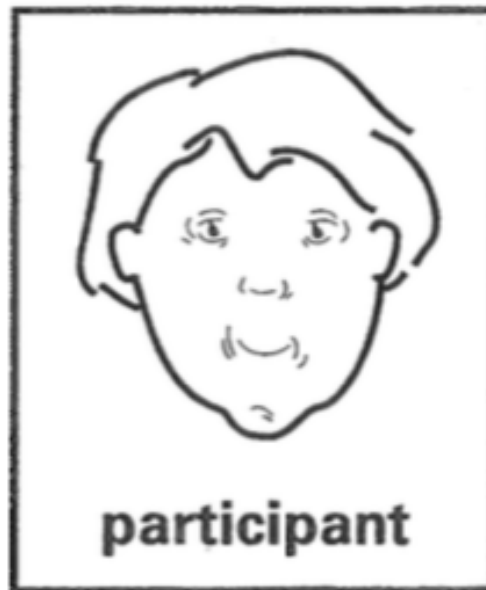
Investigators: <u>Catherine Off, Lisa Milman, Jenna Griffin, and Kirsten Murray</u>

Project Title: <u>The Big Sky Aphasia Program: Patient, Caregiver, and Student Training Outcomes</u>
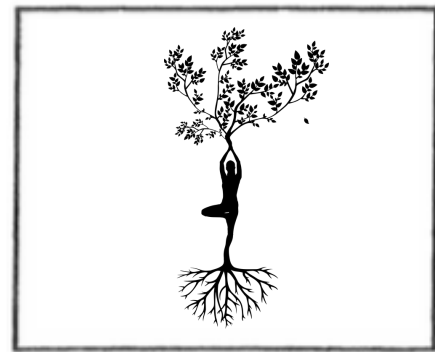
Purpose
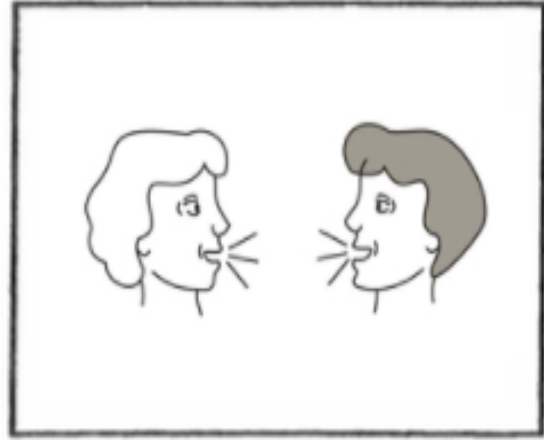
In the **clinic**, we work on **communication**.
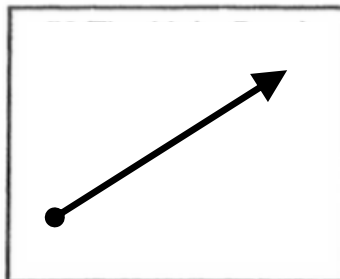
We want to know **how** your
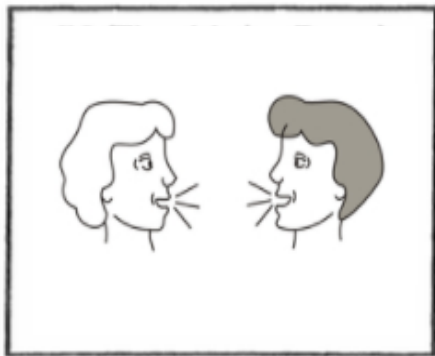
communication & **well-being**

change.

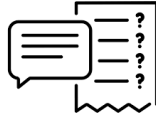# We want to know your **experience** with

individual therapy

group therapy

technology

social outings

Procedures

- ✓ questionnaire

- ✓ medical history

- ✓ hearing

- ✓ vision

- ✓ speech, language & thinking pretests

- ✓ treatment

- ✓ interview

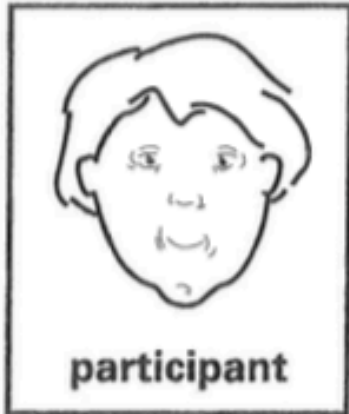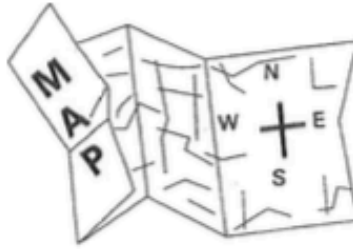- ✓ speech language & thinking posttests

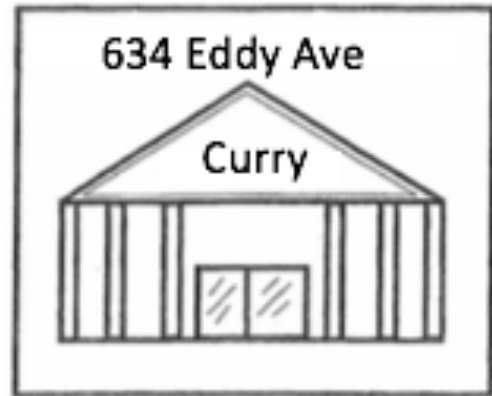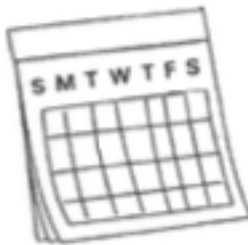- ✓ satisfaction survey

- ✓ electronic survey

- ✓ no payment, results

Where

You   at the   **DeWit Rite Care Clinic**

634 Eddy Ave
Curry

participant

When

May						
Mon	Tues	Weds	Thurs	Fri	Sat	Sun
28	29	30	31	1	2	3

Tuesday, May 29th

to

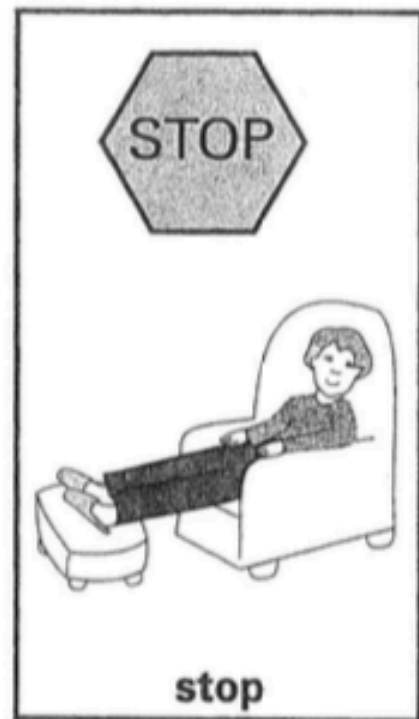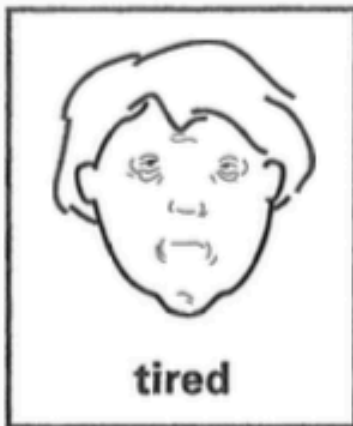| **June**						
Mon	Tues	Weds	Thurs	Fri	Sat	Sun
25	26	27	28	29	30	1

Thursday, June 28th
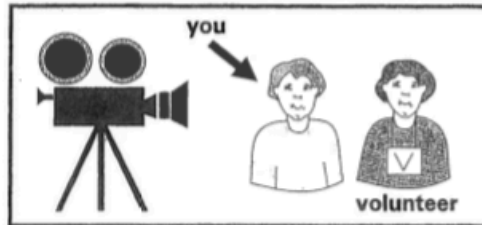
How Often

4.5 hours

Tuesday → Friday

BUT

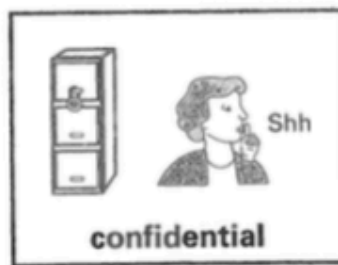If you get **tired** we will **stop** and take a break.

Risks

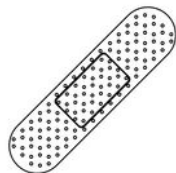Some people **do not like** being **audio or video taped**.

Some people get **tired** or **frustrated.**

There is a risk to your **confidentiality**.

Plans to **hurt yourself** will be **shared**.

Benefits

✔ This will **help research**!

✔ This could **help** others with aphasia!

research

Will this **help research**? YES 👍

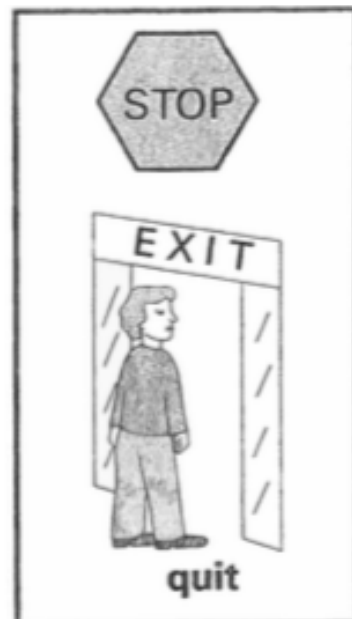Will this **help you** to **talk** better? MAYBE 🤚

Confidentiality

✓ Records will be kept **private**.

confidential
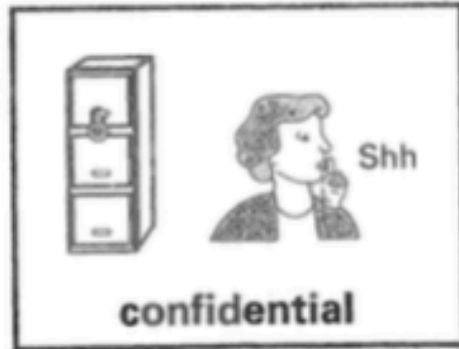
Voluntary

✔ You **can stop** at any time.

✔ It is **your choice**.

✔ It is **ok** to quit.

STOP

EXIT

quit

Questions **?**

Catherine Off → (406) 243-2104

Jenna Griffin → (406) 243-2375

Chair of the IRB → (406) 243-6672

at the University of

Montana Research Office

Appendix C. Pre/Post Treatment Assessment Battery for Individuals with Aphasia

Outcome Measure	Purpose	Type of Measure
Western Aphasia Battery, Revised, Part 1 (WAB-R; Kertesz, 2006)	To detect the presence or absence and type and severity of aphasia	Cognitive-Linguistic Impairment-Based Outcome Measure
Boston Naming Test, second edition, standard form (BNT-2; Kaplan, Goodglass, & Weintraub, 2001)	To assess lexical retrieval through confrontational naming of black and white pictures of decreasing word frequency	Cognitive-Linguistic Impairment-Based Outcome Measure
Raven's Coloured Progressive Matrices (RCPM; Kertesz, 2008)	To assess nonverbal problem solving and reasoning	Cognitive-Linguistic Impairment-Based Outcome Measure
Screen for Language Rehabilitation (SLR, Milman, 2010)	To characterize the nature of: (1) lexical retrieval through picture naming, (2) verbal sentence production, (3) verbal discourse production	Cognitive-Linguistic Impairment-Based Outcome Measure
AphasiaBank Discourse Protocol (MacWhinney, 2000)	To characterize the nature of verbal discourse production through narrative, procedural, and picture description tasks.	Cognitive-Linguistic Impairment-Based Outcome Measure
Geriatric Depression Scale (GDS; Sheikh & Yesavage, 1986)	To assess mood within the last month	Patient-Report Psychosocial Outcome Measure
Communicative Participation Item Bank (CPIB; Baylor et al., 2013)	To assess current level of communicative participation	Patient-Report Participation-Based Outcome Measure
Communicative Confidence Rating Scale for Aphasia (CCRSA; Cherney, & Babbitt, 2011)	To assess current level of confidence during communication	Patient-Report Psychosocial Outcome Measure
Communicative Effectiveness Index (CETI; Lomas et al., 1989)	To assess communicative participation through proxy (i.e., caregiver report)	Proxy-Report Participation-Based Outcome Measure

Interview Questions

ASK PARTICIPANTS TO BRING WHATEVER COMMUNICATION TOOLS THEY NORMALLY USE. COMMUNICATION WILL BE SUPPORTED BY INTERVIEWERS, CAREGIVERS WILL NOT ATTEND INTERVIEWS.
The following scripts and questions may be modified as needed for comprehension.

COMM STRATEGIES SCRIPT: I want to let you know that I'm expecting that some communication difficulties during the interview. Some of the questions might be hard to answer. If this happens, I would love to work through this with you as best as possible. Let me know if there's something I can do to help with communication. This is not a test. We are here to support communication. This session has a different purpose than therapy. We want to know the good, the bad, and the in between. You will not hurt our feelings if something you share critiques the program.

INTRO TO INTERVIEW SCRIPT: I want to talk to you about this program and about your aphasia to get a better idea of what this program is like for you. I'm interested in *your* perspective. Let's start by talking about your talking.

MIDDLE INTERVIEW INTRO SCRIPT: Today, we will review ideas from the first interview. We have similar questions. Now we want to hear about where you are now and if anything has changed since.

TABLE KEY

- Questions in the light blue boxes are the core set of questions that will be asked in every interview.
- Questions in the unshaded boxes below are provided as examples of ways to expand the core questions for occasions in which participants require more specific, directed wording for comprehension of questions posed.
- *Italicized text* represents rephrasing of a question for occasions in which different word choice facilitates comprehension.

Initial Interview (1)	Middle Interviews (2 and/or 3)	Final interview (3 and/or 4)
What kinds of things *(strategies or tools)* help you to communicate or have a good conversation?	---- [tweak communication strategies based on initial interview]	---- [tweak communication strategies based on previous interviews]

How is your day going today? *How was today for you?*	How is your day going today? *How was today for you?*	How is your day going today? *How was today for you?*
What was the first day of the program like for you? *I'd like to hear more about your first day.*	What thoughts did you have about the program today? *What thoughts have you had about the program so far?*	How did the last couple weeks in the program go?
Why did you sign up for this program? *Tell me about some of your past experiences with treatment.*	What has it been like to participate in this program so far? *How did the last couple weeks in the program go?*	What was it like to participate in this program?
What are your expectations for this program? *What are your thoughts going into the program?*	What are your expectations for the remainder of this program?	What are you thinking about now heading home? *What are your expectations now as you leave this program?*
• Tell me about your experience yesterday in the testing (*meeting everyone*). What was that like for you? • Tell me about your experience getting to Missoula, what was that like?	• A couple weeks ago, you mentioned ___ was scary. How is that going?	• A couple weeks ago, you mentioned ___ was ___. How is that going? • ___ was interesting. What do you think about that experience?

Examples of questions to help narrow the content for PWA, as needed:
• I'd like to hear more about _____.
• What was that like for you?
• Tell me about _____.
• How did _____ go?
• It sounds like _____ was [important or memorable]. What made it a memorable experience?"
• It sounds like _____ has been [challenging]. How do you feel about that?
• It sounds like _____ has not lived up to your expectations. I'm fine hearing about these experiences, too.
• Tell me about your experience during the individual treatment sessions.
• Tell me about your experience during group sessions.
• Tell me about your experience during group outings.
• Tell me about your experience during the testing and interviews.
• Tell me about your experience during club time.

Interview Questions – INTIAL

1. What kinds of things help you to communicate?

2.   How is your day going?

3.   What was the first day of the program like for you?

4. What has it been like to participate in this program so far?

2018 JUNE

SUN	MON	TUE	WED	THU	FRI	SAT
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

you   volunteer   staff person
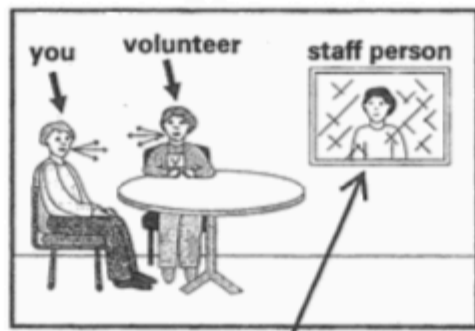
5. Why did you sign up for this program?

6. What are your expectations for the rest of this program?

2018 JUNE						
SUN	MON	TUE	WED	THU	FRI	SAT
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

Interview Questions – POST-TREATMENT

1. How is your day going today?

2. How did the last couple weeks in the program go?

2018 JUNE

SUN	MON	TUE	WED	THU	FRI	SAT
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

3.   What was it like to participate in this program?

2018 JUNE						
SUN	MON	TUE	WED	THU	FRI	SAT
					1	2
3	4	5	6	7	8	9
10	11	12	13	14	15	16
17	18	19	20	21	22	23
24	25	26	27	28	29	30

634 Eddy Ave

Curry
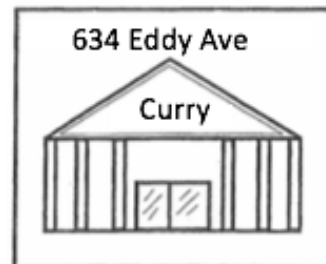
4.   What are you thinking about now heading home?

Appendix F. Transcription Conventions

Key

Transcription Convention	Definition of Convention
Italicized text	AAC generated speech
[notes]	Notes about time, logistics, de-identifying substitutions
(interpretation)	Details and/or interpretation of meaningful, non-verbal communication (e.g., suprasegmental aspects like tone and stress, gestures, expressions) as interpreted by AL
XXX	Unintelligible speech (i.e. phonemes, syllables, and words)
word—word	Interrupted thought within speaker's utterance
No punctuation at the end of an utterance	Indicates a speaker interrupted the last speaker's thought (includes natural conversation overlap)
…	Pause that conveys meaning or indicates that the speaker was pausing to reflect

Appendix G. Fieldnotes Worksheet

Date: Researcher: Client Initials: Interview #

PATIENT EXPERIENCES
FIELDNOTE FORM

Thoughts & Quotes	Facilitative Modalities	Affect	Themes

Notes and post-interview fieldnote and theme review:

PATIENT PERSPECTIVES OF AN INTENSIVE COMPREHENSIVE APHASIA PROGRAM FOR STROKE SURVIVORS
Codebook Round 5

EXAMPLE(S)	CODE	DEFINITION
PWA1 25-90	1) How I Communicate	PWA discuss the modes and methods they use to communicate within or across contexts. For example, a participant discussed a combination of AAC-generated speech, finger cuing, and communication partner support facilitates efficient communication in everyday conversations and in group therapy.
	2) Impact of Aphasia on Life	PWA share how aphasia has impacted their life. This code excludes thoughts on communication skills and is therefore distinct from code 1, How I Communicate.
	3) Broader Stroke Experience	PWA share current stroke recovery experience. This code identifies broader stroke context (e.g., regaining independence with improved mobility); it does not identify thoughts shared about communication skills.
PWA1 161-166	4) Features of BSAP; Assessment	PWA share experiences with the ICAP assessment components.
	5) Features of BSAP; Treatment	PWA share experience with ICAP treatment components. This code includes thoughts shared about clinicians in the context of treatment.
PWA1 240-248	6) Features of BSAP; ICAP Logistics	PWA discuss a view about the ICAP logistics (e.g., overall schedule, location, daily schedule). This code does not include content about assessment or treatment features of the program.
	7) Motivating Factors to Attend/Persist ICAP	PWA explain what motivated or inspired them to sign up and/or why they continue to participate in the program.

	8) Expectations for the Program	PWA share thoughts about what they expect during the ICAP.
PWA1 251-257	9) Impact of ICAP on Communication Skills	PWA discuss their communication aptitude including general skill or change in ability (i.e., progress, maintenance, or regression of skills).
PWA1 99-144	10) Connections to People in ICAP	PWA discuss their relationships and interactions with people related to ICAP (i.e., cohort members, clinicians, directors, etc.). This code is for comments about clinicians when unrelated to treatment.
PWA1 170-173	11) Connections to People Outside of ICAP	PWA discuss their relationships and interactions with people outside of the ICAP experience (i.e., family, friends, colleagues).
PWA1 146-160	12) Familiarity	PWA share about ICAP-related aspects that are familiar (e.g., people, location, activities, routine).
PWA1 216-234; PWA1 258-263	13) Thinking About the Future	PWA share thoughts on the relationship between their ICAP and the future of living with aphasia (e.g., hope and potential). This code identifies views about what it will be like to live with aphasia *after* the ICAP. This code does not include thoughts on communication skills specifically.
PWA1 179-234	14) Patient Backstory	PWA tell a story about themselves; personal details are shared. This code is for information related to pre-stroke, "historical biographical," information.
PWA1 148-149; 170-171	15) Quote	PWA say something poignant or concise that conveys a powerful/meaningful perspective.
	16) Miscellaneous	PWA share thoughts or opinions about the ICAP that do not align with another code's definition.