

ABAC effects on quality of life for PWA

The Effects of Alberta Aphasia Camp on Quality of Life for People Living with Aphasia

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## **ABSTRACT**

*Background:* In aphasia therapy, there has been a shift in focus from impairment-level intervention towards ones focusing on enhancing life participation. Within Canada and the United States there exist several weekend camps that provide examples of participation-level interventions for people with aphasia (PWA); however there is presently limited evidence for the efficacy of camp-based models.

*Purpose:* The purpose of the Alberta Aphasia Camp (ABAC) was to provide PWA and their care partners (CPs) the opportunity to experience therapy, recreational activities, respite, and to create social connections in a supported communication environment. The purpose of this research project was to examine the efficacy of a retreat-based treatment model as a means of increasing the quality of life and life activity/participation in PWA.

*Methods:* ABAC was held at YoWoChAs Outdoor Education Center on September 12-14, 2014. Data from nine PWA and five CPs are reported here. Three assessment tools were used to gather pre- and post-camp data: the *Assessment for Living with Aphasia (ALA)*, the *Australian Therapy Outcome Measures (AusTOMs)*, and the *Communicative Effectiveness Index (CETI)*.

*Outcomes & Results:* Significant improvements were observed from pre- to post-camp on the ALA (participation domain, personal domain, composite score), the AusTOMS (expressive and receptive language impairment scales, cognitive-communication activity limitation scale) and the CETI.

*Conclusions:* Attending ABAC was associated with significant positive effects for PWA across all measures, providing evidence to suggest that a weekend retreat is an efficacious intervention model for participation-level improvement for PWA and their CPs.

## INTRODUCTION

Aphasia is an acquired language disorder, which can affect language expression and/or comprehension. It can occur after a stroke, traumatic brain injury, or brain disease. Over 100,000 Canadians are currently living with aphasia (Aphasia Institute, 2012). This incidence is expected to rise as a result of medical advances, which improve the survival rate of those who have experienced a stroke or brain injury (Code & Petheram, 2011). The effects of aphasia can be extremely pervasive, and can be particularly damaging to one's social engagement, social integration, personal relationships and activity participation, resulting in a lowered quality of life (QoL). For example, Hilari (2011) found that in general, people with aphasia (PWA) participated in fewer activities and reported a lower QoL than people without aphasia, even when they were comparable in terms of physical abilities, general well-being, and social support. Additionally, PWA often experience feelings of social isolation and exclusion even when participating in a social activity (Dalemans, De Witte, Dale & Van Den Heuvel, 2010), and frequently experience a decreased social network, anxiety in meeting new people, and a loss of means of engaging in social interactions (Le Dorze & Brassard, 1995).

The aforementioned findings highlight the importance of targeting the social engagement and activity participation of PWA as a means of increasing their QoL. Particular attention should be paid to participation-level and community-based interventions where PWA can learn to re-engage in life activities and social interactions in a personally relevant and meaningful way. This view is in line with the World Health Organization's (WHO) International Classification of Functioning, Disability and Health (ICF), which identifies activities and participation as interactive domains that affect the health and overall well-being of PWA. In

keeping with the WHO-ICF, there has been a shift in focus from only impairment-level intervention, which focuses on the PWA's communicative deficits, to participation-level intervention, which focuses on developing supports and access to activities as a means of meeting the full range of communicative needs of PWA (Dietz et. al, 2013). The conceptualization of this framework has increased the need for alternative intervention techniques and service delivery models that identify and help remediate the impact of a communication disability on one's QoL and life participation.

According to Papathasiou, Coppens and Potagas (2013), social isolation is a common occurrence for both PWA and their CPs following stroke or brain injury. Group therapy has emerged as a prominent intervention technique for those with aphasia. The therapy may be specific to speech and language goals but often works toward community reintegration following stroke or brain injury. Elman & Bernstein-Ellis (1999) propose that aphasia group treatment provides a supportive environment through inclusion of others with similar experiences and issues, thereby improving psychosocial functioning. For PWA, group therapy provides a sense of community and camaraderie such that participation and acceptance is encouraged.

As already noted, aphasia does not just affect the person who has acquired the impairment. Rather, friends and family must also deal with the loss of communication (Draper et al., 2007; Hilari & Northcott, 2006). Yet friends and family are not typically involved in traditional therapy approaches for PWA. This lack of involvement could be a result of many factors, such as constraints of time, logistics, or comfort level on behalf of the CP or even the speech-language pathologist (SLP). As an alternative to traditional impairment-based therapy,

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aphasia camps have emerged across North America and are growing in terms of anecdotal evidence of their efficacy. The focus of these camps is to provide PWA and their CPs an enjoyable retreat and opportunities to participate in fun activities while in a supported and communication enriched environment. In relation to the WHO-ICF model, aphasia camps go beyond treating the impairment to focus on personal, environmental and participation domains. By providing a safe and secure environment for PWA and their CPs, the camps enable participation in a number of activities. These experiences allow the participants to create new memories, meet new people and forge new relationships, and increase feelings of self-efficacy, thereby motivating them to develop goals for their lives that extend beyond the context of camp. Research on social relations has found that people with strong social support often have better prognoses and better psychological health and reported quality of life (Hilari & Northcott, 2006).

Major camps across North America include the Aphasia Camp Northwest (est. 1999), the Aphasia Camp Eau Claire in Wisconsin (est. 2003), the Adult Recreation Therapy Center (ARTC) Aphasia Camp near St. George, Ontario (est. 2008), and the Sea to Sky Aphasia Camp in Squamish, B.C. (est. 2010). Established in 1999, the Aphasia Camp Northwest (ACNW) in Oregon is the longest running camp in North America. Subsequently, it has served as a foundational model for many other camps established since its inception. These camps have created a subculture of aphasia therapy that is becoming increasingly recognized and sought-after by those living with aphasia. Many of these camps have partnerships with educational and health institutions as well as charitable organizations (e.g., Portland State University, Pacific University and the Aphasia Network with the ACNW; Mayo Clinic with the Eau Claire camp). Through these

affiliations, and with the help of many volunteers and donors, these camps have become quite successful.

In recent years, aphasia camps have become multidisciplinary, including a combination of rehabilitation specialists, such as physical therapists, occupational therapists, recreation therapists, psychologists, and speech-language pathologists. Within this context, there exists a unique opportunity for peer-to-peer learning and experiential learning for students in the aforementioned fields (Hoepner, Clark, Sather, & Knutson, 2012).

Within the available literature regarding aphasia camps, many of the North American aphasia camps report positive and encouraging anecdotal evidence of success; however, there is very little published qualitative or quantitative data on outcomes following participation in an aphasia camp. Therefore, there is a need for research regarding the efficacy of this alternative service delivery model. It is for this reason that the ABAC has chosen to take qualitative and quantitative data in regards to QoL and functional outcomes of PWA following their attendance at camp.

### ***Purpose***

The purpose of the ABAC was to create an opportunity for PWA and their CPs to participate in supported therapeutic and recreational activities, to offer respite for CPs, and to facilitate building social connections with others who have had similar experiences. The aim of the research surrounding the ABAC was to examine the efficacy of a retreat-based service delivery model as a means of increasing activity participation and QoL in PWA.

### ***Hypotheses***

As a result of having experienced recreational activities and meaningful social connections within a supportive communication environment, the researchers hypothesize that the following effects will be seen in the PWA:

1. An increase in the ALA participation domain score.
2. An increase in the ALA personal domain score.
3. An increase in the AustOMs participation restriction score.

Furthermore, the researchers hypothesize that the effects of ABAC on the PWA will be noticeable by the CPs as demonstrated by an increase in post-camp CETI scores.

## **METHODS**

### ***Participants***

This study included 9 participants with aphasia (4 women, 5 men, mean age = 57.33 years, age range: 41-70 years). The average number of years post-onset for the participants was 6.11 years. Participants for this study were recruited from campers who attended the 2014 ABAC. Recruitment for ABAC occurred by contacting SLPs throughout Edmonton and student clinicians at the University of Alberta's Corbett Clinic. Information was also posted on the Alberta College of Speech-Language Pathologists and Audiologists (ACSLPA) and the Alberta Speech-Language Association of Private Practitioners (ASAPP) websites. In addition, a segment discussing the inaugural ABAC was featured on Global TV on July 29, 2014. In order to be considered for the camp, participants were asked to apply online by registering on the MoDC website by July 31, 2014. After all registrants for the camp were confirmed, they were contacted via email and/or telephone regarding their interest in participating in this study. Participants in the research study were required to attend pre- and post-camp assessment

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sessions at the University of Alberta. Of the 16 PWA who attended the ABAC, 11 volunteered to participate in this study. Two of the participants were unable to complete the post-camp assessment and therefore their scores were not included in the data. All participants in the research study were Caucasian, residents of Alberta and spoke English as their primary language. All participants reported receiving speech-language therapy in the past, and some were currently receiving therapy. Table 1 presents a summary of participants' demographic characteristics.

Each camper was given the option of registering one person to attend the camp alongside them. A total of 12 CPs attended the camp, and five of these volunteered to participate in the study. The CPs in this study consisted of one child and four spouses of the PWA. One of the spouses did not complete the post-assessment; therefore, data presented here represent four CPs.

Table 1. Participant sociodemographics.

<b>Participant</b>	<b>Age</b>	<b>Sex</b>	<b>TPO</b>	<b>Etiology</b>	<b>Education</b>	<b>Aphasia Type*</b>
P1	70	Male	7	L CVA	< High school	Conduction
P2	61	Male	2	L CVA (MCA)	High school	Anomic
P3	41	Female	1	TBI	Post-secondary	Wernicke's
P4	45	Female	11	L CVA	High school	Broca's
P5	61	Male	1	L CVA	Post-graduate	Anomic
P6	59	Male	1	L CVA (MCA)	Post-graduate	Global
P7	65	Female	12	L CVA (MCA)	Post-secondary	Broca's
P8	56	Female	7	L CVA (MCA)	Post-secondary	Broca's
P9	58	Male	12	L CVA (MCA)	Post-secondary	Anomic

\*The aphasia type information was obtained from clinical records.

TPO= time post onset in years, L= left, CVA= cerebrovascular accident, MCA= middle cerebral artery, TBI= traumatic brain injury



### ***Volunteers***

Of the 30 volunteers present at the camp, 25 were second year SLP students from the University of Alberta, and five were registered speech-language pathologists. A MoDC Conductive Educator was also present during the camp duration. The camp provided an educational experience that allowed the student volunteers to consolidate their newly acquired skills and to draw upon their own life experiences. The volunteers helped the PWA use different strategies to communicate, get to their desired destinations and succeed with the activities that took place at the camp. The volunteers were also essential in the planning, preparation and cleaning up of the activities that took place throughout the camp.

### ***Ethics***

This research project was approved by the University of Alberta Research Ethics Board.

### ***Design***

In order to address the research question of whether participation in the ABAC would result in improved QoL for PWA, a quasi-experimental, pre-/post-test design without a control group was used. Both quantitative assessment tools and qualitative (semi-structured interviews) were administered; only the quantitative results are reported here.

### ***ABAC Programming***

The Alberta Aphasia Camp (ABAC) established a partnership with March of Dimes Canada (MoDC) during the development stage and was designed based on the retreat-weekend model featuring a combination of activities and communication opportunities put forth by ACNW. The ABAC took place over the course of a weekend (Friday evening to Sunday afternoon) at YoWoChAs Outdoor Education Centre approximately 80 km outside of Edmonton,

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AB, Canada. The camp provided opportunities for PWA and their CPs to engage in a combination of therapeutic and recreational events over the weekend. There were two recreational rotations offered on Saturday morning and one therapeutic and one recreational rotation offered in the afternoon. Each recreational rotation included a choice of one of four activities that were 75 minutes each. Activities offered included swing by choice (one component of a high ropes course), low ropes course, yoga, voyageur canoe, guided hike, card/board games, lawn games, and arts and crafts. These activities were adapted where necessary to accommodate participants who had mobility issues. The swing-by-choice, low ropes course, voyageur canoe and guided hike activities were facilitated by the YoWoChAs staff with assistance provided by volunteers, and the remaining activities were overseen by the volunteers. The therapeutic activities were scheduled in a way that accommodated separate but concurrent groups for both the PWA and for their CPs. Registered speech-language pathologists led the groups for PWA and a certified psychologist, along with an SLP, led the CP group. During the CP session, the leaders provided an opportunity for CPs to share their stories, facilitated discussion about self-care and encouraged resource sharing.

On Sunday morning, one recreational and one therapeutic activity were scheduled. The therapeutic session included a modified Activity Card Sort (Baum & Edwards, 2001) activity where the PWA worked both in a group and one-on-one with student clinicians to sort a deck of 89 cards depicting various pictures of instrumental, leisure, and social activities into two piles: *“do now”* and *“don’t do now”*. From there, the PWA further sorted the *“don’t do now”* pile into two additional piles, *“want to do”* and *“don’t want to do”*. After all of the cards were sorted the PWA were asked to create one to three goals for themselves based on the *“want to do”* pile.

The PWA were then challenged to accomplish their goals within the year. The Sunday recreational activity was a group drumming circle for all campers and volunteers. The goal of this activity was to create a collective voice from the group as they drummed in rhythm with one another in order to transcend the language barriers of aphasia and to create a unifying experience for all.

### ***Data Collection***

Three assessment tools were used to gather pre- and post-camp quantitative data from the PWA participants and their CPs: the *Assessment for Living with Aphasia* (ALA) (Simmons-Mackie et al., 2013), the *Australian Therapy Outcome Measures* (AusTOMs) (Perry & Skeat, 2004), and the *Communicative Effectiveness Index* (CETI) (Lomas et al., 1989). The ALA is a pictographic self-report tool based on the WHO-ICF model, which defines health in terms of Body Structure and Function, Activities and Participation, and Personal and Environmental Factors (Simmons-Mackie et al., 2013). The ALA was used to measure the quality of life in PWA and was administered to the PWA by student clinicians one week prior to camp and again six weeks after the end of camp. Registered SLPs observed the administration of the ALA to ensure fidelity of test administration protocol were followed.

The Australian Therapy Outcome Measures (AusTOMs) is an observational tool that measures patient functioning as a result of intervention and was used to measure improved functioning in PWA (Perry & Skeat, 2004). An outcome measure tool allows for documentation regarding a client's status following intervention. The AusTOMs was used to measure improved functioning in the PWA participants. The AusTOMs consists of six scales that SLPs use to rate their clients. These scales consist of Speech, Language, Voice, Fluency, Swallowing and

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Cognitive-Communication. Based on the purpose and goals of the camp, only the Language and Cognitive-Communication scales were used. The Language scale examines the participant's receptive, expressive, reading and writing disorders/delays. In order to be more specific, receptive and expressive language ratings were completed separately. The Cognitive-Communication scale incorporates all aspects of cognition that impact communication. Each scale includes four domains; Impairment, Activity Limitation, Participation Restriction and Distress/Well-being. These domains are scored on a scale from 0-5, where 0 represented "complete difficulty" in each domain and 5 represented "no difficulty". Half points were also used if the client was found to be in between two scores.

The AusTOMs was used to document any changes in activity limitations and participation restrictions with respect to language and cognitive-communication abilities that may have occurred as a result of the camp. Each participant was evaluated the Friday evening they arrived at the camp as well and again a few days after camp. Four second year SLP students were responsible for evaluating and measuring the participants with the AusTOMs. Previous research by Unsworth et al., (2004) compared the AusTOMs with the EQ-5D and found the AusTOMs tool to have similar constructs and offered support for the construct validity of the tool. Therefore, given the AusTOMs quick and easy administration time and ability to measure global client outcomes, it was found to be an appropriate tool for the purpose of this study.

The CETI is a caregiver report measure. The CETI utilizes a visual analogue scale (VAS), a 100 millimeter line graph with *not at all able* on one end and *as able as before the stroke* on the other, because it is believed to be a sensitive measure of change over time (Lomas et al., 1989).

The CPs of the PWA participants rated actual (not potential) communicative performance in 16 relevant daily activities and/or situations. The CETI is a reliable and valid assessment tool used to measure a change in functional communication ability for an adult with aphasia (Lomas et al., 1989). A study by Lomas et al., (1989), found the CETI to have internal consistency, acceptable test-retest and inter-rater reliability, and to correlate with other measures including the Western Aphasia Battery and the Speech Questionnaire.

In addition to using formal assessment tools to gather quantitative data, a short semi-structured interview was conducted pre- and post-camp during the same appointment time as the ALA was administered. The student clinicians asked the PWA participant a series of questions regarding his or her expectations for the camp and, during the post-camp interview, whether his or her expectations were met. The qualitative data from these interviews is in the process of being thematically analyzed and are not reported on here.

### ***Statistical Analyses***

**ALA.** The data collected from the ALA was coded on a nine point Likert scale (0-4 scale with 0.5 point intervals). An average for each participant was then created per domain (Aphasia domain, Participation domain, Environment domain, Personal domain, and the Wall Question) with scores ranging from 0-4. A paired-sample *t* test was performed to compare pre- and post-camp measures, with significance set at  $p < 0.05$ .

**AusTOMs.** The data collected from the AusTOMs was coded on a scale of 0-5 for each subtest/domain. An average for each participant was created per subtest on the Language (impairment, activity limitation, participation restriction and distress and well-being) and

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Cognitive-Communication scale (impairment, activity limitation). A paired-sample  $t$  test was performed to compare pre-camp and post-camp measures, with significance set at  $p < 0.05$ .

**CETI.** The data collected from the CETI was coded on a 10-cm VAS. The CPs response was given a numerical value somewhere between 1 and 100 millimeters, corresponding with where on the graph they marked their response. An average rating score was then created. A paired-sample  $t$  test was performed to compare pre-camp and post-camp measures, with significance set at  $p < 0.05$ .

### RESULTS

Statistically significant differences were found for the Participation domain  $t(8) = 2.46$ ,  $p = 0.02$ , the Personal domain  $t(8) = 2.51$ ,  $p = 0.02$ , and the composite score  $t(8) = 3.69$ ,  $p = 0.003$  (see Table 2) of the ALA. The results were not corrected for multiple comparisons.

Table 2. ALA pre- and post-camp mean values and standard deviations.

ALA Domain	Pre-Camp	Post-Camp
Aphasia	2.61 (0.44)	2.68 (0.48)
Participation	2.74 (0.50)	3.00* (0.40)
Environment	3.06 (0.45)	3.13 (0.30)
Personal	3.07 (0.38)	3.30* (0.22)
Wall Question	2.83 (0.79)	2.89 (0.66)
Total	2.82 (0.33)	3.05** (0.31)

*significant at \* $p < .05$ , \*\* $p < .01$*

Statistically significant differences were also found on the AusTOMS in the Language scale for the Receptive Impairment  $t(8) = 1.95$ ,  $p = 0.04$ , and Expressive Impairment domain  $t(8) = 4.26$ ,  $p = 0.001$ , and in the Cognitive-Communication scale for the Activity Limitation domain  $t(8) = 2.31$ ,  $p = 0.03$  (see Table 3). The results were not corrected for multiple comparisons.

Table 3. AusTOMs pre- and post-camp mean values.

Scale	Domain	Pre-Camp	Post-Camp
Language	Receptive Impairment	3.50 (0.88)	3.94* (0.45)
	Expressive Impairment	3.11 (0.94)	3.67* (0.67)
	Activity Limitation	3.33 (0.54)	3.50 (0.43)
	Participation Restriction	3.28 (0.72)	3.39 (0.54)
	Distress and Well-Being	3.94 (0.97)	4.06 (0.80)
Cognitive - Communication	Impairment	4.17 (0.64)	4.50*(0.51)
	Activity Limitations	4.11 (0.63)	4.11 (0.57)

significant at \* $p < .05$

Statistically significant differences were also found between pre- and post-camp CETI scores  $t(3) = 2.32, p = 0.05$ . Pre-camp mean was 52.16 ( $\pm 26.05$ ) and post-camp mean was 64.41 ( $\pm 32.55$ ).

## DISCUSSION

This study addressed the effects of attending the ABAC on the activity participation and QoL of the participants with aphasia. Nine PWA were assessed pre- and post-camp. The results provide evidence that attending ABAC resulted in a significant improvement in the ALA, AusTOMs, and CETI scores. The results will be discussed in further detail with regards to the sections previously noted.

### ***Assessment for Living with Aphasia (ALA)***

***Participation.*** A significant increase in pre- and post-camp scores for the participation domain of the ALA was found. This coincides with the hypothesis that the camp would lead to an increase in ability to participate in more activities. This finding may have been a result of the supported environment at the camp that allowed the PWA to have numerous opportunities to participate in several different activities that they may not typically experience in their everyday life. Havighurst's activity theory argues that older adults benefit from social activities because

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they find social approval and ego involvement in participation (as cited by Reitzes, Mutran & Verrill, 1995). Reitzes et al. (1995) extended the activity theory by looking at informal, formal, and solitary activities and how they related to self-esteem in 58 to 64 year olds. This study discusses how the quality of activities, rather than the quantity, may have a larger impact on an individual's self-esteem. They found that activities are likely to generate support for self-esteem and well-being if they confirm identities and allow for participation in valued roles.

At the ABAC, successful participation in several activities in different contexts may have resulted in an increase in the PWA's self-efficacy and therefore led to an increase in their participation scores. A study by Natterlund (2010) found that PWA had difficulties with daily activities which forced a close relative to take over their primary role in the activity. The study discussed how important it is for the PWA's self-confidence to be able to participate in everyday activities. The ABAC allowed for the CPs of the PWA to step out of their roles as "care partners" and move into their roles as partners. This allowed PWA to be involved in activities independent of their CP and for them to have their own valued roles at camp. This may have resulted in a strengthening of the relationships of the PWA and their CPs. In addition, the camp allowed the PWA to meet other individuals with aphasia and to interact with, and get to know, each other on a personal basis. A study by Le Dorze, Salois-Bellerose, Alepins, Croteau & Hallé (2014) looked at the personal and environmental determinants of participation in PWA, and found that the PWA identified some facilitators, including the ability to disclose their experience of aphasia to strangers. The camp included intimate discussion circles which allowed for discussion around some of the difficulties of living with aphasia and how they have dealt with these challenges. This may have allowed the PWA to learn about others' experiences and



be more willing to try things that they were previously unwilling to attempt, thereby increasing their participation upon returning home

**Personal.** Pre- and post-camp scores in the Personal domains of the ALA also improved statistically. This may be related to the increase seen in the Participation domain. The researchers hypothesized that an increase in the Participation domains would be correlated with an increase in Personal domains because of their close relationship to one another. The opportunity to meet other PWA may have allowed the participants to feel less isolated and alone. The camp allowed the participants to identify with other PWA who may have had similar experiences, and therefore a shared understanding of what living with aphasia entails.

As cited by Vickers (2010), Pound, Parr, Lindsay, and Woolf (2000) discuss how aphasia groups facilitate an environment to build new relationships within the group and conversational encounters. At the ABAC, PWA were able to identify with and learn from each other regarding their challenges and successes. Forming relationships with one another may therefore have resulted in increased QoL scores as the PWA may have felt like they were a part of a social network. Hilari and Northcott (2006) discuss that there is relationship between social networks, well-being, and life satisfaction in chronic stroke survivors. This may explain why the PWA reported higher values in the personal domain after camp, which involves features that are closely related to an individual's well-being.

As previously discussed, the ability to participate in several recreational activities may have also led to increased self-efficacy in the PWA and consequently an improvement in personal domain scores. As discussed by Reitzes, Mutran, and Verrill (1995), activities provide opportunities for individuals to confirm their respective identities and receive positive feedback

from others. The ABAC provided a supported environment that facilitated success. This may have led to an increase in the PWA's self-confidence, and may explain why the PWA had an increase in Personal domain scores on the ALA.

A review by Forster et al. (2012) found that providing information to stroke patients and their CP's increased the knowledge and satisfaction of stroke survivors. Similarly, Hinckley, Hasselkus, and Ganzfried (2013) discuss that PWA reported not receiving as much information as they would like post-stroke. At the ABAC, sharing of resources occurred in group discussions with the CPs and PWA by the speech-language pathologists at the camp. There was also time allotted for questions and concerns. This may have allowed the PWA and their CPs an increase in satisfaction regarding their knowledge of aphasia, thereby resulting in an increase in their personal domain score.

**Composite.** The overall composite score provided in the ALA, which included all four domains, was also statistically significant. The improvement of the PWA's composite scores on the ALA can be accounted for by statistically significant increases in values of the Participation and Personal domains, as well as small gains in the other domains tested. The Environment and Aphasia domain scores were not expected to show a statistically significant increase because the camp did not include impairment-based therapy and/or discuss potential environmental modifications. However, although unexpected, there were improvements in the impairment domain on a different measure (AUSTOMS), as discussed below.

**ALA Limitations.** One potential limitation with using the ALA was that in order for the test to be considered valid and reliable the administrator needs to have appropriate supportive communication skills because some participants may have difficulty comprehending the

questions (Simmons-Mackie et al., 2013). Since student clinicians administered the test before and after the camp, it is possible that there was a discrepancy in their supportive communication skills from the first time they administered the ALA to the second time.

As mentioned, the ALA is based on the WHO-ICF model and involves the Aphasia, Participation, Personal Factors and Environment domains. The use of this measure allows one to highlight each individual's unique context, and thereby constitutes a more holistic approach when assessing PWA (Simmons-Mackie & Kagan, 2007). Furthermore, outcome measures are enhanced for PWA because it is person-centered (Kagan et al. 2008). Based on the results of the ALA the researchers have determined that an alternative service delivery model, such as an aphasia camp, is efficacious in improving QoL measures in PWA. These findings confirm the hypotheses that there would an increase in the ALA participation and personal domain scores.

### ***AusTOMs***

***Expressive and Receptive Language Impairment.*** The positive effect found on the Expressive and Receptive Language scales in the Impairment domain of the AusTOMs was somewhat unexpected because, as previously discussed, the camp was not impairment-based in nature. The observed increase in the Expressive and Receptive Language scale in the Impairment domain may have been a result of the individualized communication support provided at the camp. At the camp, all participants, CPs, and volunteers were provided with low-tech picture communication books, and it is possible that the use of these books contributed to improved expressive and receptive communication of the PWA.

Hux, Buechter, Wallace, and Weissling (2010) conducted a study looking at the use of low-tech visual scenes to create a shared environment between a PWA and an unfamiliar

communication partner. While they were not using communication books specifically, they were using pictures and written text to examine how the shared use of an AAC system would affect conversations. The experimenters found that when communication partners and PWA shared the aid it resulted in more conversational turns than when they did not share the aid. Furthermore, the PWA conveyed the greatest number of content units and demonstrated an ease of conversational interaction. By providing all participants and volunteers at camp with communication books, a shared communication aid context therefore resulted, wherein individuals and their communication partners were better supported during communication endeavours. This may have resulted in higher outcome scores by the assessors. It should also be noted that the PWA may have been more inclined and willing to attempt communication as the camp progressed due to increased familiarity and the supported communication strategies being employed by volunteers. Therefore, it may not have been the individual's expressive and receptive abilities that increased, but rather they experienced an increased ability to understand and communicate their message due to the supported communication environment.

***Cognitive-Communication.*** The Cognitive-Communication scale of the AusTOMs revealed a statistically significant effect in the Impairment domain. The pre- to post-assessment results demonstrate the student clinicians rated the participants as significantly less impaired by cognitive communication deficiencies. The same arguments made for the Receptive and Expressive Language scales could also be argued for the Cognitive-Communication scales. For example, it could be that the participants did not necessarily improve on their cognitive communication abilities, but rather that the assessors became increasingly familiar with the

participants and thereby better understood their communication strengths and limitations.

However, it is possible that the supportive and relaxing nature of the camp alleviated some of the impairments experienced by the PWA, thus providing an opportunity to indirectly target those impairments which may have led to the improvements seen.

***AusTOMs Limitations.*** While the results indicated statistically significant effects on the three above mentioned scales of the AusTOMs, it is important to recognize specific limitations of this measure. First, the pre-assessment measures were taken within two hours of the participants arriving at camp. During this time they may have been slightly uncomfortable and/or overwhelmed by meeting a large number of people and being in a new environment. For this reason, it is quite possible that the assessors may have misattributed the participants' behaviour as cognitive impairments because aphasia is often accompanied by deficits in working memory (Mayer & Murray, 2012; Murray, 2012). Second, the AusTOMs manual states that the descriptions provided are not likely to be a perfect fit for any one client (2004). In an attempt to control for inter-rater reliability, assessors were paired when observing PWA; however, not every student clinician gave ratings for each participant and therefore it cannot be ruled out that there are potential differences in ratings. Furthermore, the pre-assessment of the AusTOMs was conducted during one 45-minute activity, whereas the post-assessment was done after experimenters had seen the participants across a variety of contexts and environments. Essentially, throughout the duration of the camp, the researchers were able to better familiarize themselves with the participants and therefore understand how they communicate in a more holistic sense. In addition, upon getting to know the participants and learning their communicative strengths and weaknesses, volunteers tailored their

communication style to support the individual with aphasia. Consequently, this could have created some experimenter bias as the researchers formed more personal relationships with the participants. Lastly, it should be noted that student clinicians conducted the assessment. While the rating scales were provided, the researchers cannot disregard the amount of knowledge and insight that a registered speech-language pathologist would have in assessing individuals on such measures. It is difficult to determine exactly what may have contributed to this finding, but it is important to note that while attending camp there was at least a “perceived” increase in receptive abilities on the part of the assessors.

### ***CETI***

The Communication Effectiveness Index (CETI) is a measure of functional communication abilities for those living with aphasia. In post-administration of the CETI, the CPs did not see their previous scores for their partners with aphasia, which is a standard procedure of the CETI. This was an error on the part of the assessors and may have confounded the results. Alternatively, the fact that a significant increase was found, despite the CPs not having access to their pre-camp ratings for comparison, is perhaps further evidence to suggest the presence of a functional change in the PWA participants. Consequently, the researchers believe that CP report via the CETI remains an informative measure of true functional change.

At camp, PWA were able to practice their communication skills in a variety of environments and with a number of communication partners. Due to the supported environment, PWA may have had more successful communication interactions than they otherwise would have had in their typical daily activities. Also, the CPs may have witnessed their partner participating in a variety of new and different contexts which could have

contributed to an altered view of the PWA's communication abilities. During the ABAC, the PWA were exposed to new opportunities and it is likely that witnessing their communication behaviours in a new context changed the CPs' perceptions of their partners' communication strengths. It is possible that the PWA had these communication skills and abilities prior to camp but their CPs may not have observed them. Again, it is difficult to say whether there was a significant change in the participants' functioning, but it stands to reason that exposure to, and participation in, a variety of new activities, or pre-stroke activities, could benefit an individual in everyday activities and conversations.

***CETI Limitations.*** Factors that support the CETI results have been discussed; however, a few limitations should be noted. As previously stated, an administration error occurred at the time of post-assessment. Furthermore, it was not explicitly stated to CPs that their ratings should be on actual observed events rather than predict potential performance for unobserved events. This may have resulted in the CPs rating what they thought the person was capable of rather than a tangible moment they had witnessed. Finally, there was a very small sample size (N=4) of CPs who participated in the pre- and post-camp assessment of the CETI. While significant results have been reported, there could have been increased reliability of the results if the sample size was larger.

## **CONCLUSION AND FUTURE DIRECTIONS**

The ABAC provided PWA and their CPs a weekend retreat that offered them opportunities to participate in activities and respite, and to form social connections in a supported environment. This study aimed to examine the efficacy of a retreat-based service delivery model for increasing activity participation and quality of life in those living with

aphasia. Across measures (ALA, AusTOMs and CETI), the researchers found that attending the camp had a statistically significant positive effect.

In regards to the ALA, there was a statistical increase in the overall Participation and Personal domains. The camp provided the resources and the opportunities to provide an enriched environment that supported the PWA and created positive change in aspects of their life that may not be addressed by traditional impairment-based therapy. The results of the AusTOMs found statistically significant increases in Expressive and Receptive Language and Cognitive-Communication scales. While statistically significant increases were found, the limitations in conducting this assessment were significant and may have resulted in skewed outcomes. There were also positive significant findings on the CETI scale. This could be suggestive of an increase in the overall abilities of the participants due to the opportunities provided at camp in regard to communicating in a variety of contexts and with several communication partners. Another explanation may be that the CPs' perceptions of the PWA's communication abilities changed as a direct result of witnessing the PWA communicate successfully in different contexts and with different people.

While quantitative data from both CPs and PWA was obtained, there is a need for assessment of the qualitative data regarding the camp. A review of the qualitative outcomes from the ABAC would provide more insight into the experiences felt by campers. It may also be beneficial to conduct research at several aphasia camps in order to further support the findings reported by this study. Finally, future research should explore the specific variables of aphasia camps which contribute to the overall success in the provision of support and opportunities to those with aphasia and their CPs. Overall, there is limited research on the efficacy of aphasia



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camps as an alternative-service delivery model; however, findings from this preliminary study suggest it is a viable therapeutic context.

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