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AN INTENSIVE APHASIA NEEDS ASSESSMENT TOOL

A Thesis
Presented to
The Faculty of the Department of Communication Sciences and Disorders
Western Kentucky University
Bowling Green, KY

In Partial Fulfillment
Of the Requirements for the Degree
Master of Science

By Dalana M Henson

May 2016

AN INTENSIVE APHASIA NEEDS ASSESSMENT TOOL

Date Recommended
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Janice Smith
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AN INTENSIVE APHASIA NEEDS ASSESSMENT TOOL

Dalana Henson May 2016 75 Pages

Directed by: Jo Shackelford, Richard Dressler, and Janice Smith

Department of Communication Sciences and Disorders Western Kentucky University Persons with aphasia (PWAs) often demonstrate challenges in the areas of expressive language, comprehension, reading, and writing. Due to these deficits, PWAs have limited opportunity to express their opinions and contribute to treatment planning. This project focused on the development of a self-report needs assessment tool for PWAs that facilitates PWAs participation in treatment planning. The needs assessment tool was designed using aphasia-friendly features including pictographic/visual analog scale, key words in bold, simple wording, large font, consistent question formatting, flexible administration, and the use of a communication partner/interview. The needs assessment tool was administered to seven PWAs in the Bowling Green, Kentucky area. Participants were recruited from short-term rehabilitation facilities, long-term care facilities, and personal homes. The needs assessment tool is comprised of 12 items targeting interest in therapeutic offerings for inclusion in a new intensive comprehensive aphasia program (ICAP). Results revealed the importance of flexible administration in response to participants' communication abilities and limitations. With use of communicative support, the needs assessment tool provided an opportunity for PWAs to effectively express treatment preferences. Participants indicated moderate interest in an ICAP at Western Kentucky University and treatment options including individual speech and language therapy, physical therapy, and community outings.

Introduction

Aphasia is a language disorder acquired after focal brain damage, most commonly stroke, resulting in difficulty communicating (Holland, Fromm, DeRuyter, & Stein, 1996). Persons with aphasia (PWAs) often demonstrate challenges in the areas of expressive language, comprehension, reading, and writing. Ongoing research identifies the most effective treatment approaches for PWAs. One such approach with a strong evidence base is the use of intensive therapy. The literature examining the intensity of aphasia therapy reflects that more intensive therapy for persons with aphasia is often more effective than the same amount of therapy delivered over a longer time period. Traditional service delivery is approximately one hour of therapy two to five times a week over a period of months. However, as stated by Bhogal, Teasell, and Speechley (2003), "the more intensive the therapy, the greater the improvement" (p. 987).

The National Stroke Association estimates an incidence of 80,000 new cases of aphasia per year in the United States as of 2008 (ASHA, 2015). Among stroke patients, 21-38% will acquire aphasia as a result of stroke (Engelter et. al, 2006). Language difficulties associated with aphasia directly impact an individual's quality of life in the areas of independence, social interaction, vocational effectiveness, and leisure activities. Intensive comprehensive aphasia programs (ICAPs) have been developed at several centers across the United States. These programs offer several hours of therapy per day for several weeks. A survey of ICAPs presented by Rose, Cherney, and Worrall (2013) defined an ICAP as providing a minimum of 3 hours of daily treatment over a period of at least two weeks. ICAPs consist of various program elements, therapies, and other additional offerings. ICAPs include individual, group, and computer based therapy.

Among these therapy formats, ICAPs target deficits in language, reading, writing, word finding, and social competence. Specific therapies frequently utilized include language impairment based strategies, constraint induced language treatment, and activities/participation based therapy.

Due to language deficits, PWAs are often denied the opportunity to speak for themselves and indicate treatment preferences; treatment planning is frequently based on proxy report rather than self-report. A proxy has been defined as a person close to the patient who provides reports for the patient (Doyle, Hula, Hula, Stone, Wambaugh, Ross, & Schumacher, 2013). A proxy makes judgments based on observation, discussion, joint experiences, or related knowledge (Hayley & Wangerman, 2012). However, proxy report may not be as reliable or in complete agreement with a self-report by the PWA. Proxy report is commonly utilized because of the difficulty language challenges create in obtaining information and perspective from PWAs (Irwin, 2012).

Language deficits make self-report a complicated, but not impossible, task. As determined by Simmons-Mackie, Kagan, Victor, Carling-Rowland, Mok, Hoch, & Striener (2014), "there is evidence that people with aphasia, even severe aphasia, can report their own perspectives if given appropriate communicative support" (p.84). There are currently several self-report measures for PWAs that have been shown to be functional and reliable which are useful for understanding the perspectives, preferences, and quality of life of individuals with aphasia. Review of existing self-report tools contributed to development and formatting of the aphasia-friendly needs assessment tool used for this project.

A review of current literature on the intensity and efficacy of aphasia treatment, understanding of current intensive comprehensive aphasia programs, the discrepancy between proxy report and self-report, and the evidence of the reliability of self-report measures indicates the need for a tool that effectively allows PWAs to communicate their perspective and preferences in program development and treatment planning.

This project utilized best practices within the field of speech language pathology to inform creation of an aphasia-friendly survey which allowed PWAs to express treatment preferences. Design elements such as pictures and simple wording were used to ensure reliability of the self-report measure (Simmons-Mackie et al., 2014). This self-report measure allowed PWAs to communicate interests, goals, and format for speech language pathology services. Administration and data collection from this survey will contribute to future program planning in terms of offered therapies, therapy format, related services, and participation in community outings.

Theoretical Framework

The idea of self-efficacy and control was introduced using the term 'locus of control' (Rotter, 1966). Locus of control refers to the extent to which individuals believe they can control events affecting them. An individual's locus of control can be both external and internal. An internal locus of control has been associated with better health outcomes (Wallston, Wallston, Smith, & Dobbins, 1987). The idea of locus of control helped shape theories of self-efficacy including Bandura's Social Cognitive Theory (Bandura 1977). In this theory, self-efficacy refers to one's ability to successfully execute a behavior to produce outcomes. However, self-efficacy is not a fixed personality

construct but is shaped from various life experiences and events that shape how individuals see themselves.

Self-efficacy is hypothesized to be a factor that influences outcomes from intervention for a communication disorder in older adults (Clark, Yeagle, Arbaje, Lin, Niparko, & Francis, 2012). As yet, use of self-efficacy theory has not been widely applied to the field of communication disorders. However, Babbitt and Cherney (2010) introduced the idea of "communication confidence" for individuals with communication disorders, with a focus on aphasia. They speculated that confidence in the ability to communicate may be strongly associated with personal autonomy, self-efficacy, and self-determination (Babbitt and Chereney 2010). Autonomy, the quality or state of being self-governed, and self-efficacy, free choice of one's own acts or states without external influence, are two key element contributing to an individual's communicative confidence (Babbit and Chereny, 2010).

A communication disorder may lead to decreased communicative confidence.

Decreased communicative confidence has been associated with a reduced ability to communicate personal wishes, diminished autonomy, and learned helplessness. In contrast, feelings of control with regard to communication may be associated with more global feelings of control and competence (Babbit and Chereny, 2010).

In order to achieve communicative confidence, individuals with communication disorders may require communicative support. The theory of person-environment fit theorizes that the environment can be adapted in order to meet the needs of the individual (Lewin 1938). Lewin states that optimal well-being is achieved when an individual's needs are in equilibrium with environmental characteristics. In terms of persons with

aphasia, communicative support aids in creating equilibrium between the PWA's communicative ability and their environment. This equilibrium allows for more successful interaction and participation.

Person-environment fit theories are in line with models of disability including the World Health Organization's International Classification of Functioning, Disability and Health which utilizes a biopsychosocial model (WHO-ICF, 2007). This model takes into consideration the interaction between the individual and the environment. The WHO-ICF model looks at the individual not only from a biological standpoint but also from a psychological and social viewpoint. The model considers the person as a whole including how their impairments may affect their lives in a variety of contexts. By utilizing the WHO-ICF model of disability, rehabilitation that focuses on aiding an individual to improve communication will likely also improve physical, social, and psychological well-being. This model allows for patients to have more involvement with decisions and direction of their course of rehabilitation treatment rather than relying on the rehabilitation specialist or caregivers alone.

Communicative support allows individuals with communication disorders to improve their ability to communicate in a variety of contexts including treatment planning. This project utilizes theories of self-efficacy, person-environment fit, and holistic models of disability to examine the use of a self-report needs assessment tool for persons with aphasia. The needs assessment tool provides the necessary environmental modification to support PWAs in improving communicative confidence and self-efficacy in order to play an active role in their rehabilitation.

Literature Review

In order to understand and develop a tool to survey PWAs, many factors must be explored. This literature review examines the incidence of aphasia and the impact of aphasia on quality of life; establishing a need for continued service development for PWAs. The efficacy of intensive aphasia treatment is studied, providing support and rationale for the continued development of intensive comprehensive aphasia programs. Existing ICAPs are reviewed and analyzed to gain an understanding of program elements to take into consideration for the development of a needs assessment tool and program elements. The examination of efficacy and elements of current self-report measures of aphasia and proxy respondents provides evidence for the use of self-report measures for PWAs and information regarding appropriate and evidenced-based development of a needs assessment tool for PWAs.

Incidence of Aphasia

It is important to understand the number of individuals affected by this communication disorder in order to determine the necessity and development of services. According to Code and Petheram (2011), incidence refers to the number of new cases per year of a disorder occurring within a specific population. Prevalence refers to the total number of cases that currently exist within a population. The National Stroke Association (2008) estimates an incidence of 80,000 new cases of aphasia per year in the United States. Among stroke patients, 21-38% will acquire aphasia as a result of their stroke (Engelter et. al., 2006). The National Institute of Neurological Disorders and Stroke estimates the prevalence of aphasia at approximately 1 million people. This statistic translates to approximately 1 in every 250 people in the Unites States are living with this disorder (NINDS, n.d) Fifteen percent of individuals under the age of 65 experience

aphasia and up to 43% of individuals over the age of 85 experience aphasia (Engelter et al., 2006). With 1 million individuals living with aphasia and 80,000 new cases a year, it becomes crucial to develop programs and services to support PWAs for an improvement in quality of life.

Aphasia directly affects individuals' ability to use language resulting in a change to their life participation. Language is directly associated with our ability to communicate and fulfill our accustomed roles in society such as roles as a friend, parent, sibling, employee, employer, and so forth. Social isolation is a common result of aphasia. Other common life consequences of aphasia are loss of income, loss of safety due to inability to express need for help, and loss of independence (Holland, Fromm, DeRuyter, & Stein, 1996).

Efficacy of Intensive Aphasia Therapy

The most effective therapy dosage for PWAs is an area of ongoing research.

Studies have examined the effectiveness of intensive therapy providing abundant support for the use of intensive aphasia therapy. Researchers have determined that intensive aphasia therapy is effective but is often dependent on individual characteristics of patients, severity level, stage of aphasia, and therapy type.

Positive Studies. Studies have shown positive support indicating efficacy of increased intensity of aphasia therapy. Bhogal, Teasell, and Speechley (2003), Bhogal, Teasell, Foley, and Speechley (2003), Basso (2005), Pullvermuller, Neininger, Elbert, Mohr, Rockstroth, Koebble, and Taub (2001), Robey (1998), and Basso and Caporali (2001) report positive outcomes of treatment by increasing the intensity of therapy.

Bhogal, Teasell, and Speechley (2003) presented a MEDLINE literature review investigating aphasia therapy after stroke from 1975 to 2002 and determined that half of the studies presented positive outcomes, while the other half presented negative or neutral outcomes. Among the positive studies, were the outcomes from patients who received therapy ranging from 8 to 25 hours a week for 6-12 weeks. Although these studies did not utilize a treatment intensity as abundant as many of the ICAPs currently available, comparatively they offer more intensive treatment regimens than traditional therapy programs. The five studies that yielded negative results provided therapy ranging from 45 minutes to 3 hours a week over a time period of 20 weeks to a year. On average, the positive studies included 108 hours of total therapy compared to only 43.6 hours in the negative studies. Participants receiving more intensive therapy had greater improvement on both the Porch Index of Communication Ability (PICA) and the Token Test. It is noted that there was no significant difference on the Functional Communication Profile scores of participants (Bhogal, Teasell, & Speechley, 2003).

Bhogal, Teasell, Foley, and Speechley published further evidence on the efficacy of intensive aphasia treatment in 2003. Expanding on the literature previously discussed, a more comprehensive search, including five electronic databases, was completed. Conclusions drawn from this review were in line with previous findings. Participants that demonstrated significant positive outcomes received an average of 8.8 hours of therapy whereas negative outcomes were found by those receiving less than 2 hours of therapy per week over a longer period of time (Bhogal, Teasel, Foley, and Speechley, 2003).

According to Basso (2005), evidence suggests that greater amounts of therapy have a better chance to affect recovery positively than smaller amounts of therapy as

evidenced by the results of multiple reviewed studies. An interesting and relevant article by Pulvermuller, Neininger, Elbert, Mohr, Rockstroth, Koebbel, and Taub (2001) was pulled from Basso's (2005) review. This study consisted of two treatment groups; one receiving conventional therapy and the other constraint-induced therapy. The constraint-induced therapy group showed significant overall improvement. The conventional therapy group showed no overall improvement. The improvement in the constraint-induced therapy group can be attributed to either the type of treatment or the intensity of treatment. The constraint-induced treatment group received more intensive treatment and demonstrated more improvement (Pulvermuller et. al, 2001). Conclusions must be used with caution from this source due to the inability to extract which factor attributed to the improvement seen in the participants.

A meta-analysis conducted by Robey in 1998 addressed the efficacy of aphasia therapy in terms of amount of therapy. This meta-analysis consisted of 55 studies.

Amount of therapy was quantified in three categories; low, moderate, and high. The low range was less than 1.5 hours per week. The moderate range was 2-3 hours per week. The high range was greater than or equal to 5 hours per week. The results indicated that treatment length in excess of two hours improved outcomes more positively than shorter durations. Robey concluded the more intensive the treatment, the greater the change (Robey 1998).

Basso and Caporali (2001) conducted a study comparing 3 patient pairs with similar diagnoses in order to determine the efficacy of increased intensity for aphasia therapy. Within the pairs, one patient received 2-3 hours of therapy per day for seven days a week. The other patient received 1 hour of therapy for five days a week. This

study looked specifically at overall improvement and improvement in quality of daily life after receiving more intensive treatment. Upon review of the results, those receiving only one hour of treatment a day plateaued. The group receiving more intensive treatment continued to make progress on assessment measures and in their daily life. For example, patients FC and MG reported that they talked to their children and partners more.

Chronic and Acute Aphasia. Recent studies suggest that intensive aphasia therapy may be more effective for individuals who have chronic aphasia versus those in an acute stage (Code, Torney, Gildea-Howardine, & Wilmes, 2010; Cherney, Patterson, & Raymer 2011; & Barthel, Meinzer, Djundja, & Rockstroth, 2008). The acute stage of aphasia refers to an individual who is recently post injury/post stroke. Chronic aphasia refers to individuals whose aphasia symptoms persist beyond the acute stages. There is no distinct time frame in which a person progresses from acute to chronic, however, language difficulties persisting six months post stroke are typically classified as chronic. Code, Torney, Gildea-Howardine, and Wilmes (2010), Cherney, Patterson, and Raymer (2011), and Barthel, Meinzer, Djundja, and Rockstroth (2008) conclude that more intensive therapy for individuals in the chronic stage of aphasia present more positive outcomes whereas PWA in acute stage of aphasia present with neutral outcomes.

A study conducted by Code, Torney, Gildea-Howardine, and Willmes (2010), examined the outcome of a one-month intensive treatment program for people with chronic aphasia. This study included eight participants of varying severity, age, time since onset of stroke, and type/nature of aphasia. Outcomes were analyzed for the participants as a group and individually. Results indicated that the intensive block of treatment was effective in improving language processing abilities for most participants.

The study resulted in significant group improvement in overall language performance on standardized tests. Individual responses were more varied but intensive therapy resulted in the most improvement in more severely impaired participants. Positive changes occurred in reading, writing, naming, and comprehension. The final conclusion from this study was "chronically aphasic people can benefit significantly from intensive blocks of impairment-based treatment" (Code, Torney, Howardine, & Willmes, 2010).

Cherney, Patterson, and Raymer (2011) stated that there is a growing body of evidence suggesting intensive therapy produces positive outcomes. However, evidence also suggests that when directly comparing intensive versus non-intensive therapy in acute aphasia, outcomes appear equivocal. In agreement with Code, Tourney, Howardine, and Willmes (2010), there is a strong relationship between intensity and positive outcomes in chronic aphasia (Chereny, Patterson, & Raymer, 2011). It can be concluded that intensive therapy produces equally positive treatment outcomes as non-intensive treatment for individuals in the acute phase of aphasia. Intensive aphasia treatment appears to produce significantly more positive outcomes for individuals in the chronic phase of aphasia.

Examining intensive language therapy in chronic aphasia, Barthel, Meinzer, Djundja, and Rockstroh (2008), conducted a study to determine which aspect of treatment contributed the most improvement. This study compared model-oriented aphasia therapy (MOAT) with the previous findings of a constraint-induced aphasia therapy (CIAT) study. CIAT employs shaping and constraint of compensatory nonverbal communication in a group setting. Shaping is defined as systematically increasing the task difficulty dependent on the individual's abilities in order to prevent failure and allow steady

reinforcement. In comparison, MOAT, also emphasizes the use of shaping but focuses more specifically on providing individual therapy based on individual symptoms.

Within the MOAT study, 12 PWAs received 30 hours of therapy over ten days. Substantial improvement of language function in chronic aphasia was achieved with the use of intensive MOAT. Improvement on standardized assessment and everyday communication was observed. The authors caution that the improvement seen in language abilities cannot be specifically attributed to the intensity of treatment alone, however, this specific type of intensive treatment for PWAs showed positive outcomes (Barthel, Meinzer, Djundja, & Rockstroh 2008).

Mixed Results and Neutral Studies. Bakheit et. al. (2007), conducted a parallel group study of the effect of speech and language therapy intensity on the early recovery from post stroke aphasia. This study compared groups of individuals with aphasia receiving 5 hours of therapy a week versus 2 hours of therapy. The study concluded that those receiving 5 hours/week of treatment did not demonstrate a greater improvement on the Western Aphasia Battery assessment than those receiving only 2 hours of therapy. In this study, 5 hours a week is considered as an intensive therapy program. In contrast, the majority of previously discussed studies received far more intensive treatment. A likely explanation of the lack of more improvement in this study is that the "intensive" group did not receive sufficient therapy that is required to begin seeing significant language improvement noted in previous studies (Bakeit et. al., 2007).

Intensive treatment has been shown to have positive outcomes for PWAs.

However, studies rarely compared intensive and non-intensive treatment. Hinckley and

Carr (2005) compared two treatment groups utilizing context based treatment. The

intensive treatment group received 20 hours of individual therapy weekly and 5 hours group therapy for a cumulative total of 25 hours of therapy per week. The non-intensive treatment group participated in 4 hours of weekly treatment. The authors utilized four assessments as pre- and post-test measures. Results indicated a similar overall improvement in both the intensive and non-intensive groups indicating the specific context based treatment outcomes are not dependent on higher intensity treatment. However, the intensive treatment group made significantly more improvement on written-naming tasks. A likely explanation of the improvement on written-naming tasks is that increased therapy intensity facilitates generalization of skills learned in therapy. The authors conclude that the study provides evidence that intensive treatment for persons with aphasia may lead to more generalized improvement in language consistent with findings of Robey (1998).

Although there is mounting evidence that more intensive aphasia treatment is effective, recent research has shown some discrepancy and caution in this notion. Results from previous research supporting the efficacy of intensive aphasia treatment must be used with some caution due to the varied types of treatments utilized and patient characteristics (Cherney, Patterson, & Raymer 2011). As mentioned in the study conducted by Pulvermuller (2001), it is often hard to determine which factor led to improvement.

Methodological concerns related to patient characteristics including severity and type of aphasia, have been discussed. Cherney, Patterson, and Raymer (2011) determined that better outcomes occurred for patients with chronic aphasia rather than those in acute stage of recovery. After a review of cumulative evidence, these authors deemed, "that

there is no clear advantage for intensive treatment schedules" (Cherney, Patterson, & Raymer 2011). However, studies comparing very similar patients using the same type of therapy have been conducted. Brady, Kelly, Godwin, and Enderby (2012) conducted a review looking at studies that directly compared higher versus lower doses of aphasia therapy. They concluded that there is "some indication of the benefits of intensive approaches" (Brady, Kelly, Godwin, & Enderby, 2012).

Future research should also address issues of discrepancy based on the inability to determine which factor of treatment led to positive outcomes. Studies should focus on aligning treatment groups to be more identical in regards to the type of treatment that is administered and variation in patient characteristics. Study design needs to be strictly focused on evaluating the effects of treatment intensity alone. In order to better align research and results, a universal definition of "intensive aphasia treatment" needs to be created and utilized. A more universal understanding of what qualifies as intensive would allow discrepancies to be examined and resolved.

Current Intensive Comprehensive Aphasia Programs

As evidenced by ongoing research, intensive language therapy, as compared to traditional speech and language therapy may be more effective for individuals experiencing chronic aphasia. Bhogal, Teasell, and Speechley (2003) completed a review of the efficacy of intensive aphasia treatment and concluded that intensive treatment produced more significant benefits than conventional speech and language therapy.

Intense therapy over a short amount of time can improve outcomes of speech and language therapy for individuals with stroke-induced aphasia.

Intensive comprehensive aphasia programs are utilized in order to maximize client outcomes and provide access to intensive therapy services (Winans-Mitrik, Hula, Dickey, Schumacher, Swoyer, & Doyle, 2014). ICAPs are implemented in small numbers in the United States. Review of current ICAPs contributed to the understanding of program elements that are considered best practice and should be included when gathering preferences and needs of PWAs.

Location. Thirteen intensive aphasia treatment programs are located throughout the United States (See Figure 1). Geographically, programs are clustered in the northeast, with additional programs available in Florida, Colorado, and Montana. There is a dearth of ICAPs in the western and southeastern regions of the country, with the exception of Florida. This locational disparity places a burden of extensive travel for many individuals who wish to take part in intensive treatment programs.

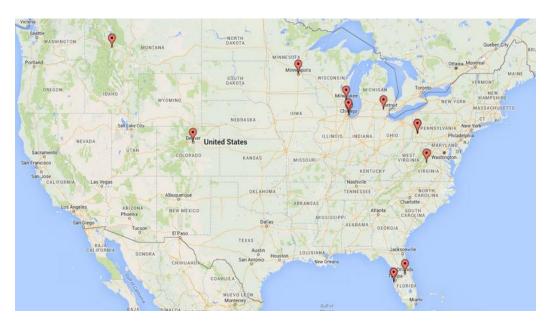


Figure 1. Location of existing ICAPs in the United States. Each point on the map represents an ICAP. Two programs are located in St. Petersburg, FL.

Program Length and Therapy Dosage. Current programs employ similar amounts of therapy, length of program, and provided services. Programs range in length from ten days to eight weeks. Most programs operate for a length of four to six weeks. It is important to note that both ten days and eight weeks are outliers in regards to program length. Programs are designed to provide patients with two to six hours of therapy a day, either four or five days a week. Due to the structured nature of intensive aphasia programs, several programs are offered specific times of the year. Programs at the Rehabilitation Institute of Chicago, Northwestern University, PIRATE, Woodrow Wilson Residential Aphasia Program, and North Memorial are offered 2 to 4 times a year (Rehabilitation Institute of Chicago, 2015; Northwestern University, 2015; U.S. Department of Veterans Affairs, 2015; Wilson Workforce and Rehabiliation Center, 2015; & North Memorial Healthcare, 2015). University programs including Aphasia House, Big Sky Aphasia Program, and Marquette University operate on a semester like schedule (Aphasia House, 2015; University of Montana, 2015; & Marquette University, 2015). Year-round programs include Yones Speech Therapy, Steps Forward, and Aphasia Center of Innovative Treatment (Yones Speech Therapy, 2015; The Aphasia Center, 2015; & Aphasia Center of Innovative Treatment, 2015). The Aphasia Center of Innovative Treatment is offered solely online (Aphasia Center of Innovative Treatment, 2015). The location, length, time, and start dates of available programs are shown in Table 1.

Table 1

Overview of Existing Intensive Comprehensive Aphasia Programs (ICAPs)

Program	Location	Therapy Dosage	Length
Constraint-Induced Aphasia Therapy Clinic	Denver, CO	3 hrs/day	10 days
Yones Speech Therapy	St. Petersburg, FL	2-5 hrs/day	Varies
Aphasia House	Orlando, FL	4hrs/ day, 4 days/wk	6 wks
Steps Forward Aphasia Program	St. Petersburg, FL	100-200hrs	4-8 wks
Rehab Institute of Chicago Intensive Aphasia Tx Program	Chicago, IL	30hrs/wk	4 wks
Intensive Aphasia	Evanston, IL	4hrs/day, 60hrs/wk	4 wks
Program University of Michigan Aphasia Program	Ann Arbor, MI	28hrs/wk	4-5 wks
Big Sky Aphasia Program	Missoula, MT	9-12hrs/wk	Ongoing
Aphasia Center of Innovative Tx	Pittsburg, PA	Customized	4 wks
PIRATE	Pittsburg, PA	6hrs/day	4-6 wks
Woodrow Wilson Residential Aphasia Program	Fishersville, VA	Varies	3 wks
Intensive Aphasia Program Marquette University Speech and Hearing	Milwaukee, WI	3hrs/day	4 wks
North Memorial's Intensive Aphasia Program	Minneapolis, MN	3.5hrs/day	

Note. Tx = treatment. hrs = hours. wk = week.

Speech Language Therapy. The type of treatment provided is comparable across programs. With the exception of The Aphasia Center of Innovative Treatment, all services are provided through group and individual therapy with computer based

treatment as a supplementary therapy. Without exception, every program offers caregiver education and support. The Steps Forward program provides more individual therapy than many other programs. This program has a 1:1 client to therapy ratio for approximately 80% of a treatment day. The Steps Forward program also provides an Aphasia Action Plan. This plan is given to patients and caregivers to provide them with a plan for life after the program. This plan includes comprehensive results of assessments and therapy to be given to the next speech therapist that will see the patient, tips and instructions for caregivers, detailed homework for continued practice, instructions for online treatment, and a several other components (The Aphasia Center, 2015). The specific type of aphasia assessment tools used in current programs is not readily available, however, programs include some type of assessment as a pre-posttest at the start and end of therapy to measure progress. While providing an evaluation is the most common practice among programs, a handful of programs accept referrals and assessments from other professionals.

A range of speech and language therapy approaches are used within ICAPs.

Programs combine the use of traditional, constraint induced, and life participation approaches among other individualized therapy techniques. Yones Speech Therapy and University of Michigan Aphasia Program focus on the use of the Life Participation Approach to Aphasia (LPAA) emphasizing client-directed goals and re-engagement in life (Yones Speech Therapy, 2015 & University of Michigan, 2012). The Woodrow Wilson Residential Aphasia Program emphasizes vocational competency and returning to the workforce through the use of life participation approaches, community outings, and vocational exploration (Wilson Workforce and Rehabilitation Center, 2015). Constrain-

induced therapy is offered at various programs. Constraint induced language therapy focuses on increasing verbal output. ICAPs focus on the implementation of evidence based practice and use a wide variety of speech and language approaches that are most appropriate for each individual client.

Additional Therapy. Current ICAPs provide concurrent therapy in combination with speech language therapy. Related therapies are frequently offered to aid in overall improvement of quality of life. Allied therapies offered include music, art, occupational, and physical therapy. The University of Michigan Aphasia Program (UMAP) employs 1 hour of daily music therapy (University of Michigan, 2012). Art, music, and horticulture therapy are utilized in congruence with speech and language services at the Aphasia House (Aphasia House, 2015). The Woodrow Wilson Residential Aphasia Program and Steps Forward program offer physical therapy and occupational therapy as needed in order to provide additional support and rehabilitation (Wilson Workforce and Rehabilitation Center, 2015 & The Aphasia Center, 2015).

Social Opportunities. Social and recreational opportunities for PWAs are offered at current ICAPs in order to improve social communication, promote re-engagement in life, and utilize learned skills in the community. Game nights, themed dinners, and outings to local attractions provide functional use of learned skills in the community.

Services for Caregivers. All ICAPs provide a form of caregiver/family support.

Each program either encourages or requires a caregiver to accompany the patient receiving treatment. Programs offer daily or weekly educational and support sessions for caregivers. The University of Michigan Aphasia Program provides two hours per week of

caregiver educational seminars or support groups exemplifying the importance of caregivers' roles in aphasia treatment (University of Michigan, 2012).

Numerous programs allow and encourage caregivers to participate in therapy.

Programs appear concerned and aware of the importance of caregivers and strive to assist and equip caregivers with the skills necessary to continue success with their loved ones after the treatment programs end as evidenced by the inclusion of caregiver education, participation, and resources implemented across programs.

Candidacy. ICAPs have eligibility requirements for participation. The most basic eligibility requirement is that a potential participant must have aphasia. The severity and type of aphasia is not characteristically a factor in determining acceptance. All programs require that the individual be medically stable and semi-independent. These requirements are in place to ensure that participants are capable of participating in the intense nature of the program. Physical, emotional, and mental capability of participating in several hours of therapy per day are considered as eligibility requirements.

Eligibility for all programs is determined through submission of an application. Applications collect basic information, medical history, questions about communication abilities, and caregiver information. Applications are intended to gather information about future participants to determine if they will benefit from the program and are capable of participating. The applications provide the program therapists with case histories and an idea about the communication abilities of future clients. This information is used to begin preparation for each program. Participants are chosen after applications are received and reviewed. Programs accept participants on a first come, first serve basis

if all candidacy requirements are met. Common reasons applicants are turned away are program capacity, medical instability, or lack of caregiver support.

While most programs are open to anyone who has aphasia, some programs are specialized to certain populations. Two examples include The Program for Intensive Residential Aphasia Treatment and Education (PIRATE) and the Big Sky Aphasia Program. PIRATE is open to only veterans and active duty service members.

Participants in PIRATE must also be enrolled in the VA Healthcare system (U.S. Department of Veterans Affairs, 2015). The Big Sky Aphasia program at the University of Montana has a stipulation requiring participants to be from the community/state (University of Montana, 2015).

Cost. The cost of participating in an intensive aphasia program ranges widely. The cost of programs must be examined based on components included in the cost. Program costs differ due to included services such as lodging, meals, length of program, number of required staff/licensed therapist, cost of locations, and other various factors. Programs vary from \$350 to \$33,000. This range is based solely on cost per program and does not account for inclusion of different elements such as housing. When broken down into cost per week the range is \$70 to \$5229.

Accepted forms of payment are also varied across programs. Insurance,

Medicare, and private pay are common forms of accepted payment. Insurance and

Medicare are less commonly accepted than private pay due to challenges with billing for
the number of treatment hours provided by ICAPs. Direct payment from
patient/caregivers is most common practice and can place a financial burden on
participants. In order to aid participants in paying for the program, payment plans and

scholarships are offered by some ICAPs. For example, the Big Sky Aphasia program and Steps Forward both offer partial scholarships and discounts (University of Montana, 2015 & The Aphasia Center, 2015).

ICAP at Western Kentucky University

Based on the geographical location of current programs, a need for the development of more ICAPs emerges. The development of an intensive aphasia program requires examination of current programs in order to determine the best service delivery options. Based on current resources and location, Western Kentucky University is a prime candidate to create a new intensive aphasia program. By reviewing current programs and developing a needs assessment tool to survey persons with aphasia, a new ICAP utilizing evidence based practice and opinions of PWAs would be beneficial.

Western Kentucky University (WKU) in Bowling Green, Kentucky is located in the south central U.S., within a day's drive of 60% of the U.S. population, making it an ideal location for an intensive aphasia program (Bowling Green Area Chamber of Commerce, 2015).

Western Kentucky University is currently home to a communication disorders clinic that largely serves a pediatric population. The Department of Communication Sciences and Disorders (CSD) at WKU, however, has the space, clinical expertise, and support services required to develop and offer an ICAP. Development of an ICAP would additionally offer CSD students a more varied clinical experience with adult clients during internship. Due to the nature of a university clinic, WKU could offer intensive services to PWA at a significantly reduced cost than many of the current ICAP programs through use of graduate clinicians and current resources.

In addition to location and current resources, the development of an ICAP program at WKU allows for students to engage in research in the area of aphasia, an opportunity that is otherwise limited. An ICAP program at WKU would provide opportunity for inter-professional collaboration among students in speech language pathology, nursing, and physical therapy.

Self-Report Measures for Aphasia

Studies have supported the idea that individuals with aphasia are able to provide meaningful responses on quality of life and severity self-report measures. Doyle et. al. (2013) evaluated whether comprehension impairments in aphasia prevented PWAs from responding meaningfully to assessment items. They determined that individuals with aphasia were able to respond appropriately and meaningful to self-report measures when examining talking, comprehension, and writing. The combination of research supporting the competency of individuals with aphasia to self-report and the existence of discrepancy between proxy responses and self-report measures provides the rationale to develop a needs assessment tool in a self-report format. The use of self-report has the potential to increase personal autonomy, self-efficacy, and self-determination improving communicative confidence as hypothesized by Babbitt and Cherney (2010).

The format of self-report measures for PWAs is very important. Research in this area has led to the development of specially-designed scales, surveys, and tools that effectively measure quality of life and severity for individuals with aphasia. Tools include: Kagan Assessment of Living with Aphasia (ALA), Communicative Effectiveness Index (CETI), Communication Confidence Scale for Aphasia (CCRSA), Visual Analog Scales for Self-Esteem (VASES), The Communication Disability Profile

(CDP), and The Aphasia Communication Outcome Measure (ACOM). These tools, offered as self-report measures, are equipped with aphasia-friendly design features such as pictures, simple wording, key words in bold, and picture rating scales. Many of these tools also share the common feature of focusing on functional communication.

This section will review best practice in creating an aphasia-friendly needs assessment tool for gauging the interests and preferences of PWAs in designing an ICAP. Quality of life, severity, and functional communication are addressed and surveyed through various self-report measures. Self-report measures will provide information regarding needs directly from the patients, rather than from caregivers. There is evidence that people with aphasia can report their own perspectives when given the appropriate support (Simmons-Mackie et al., 2014). In the case of developing a needs assessment tool, the appropriate support will refer to a questionnaire format that is clear and can be easily understood by patients with aphasia. A review of existing self-reporting tools is offered by Leofsky (2015) and summarized below. Examining current assessments will allow a needs assessment tool to be developed by pulling various formatting principles such as question design and format.

Quality of life measures include the Quality of Communication Life Scale-ASHA (QCL-ASHA), the Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39), and Kagan Assessment of Living with Aphasia (ALA). The QCL-ASHA assesses the quality of the individual's communication and communication confidence. The SAQOL-39 aims to measure health-related quality of life for individuals with long term aphasia. In order to accommodate language difficulties in PWAs, the SAQOL-39 utilizes a self-report measure through interview. The patient is asked to rate their overall quality of life

compared with before stroke on a five point scale. The SAQOL-39 is only 39 items that attempt to address the most important factors (Hilari, Owen, & Farrelly, 2007).

According to Hilari, Byng, Lamping, and Smith (2003), the SAQOL-39 is an acceptable, reliable, and valid measure of health-related quality of life in people with aphasia. The ALA also assesses health-related quality of life. The ALA attempts to capture the subjective life experiences of PWAs. In order to accomplish this goal, the ALA uses a conversational format with options to make accommodations including alternative wording, added questions, and feedback. Each question is paired with pictographic support and a conversational script. Each questioned is answered using a nine point scale. As determined by Simmons-Mackie et al. (2014), the ALA is a reliable and valid self-report measure.

Self-report tools to measure severity and communicative functioning of PWAs include the Communicative Effectiveness Index (CETI), The Communication Disability Profile (CDP), Communication Confidence Scale for Aphasia (CCRSA), and the Aphasia Communication Outcome Measure (ACOM). These tools are intended specifically for PWAs.

The CETI measures functional communication versus language ability for PWAs. This tool is comprised of 16 items that refer to important activities or events in the PWAs' daily life. The questions are formatted using a linear visual analog scale. The low end of the scale is labeled as "not at all able" and the high end is labeled as "able before the stroke." The CETI uses a proxy respondent to fill out the survey; however, the PWA answers the questions. A psychometric evaluation conducted by Lomas, Pickard, Bester, Elbard, Finlayson, and Zoghaib (1989) determined that the CETI is internally consistent

and has acceptable test-retest and interrater reliability. It is important to note that the CETI is still considered to be early in development.

Like the CETI, the CCRSA is also considered to be at an early stage of development. The CCRSA aims to measure communication confidence of PWAs. The tool is made up of a ten item questionnaire using a number rating scale analysis.

The CDP utilizes an aphasia-friendly design and acts as a self-report measure to analyze various areas of aphasia's impact. The CDP includes the use of pictures, visual aids, simple wording, key words in bold, and a picture rating scale in order to be more aphasia-friendly. The questionnaire items are answered using a self-rated, simple picture rating scale. The CDP is also used to support joint-planning and goals setting, a similar goal to developing a needs assessment tool. It has been determined by Chue, Rose, and Swinburn (2010) that the CDP shows high reliability in the Activities and Participation sections. This data continues to support the use of self-report measures for individuals with aphasia.

The ACOM is made up of 177 items related to communication-related behaviors, tasks, activities, and life situations designed specifically for PWAs. Individuals are asked to rate how effectively they are able to perform each activity using a 4 point scale from "not at all" to "completely." This tool is administered through an interviewer-assisted administration format in order to adapt questions to best suit the understanding of the PWA. The ACOM question items are presented in a large font on the computer screen with the consistent question of "How effectively do you..." The PWA can have the question read to them or read it independently. This tool also incorporates the use of a visual representation of response categories with text labels. The PWA is allowed to

answer verbally, by pointing to the response, or a combination of the two. According to Hula, Doyle, Hula, Kellough, Wambaugh, and Jacque (2015), the ACOM has been determined to provide a "reliable measurement of patient-reported communicative functioning of aphasia."

After review of current self-report measures for PWAs, commonalties among formatting have emerged. The majority of the reviewed tools use a 4 to 9 point rating scale for their measures. The rating scales are linear and have a visual component. By combining the use of a number, pictographic, and visual analog scale utilized in existing tools, a new needs assessment tool can attempt to account for the various language difficulties associated with aphasia. It is also clear that consistency among question items is an important factor to guide PWAs through a survey. The use of an interview format or interview-assisted format is also a commonality among tools and should be considered when developing the needs assessment tool. Features to make the assessment tool more aphasia friendly include large font, important words in bold, choices in communication modality, and the use of visual support.

Conclusion

In regards to the efficacy of intensive aphasia therapy, evidence suggests that more intensive treatment results in positive outcomes for PWAs. Intensive therapy schedules have proven to result in improved language and life participation outcomes for PWAs, especially those in chronic stages. Individuals within the acute phase of aphasia may have more difficulty participating in intensive aphasia therapy schedules due to current level of functioning and fatigue. However, intensive aphasia treatment has demonstrated equivalent improvement outcomes across stages of aphasia. These results

demonstrate that intensive aphasia therapy is effective and can result in significant improvement in communicative functioning for PWAs.

PWAs are capable of reporting their own ideas and preferences through carefully constructed measures of self-report when provided with appropriate communicative support. Review of current self-report measures for PWAs indicates the need for common formatting characteristics to be utilized in creation of a needs assessment tool. The use of visual analog scale, consistent question formatting, key words in bold, simple wording, large font, and communicative support through interview are features proven to be successful when administering self-report tools. Existing self-report measures have proven reliable and valid for use with persons with aphasia.

Review of efficacy of intensive aphasia therapy, current ICAPs, efficacy of self-report by PWAs, and existing self-report measures indicates the need for additional intensive aphasia programs and the efficacy of developing a needs assessment tool for persons with aphasia to aid in program development and treatment planning.

Purpose of Current Study

As a first step in moving forward with development of an intensive aphasia program at Western Kentucky University, a needs assessment tool will provide critical information in designing a program that would be valued by prospective attendees. Preferences related to type of intervention approaches could be determined, along with interest in supplementary offerings such as physical therapy, dietary consult, art, music, and community outings.

The needs assessment tool was developed according to principles of current selfreport measures and need communicative support. Development of an aphasia-friendly needs assessment tool provides a means to adapt a PWA's environment in order to better fit the individual's needs as theorized by Lewin (1938) and increase communicative confidence as theorized by Babbitt and Cherney (2010).

This study was submitted and approved by the Institutional Review Board (IRB) on September 23, 2015 reference number 16-061. A copy of IRB approval can be found in Appendix A.

Method

Needs Assessment Tool Development

In order to gather valid and reliable opinions of PWAs the development of an aphasia-friendly survey tool was crucial. The tool was developed upon review of current self-report measures for quality of life and experience with aphasia. An aphasia-friendly tool must encompass communicative support to aid individuals who may have difficulty with comprehension, written language, reading, and expressive difficulties.

Review of reliable self-report measures yielded commonalities among design and communicative support features. The tool developed for this study utilized a pictographic/visual analog scale, key words in bold, simple wording, large font, consistent question formatting, flexible administration, and the use of a communication partner/interview. Each of the twelve questionnaire items is formatted identically. Each question reads "Are you interested in...? This question format uses direct language that is more easily understood by individuals with comprehension and language processing difficulty. The element being asked in each question is in bold. By bolding key words, it signals importance and has the potential to enhance comprehension for the participant. Each survey question is followed by a picture representing the program element such as a

music note on the item related to music therapy. The added visual element provides further visual support for improved comprehension of what is being asked. Many people with aphasia have difficulty processing written language and are supported by the use of multi-modal stimuli and explanation. Survey items are accompanied by a 6 point, 0-5, visual analog scale. Each point on the scale is represented by a written number and a face with an associated facial expression. At the high interest end of the scale, level 5, the word "very" is written and the face image shows a happy expression. At the low interest end of the scale, level 0, the phrase "not at all" is written and the face image shows a sad/crying expression. The pictures, numbers, and words provide multiple means of support for improved comprehension and ability to respond. By including multi-modal of communicative supports, the tool aims to provide enough support for a range of severity and type of aphasia.

In order to ensure construct validity, the content of the needs assessment was developed based on the therapeutic offerings of current intensive comprehensive aphasia programs. The tool consists of twelve items gathering information regarding therapy format, additional services, and program elements that are utilized in current ICAPs. The 12 items include: general interest in program, individual therapy, group therapy, computer therapy, physical therapy, nursing assistance, dietary services, art therapy, music therapy, community outings, housing, and transportation. The survey asks two demographic questions, gender and age in order to determine any trends.

Modifications and adjustments to the survey tool were made per suggestions from expert reviewers. Three experts in the field of speech language pathology with expertise in the area of aphasia were contacted. An email was sent to each expert reviewer with a

brief description of the current study and a request for suggestions/comments regarding content and design of the survey tool. Per suggestion, the visual analog scale was adjusted to a vertical orientation rather than the original horizontal orientation. The vertical orientation aids individuals who may experience visual cuts post stroke. An individual with a visual cut often has difficulty with visual scanning and would only see what is in the middle of the page. This deficit could result in selecting a level on the scale based on it being in the center rather than their true preference. The vertical orientation puts the entire scale within the visual field.

Minor adjustments to wording were also made per expert review such as the term "nursing services" being changed to "nursing assistance" which is a more precise indication of what is to be offered. A complete copy of the needs assessment tool is found in Appendix C.

Participant Sample

Participants for this study were individuals diagnosed with aphasia currently participating in or discharged from speech language therapy services. Inclusion and exclusion criteria were developed in alignment with current ICAPs' candidacy requirements.

Inclusion Criteria. Participants included in this study presented with a current aphasia diagnosis. No limitations were placed on type and severity of aphasia. In alignment with ICAP candidacy, participants were medically stable and semi-independent. Participants resided within approximately 75 miles of Bowling Green, KY.

Exclusion Criteria. Exclusion criteria included residing outside an approximate 75 mile area of Bowling Green, KY. This exclusion criterion was developed in order to

ensure that this study sampled the target population for the development of an ICAP program at Western Kentucky University.

Identification Procedure. Participants were identified and selected through discharge planners, case managers, and rehabilitation therapists serving PWAs in a manner protecting patient privacy. Discharge planners, case managers, and rehabilitation therapists were emailed a description of the project and asked to pass on a letter or email describing the study to persons with aphasia or their caregivers. The letter and email asked the potential participant to contact the researcher if interested in participating. Contact information was gathered from responders and entered into a database. Participants were contacted by phone, email, or in person in order to set up a time to complete the consent form and survey. Discharge planners, case managers, and rehabilitation therapists and participants were contacted a maximum of three times in the event of no response. This method of participant identification yielded 0 participants.

Additional participants were identified in the community through speech language pathologist and word of mouth recruitment. A flyer was presented to speech language pathologists who then shared the flyer with their churches in order to reach individuals with aphasia no longer receiving speech and language services. Caregivers and individuals with aphasia then chose to contact the researcher if interested in participation. This method of participant identification yielded 1 participant.

Word of mouth recruitment was utilized among speech language pathologist in the community. Speech language pathologists shared an overview of the project with PWAs in the community and asked for consent for the primary investigator to speak with them about participation in the study. If the PWA consented, the primary researcher met

with the participant to discuss the study, obtain consent, and administer the survey. This method of participant identification yielded 5 participants.

Characteristics of Sample. This study consisted of 7 participants. The low sample size indicates the use of qualitative analysis for a more in-depth analysis of individual participants. The age range of participants was 40-87 years old. The participant group was comprised of 1 male and 6 females. 3 participants were considered in the acute stage of aphasia and 4 were in the chronic stage of aphasia indicating a balance among the sample. For descriptive statistics of the sample see Table 2.

Table 2

Descriptive Statistics for Sample

Sample	Frequency	М	SD	Percent	Min.	Max
Gender						
Male	1			14.29%		
Female	6			85.71%		
Age		70.7	15.2		45	87
Setting						
Long-term care	3			42.86%		
Short term rehab	3			42.86%		
Independent	1			14.29%		
Stage						
Chronic Stage	4			57.14%		
Acute Stage	3			42.86%		

Note. Chronic stage = > 6 months post stroke; Acute stage = < 6 months post stroke.

Procedure

Participants were given the consent form outlining the purpose of the project, an explanation of procedures, possible discomforts and risks, benefits of completing the survey, methods maintaining confidentiality, and their right to refuse or withdraw participation at any time. The researcher also verbally described the project and its purpose in order to increase comprehension. The researcher emphasized that the intensive

aphasia program is currently unavailable but this survey would be a tool for developing a program in the future. Participants indicated their consent by signing the consent document. (See Appendix B)

Administration of Survey

The survey was administered by the primary investigator in an interview format at the participant's residence, agreed upon meeting place, or current care facility. To ensure interrater reliability, the primary investigator administered all surveys. The primary investigator read the instructions of the survey to the participant and allowed participant to read the instructions themselves. The participants chose to have the survey read to them and answer aloud or complete the survey independently. The twelve survey items were displayed using a visual analog scale to support communication. Participants chose to respond using preferred mode of communication such as writing, verbal response, or gesture. Participants were provided the opportunity to offer additional comments on treatment preferences. The flexibility of administration aimed to collect the most accurate responses from the PWA. Administration time was approximately 10 to 15 minutes.

Data Collection

After administrating the survey to PWA, a 0-5 response rating was recorded for each item number on the needs assessment protocol. Responses were recorded in an electronic data base. The 0-5 response ratings were coded on a 1 to 6 scale so that 0 = 1, 1 = 2, 2 = 3, 3 = 4, 4 = 5, 5 = 6 for the purpose of statistical analysis. For example, a response rating of "2" on the needs assessment tool would be recoded as a "3" during data analysis. Data was analyzed using descriptive statistics including mean, standard deviation, maximum response, and minimum response across survey items and

participants to determine highest level of interest, least amount of interest, and any trends present. Additional comments offered by participants and observations were analyzed to form more qualitative conclusions regarding treatment preferences and themes.

Inferential analyses were not used due to small sample size.

Results

Results were analyzed using quantitative and qualitative methods. Descriptive statistics and qualitative observation revealed information regarding inclusion of various therapeutic offerings during ICAP development and information regarding tool administration. Results are reported across survey items and across participants.

Results Across Survey Items

Descriptive statistics were examined across survey items (See Table 3) to determine interest, trends, and themes for each of the therapeutic offerings surveyed.

Mean, standard deviation, minimum response rating, and maximum response rating were calculated.

The mean response rating for general interest in the program was 4.86 (SD = 1.21). Four out of seven participants rated this item a "6" or "5" indicating general interest in the program.

The items receiving the highest average response were general interest in the program(M = 4.86, SD = 1.21), individual therapy (M = 5.0, SD = 1.15), and physical therapy (M = 4.43, SD = 1.72). Other offerings that received high ratings were transportation (M = 4.43, SD = 1.), art therapy (M = 4.29, SD = 1.98), and community outings (M = 4.29, SD = 1.25). The average ratings for these therapeutic offerings indicate that they should be highly considered for inclusion in an ICAP.

Table 3

Results Across Survey Items

Survey Item	М	SD	Min	Max
Are you interested in attending a 4-6 week long program to help with your aphasia?	4.86	1.21	3	6
Are you interested in individual therapy?	5.00	1.15	3	6
Are you interested in group therapy?	4.14	1.07	3	6
Are you interested in computer therapy?	4.00	1.63	1	6
Are you interested in physical therapy?	4.43	1.72	1	6
Are you interested in nursing assistance?	4.00	1.53	1	6
Are you interested in dietary services?	4.14	1.46	1	5
Are you interested in art therapy?	4.29	1.98	1	6
Are you interested in music therapy?	4.00	2.00	2	6
Are you interested in community outings?	4.29	1.25	1	5
Are you interested in on-site housing?	3.57	1.27	1	5
Are you interested in transportation?	4.43	1.81	1	6

A mean rating of 5.0 (SD = 1.15), the highest mean, was collected on survey item 2, individual therapy. As evidenced by this mean, individual therapy is important to the PWAs sampled in this study. The minimum response for "Are you interested in individual therapy?" was "3" and the maximum response was "6." Although one participant indicated a "3," the increased mean indicates interest in individual therapy.

Data for "Are you interested in physical therapy?" (M = 4.45, SD = 1.72) indicated inclusion of physical therapy in an ICAP was of moderate interest. One participant rated this item as a "1." However, the other six participants indicated a response of "3" or above.

The survey items that received the lowest mean responses were on-site housing (M = 3.57, SD = 1.27), music therapy (M = 4.00, SD = 2.0), nursing assistance (M = 4.00, SD = 2.0)

SD = 1.53), and computer therapy (M = 4.00, SD = 1.63). Although these offerings received the lowest mean responses, the mean scores were not substantially lower than the mean for highly rated survey items, indicating the need for further analysis of interest in these therapeutic offerings during program development.

The lowest mean calculated was for interest in on-site housing at 3.47 (*SD*=1.27). This indicates that, for this sample, on-site housing is not a priority for an ICAP program. Due to the sample being selected from local PWA, on-site housing may not be a priority due to the close proximity of Western Kentucky University to the participant's current homes.

A mean response rating of 4.0 was calculated for music therapy (SD = 2.0), nursing assistance (SD = 1.53), and computer therapy (SD = 1.63). This mean response does not suggest exclusion of these offerings from a program because a rating of 4.00 is not associated with an individual not being interested. A rating of "4" lies in the middle of the scale indicating moderate interest. Participants rated music therapy and computer therapy with a wide range of scores indicating varied interest among participants.

Across survey items, a low standard deviation, ranging from 1.07 to 2.00, was obtained for all items. The low standard deviation indicates little variance across items. Art therapy and music therapy had the highest standard deviation at 1.98 and 2.0 respectively. This slightly elevated standard deviation indicates varied responses among participants. For these two therapeutic offerings, participants appeared very interested or not interested at all.

Results Across Participants

Each of the seven participants offered unique insight on the administration of the needs assessment tool. Data was used to describe participant's responses (See Table 4) to determine patterns and themes that may be influenced by individual characteristics.

Mean, standard deviation, minimum response rating, and maximum response rating were calculated.

Table 4

Participant Interest in Therapy Offerings

Participant	M	SD	Min	Max
P1	5.42	1.00	3	6
P2	4.25	1.36	1	6
P3	5.17	0.83	4	6
P4	3.75	1.29	1	5
P5	4.17	1.34	2	6
P6	3.91	1.00	2	5
P7	3.17	2.12	1	6

Factors including characteristics of impairment, individual values, and unique communication styles aided in understanding strengths, weaknesses, and modifications to the tool for future use. Characteristics of each participant are summarized in Table 5.

Analysis of qualitative measures including comments offered by participants, observation of participants behavior/facial expression, and observation of communicative support utilized during administration contribute to a better understanding of responses and administration of the needs assessment tool.

Table 5

Characteristics of Participants

Participant	Age	Gender	Setting	Stage	Characteristics of Impairment
P1	57	Female	LTC	Chronic	Impaired comprehension Moderate word-finding difficulties Slow, choppy speech
P2	86	Female	STR	Acute	Impaired comprehension Confusion Moderate word-finding difficulty Fluent speech
P3	87	Female	STR	Acute	Relatively intact comprehension Severe word finding difficulty Frustration with impairments Fluent speech
P4	63	Female	STR	Acute	Impaired comprehension Non-fluent, effortful speech Intact automatic speech Severely impaired writing
P5	45	Female	LTC	Chronic	Limited verbal output Intact automatic speech Impaired comprehension Reliant on use of gesture
P6	74	Male	LTC	Chronic	Mild comprehension impairment Slow, effortful speech Moderate word finding difficulty
P7	71	Female	IND	Chronic	Mild-word finding difficulty Intact comprehension Intact verbal expression

Note. LTC = Long-term care. STR = Short-term rehabilitation. IND= Independent

Responses to Individual Items. Participant 1 (P1) was very eager to participate in the survey and help other individuals in similar situations as herself. She stated, "I would love to help! I think it is great." This participant had the highest average ratings overall at 5.42 (SD= 1.00) across survey items indicating a very high interest in the

program and program elements. The lowest rated items were Items 3 and 4, group therapy and computer therapy respectively. P1 provided logical reasoning in conjunction with her responses. Item 3, group therapy, received a rating of "3" because she felt like she was ready for more individualized therapy as evidenced by her statement, "I think I want help with just me." She rated Item 4, computer therapy, as a "4" stating, "Computers are hard for me." P1 expressed explicit interest in art therapy, music therapy, and community outings. She stated "I love art!" in reference to Item 8. This participant also stated that transportation such as a van would be helpful and that living on-site would make attending easier. P1 suggested a component to the program development not surveyed with the needs assessment tool. She stated that offering a tour prior to enrollment would be a good addition to the program.

Participant 2 (P2) was most interested in individual therapy and art therapy. This participant did not offer many additional comments specific to item numbers. P2 expressed concern in regard to program cost. She asked "How much will this cost?" several times throughout administration.

Participant 3 (P3) smiled and stated "Of course I'll help." when the project was presented to her. P3 rated Item 4, computer therapy, with a "6" stating "There is so much done on the computer now." As compared to P1, this participant indicated a desire to increase her technology skills even though it is difficult. P3 also expressed that some elements that she rated lower, such as physical therapy, were not important to her but would be for some people

Participant 4 (P4) responded with a mean of 3.75 (SD = 1.2) indicating moderate interest across survey items. P4 exhibited the most impaired comprehension among the

participant sample. P4 rated "Are you interested in art therapy?" the lowest with a rating of "1" P4 also expressed her disinterest using a disgruntled facial expression in association with this survey item.

Participant 5 (P5) rated the general interest item and physical therapy item with a "6." P5 was least interested in community outings and on-site housing. She rated both these items as a "2."

Participant 6 (P6), the only male participant, appeared happy when asked to complete the survey as evidenced by his broad smile and the statement, "Oh yeah, that sounds good." P6 is approximately 3 years post stroke, the furthest post-stroke among the participant sample. P6 did not select a 6 for any item number. However, in reference to item 5, physical therapy, he stated "That be good." He was least interested in art and music therapy. In reference to music therapy he stated, "I don't know much about music."

Participant 7 (P7) was the only participant living independently following her stroke and acquisition of aphasia. P7 responded with the lowest overall rating across survey items at 3.17. Her highest rating went to computer therapy stating, "I would like to be more proficient."

Tool Administration. In addition to information regarding which therapeutic offerings to include in a future ICAP program, this study provides information contributing to a better understanding of how the needs assessment tool works, what communicative supports are needed during administration, and important elements needed for successful use of the tool. Each participant's individual needs and responses were examined to improve understanding of the needs assessment tool.

P1, whose aphasia symptoms were impaired comprehension and word finding difficulties, had difficulty comprehending the abstract nature of a future ICAP at the beginning of survey administration. The use of the calendar visual (See Appendix A) and additional verbal explanation increased comprehension.

P2 demonstrated the most difficulty understanding the need to sign her name on the consent form due to impaired comprehension/confusion. She gave her verbal consent but when asked to sign her name she asked, "Why? Can't you write my name?" The primary investigator utilized additional verbal explanation of the consent documentation. By using the word "permission" instead of "consent" P2's comprehension increased. She stated, "Oh okay, let me sign it." The use of the calendar visual increased comprehension of the nature of the program as evidenced by her response, "So this will be in the summer? But not now."

P3 demonstrated impairments including moderate-severe word finding difficulty and associated frustration. Due to this participant's characteristics of impairment, communicative support in the form of extended wait time and multi-modal cues were utilized during administration. The primary investigator allowed P3 additional time to respond and gave verbal cues when P3 appeared unable to come up with the word she was looking for. P3 also benefited from explanations being re-worded. This participant required reassurance that she was doing okay and being helpful. The strategies utilized to provide communicative support aided P3 in providing adequate responses and comments.

Participant 4 (P4) demonstrated more severe impairments among the participant sample. P4's impaired comprehension and limited verbal output required the use of multi-modal stimuli and responses. For P4, the primary investigator pointed the visual

stimuli that accompanied each survey item and offered multiple verbal explanations. P4 utilized pointing as her main mode of communication in response to items and by verbally identifying the number. P4 also stated "That'd be good" rather than stating a number or pointing to a number on the scale. The interviewer prompted the participant with the phrase, "It would be. What number would you give it?" This prompt was successful in eliciting a number rating on the scale. The interviewer also went over the levels of the scale for each question, reminding P4 that a "5" and "happy face" was really interested and that a "0" and "sad face" was not interested at all. It was important to provide this participant with repetitive and expanded verbal prompts.

Out of all the participants, P5 relied the most heavily on the use of gestures as a mode of communication. She used pointing in response to survey items. P5 occasionally paired a verbal response with gesture in response to survey items. Although verbal expression was limited, the primary investigator noted facial expressions indicating P5's feelings towards the various therapeutic offerings in conjunction with her gestural response. P5 exhibited a delayed response after each question was read. The primary investigator used a combination of extended wait time, repetition of survey item, and pointing to the page as multi-modal cues to prompt P5.

P6's aphasia is characterized by word-finding difficulties and impaired comprehension. P6 utilized gesture, facial expression, and verbal speech to express his opinion about each survey item. P6 utilized the visual stimuli presented in the survey tool as evidenced by his behavior of pointing to the picture then selecting his response. The pictographic representation of each survey item increased comprehension.

P7 presented with the least severe symptoms of aphasia. P7 required little communicative support to comprehend and respond appropriately to survey items. P7's most marked symptom was mild word finding difficulty. P7 also offered a unique perspective as a retired speech language pathologist. P7 expressed that as a retired SLP and PWA she understands the importance of an ICAP and believes that more services are needed for PWAs. P7 required little support to successfully utilize the needs assessment tool which provided evidence that the tool is easy to understand when considering content, administration, and purpose.

Discussion

Quantitative and qualitative results revealed the emergence of several themes that can be utilized in program development and administration of the needs assessment tool. Program development is largely affected by understanding what therapeutic offerings should be included as well as why those elements may be important to participants. Results offer a plethora of information regarding the success of the needs assessment tool and future administration of the tool.

Indications for Program Development

Participants responded with a mean of 4.86 (SD = 1.21) for the item "Are you interested in attending a 4-6 week long program to help with your aphasia?" The mean and response pattern indicates that the PWAs in this sample are highly interested in attending an ICAP program at Western Kentucky University. Due to an overall high interest, the next step would be program development. The selection of therapeutic offerings and program elements is a crucial step in program development.

Based on the results of this study, individuals are most interested in individual therapy, physical therapy, art therapy, community outings, and transportation. These survey items received the highest mean responses. However, the survey items receiving the lowest mean responses should not be discarded or excluded from an ICAP program. "Are you interested in attending a 4-6 week long program to help with your aphasia?" received the highest mean response of 5. "Are you interested in on-site housing?" received the lowest mean response at 3.47. The difference of 1.53 is not a large enough gap to exclude on-site housing as a program element without further analysis based on more in-depth analysis of why on-site housing was not rated higher. As with on-site housing, other lower rated items including music therapy, nursing assistance, and computer therapy indicate a need for further analysis utilizing a larger sample. It would be premature to exclude lower rated items until a large sample is obtained and analyzed.

Pre-morbid interests and skills emerged as a contributing factor for responses. Art therapy, music therapy, and computer therapy were indicated to be highly reliant on pre-morbid interest and skills based on qualitative observations and comments. P1 stated "I love art" and rated this item at the top of the scale. Her comment indicates that due her interest in art she is would like art therapy to be included in a therapy program. P6 expressed "I don't know much about music." P6 indicated that a lack of knowledge in the area of music made him less interested in pursuing music therapy. Computer therapy was also affected by pre-morbid skill and interest. P1 expressed "Computers are hard for me," and rated this item as a "4" which was one of her lower responses. P7 also expressed that computers are not her strength. However in contrasts to P1 she rated this item as a "6" stating, "I would like to become more proficient." P3 also rated computer therapy higher

with intent to improve her skill level with the comment, "There is so much done on the computer now." The comments and responses indicate that pre-morbid interest and skills are an important factor to consider when examining the results. A lack of knowledge/skill in an area motivates some individuals to pursue that area in order to improve where others are not motivated to pursue therapy in that area. Due to variance among scores in the areas of music therapy, art therapy, and computer therapy, inclusion of these elements has the potential to be offered as an optional therapy choice within the ICAP. Rather than excluding these offerings or mandating these offerings, ICAP participants could choose to participate in art therapy, music therapy, or computer therapy as an additional session.

Similar to the effect of pre-morbid skills/interest is the effect of current needs and impairment level. The survey items "Are you interested in nursing assistance?" and "Are you interested in physical therapy?" were dependent on the level of need of each individual. Physical therapy was only indicated as an interest by individuals who would currently need physical therapy. Another example of the effect of current need was participant 6. P6's time post-stroke, residency in a long-term care facility, discharge from previous speech and language therapy, and satisfaction with current living situation may have attributed to his slightly lower interest in program elements. One participant's responses, P7, were highly influenced by her current level of impairment. P7 expressed that she would have been highly interested in the program and therapeutic offerings directly following her stroke. Due to her level of recovery and independence she felt that program would not be as beneficial to her currently.

On-site housing and transportation are also highly dependent on need. Individuals currently living at care facilities or at home in Bowling Green were surveyed. Due to the

locality of the sample, on-site housing would not be as important to these individuals. Transportation, which received a high mean response, was indicated as a need by this sample. P1 stated "A van would be nice."

The low level of variation between highly rated items and lower rated items, effect of pre-morbid interest, and effect of current needs emerged as the major themes of this study affecting program development.

Indications for Tool Administration

Observation of participants and analysis of comments offered insight for future use of the tool. By administering the tool to several different participants, the primary investigator noticed several themes and important features of the tool. Based on administering the tool and responses of participants, flexible administration of the tool stood out as a key element of tool use. By allowing for flexible administration, each participant received the most appropriate communicative support.

As described in the procedure section, this needs assessment tool offers flexible administration to ensure the most reliable responses. Every PWA presents with unique characteristics of impairment. In order to provide effective communicative support each participant chose to read the survey and answer independently or have the primary investigator read the items. Participants also chose to respond using verbal speech, gesture (i.e. pointing), or a combination of the two. The flexibility of administration, as evidenced by the various modes of communication observed, is a key component to the success of the tool.

Every participant chose to have the needs assessment tool read aloud to them.

This allowed the participants to use auditory comprehension, reading, and visual stimuli

to improve their comprehension. Several participants, P1, P2, P3, P6, and P7 utilized verbal responses. However, P4 and P5 relied heavily on the use of gesture (pointing) to respond to survey items. For P4 and P5 verbal speech was very difficult. By allowing these participants to respond with their best mode of communication, gesture, they were capable of responding accurately to survey items.

The flexibility of administration allowed for the use of necessary communicative support including additional explanation, re-wording of survey items, extended wait time, additional cues/prompts, and repetition. All participants, with the exception of P7, required some form of additional communicative support. Without the use of additional communicative support during administration comprehension of the survey items would been more challenging form participants.

Results also spoke to the importance of the visual support included in the tool design. The visual analog scale offered a concrete representation of the response options. Participants often looked at the picture stimuli that accompanied the written survey item. The use of the visual analog scale also allowed the use of gesture. Reference to the scale as a prompt was utilized during administration indicating the importance of the visual element in increased comprehension.

The need for skilled communicative support across participants indicates that the administrator should be an individual with a basic understanding and training in working with PWA. An understanding of aphasia symptoms and how to provide support for PWA allows for effective communicative support for participants.

The use of communicative supports with this tool contributed to more reliable responses by participants. Comprehension was evidenced by comments of explanation

offered by participants. Flexibility of tool administration, the use of multiple forms of communicative support, and the inclusion of visual stimuli emerged as the key components to success of the needs assessment tool.

Limitations

The small sample utilized in this study limits generalization of the results. The limited sample can not be used to draw conclusions about the population of PWAs as a whole. However, the small sample allows for detailed examination of each participant and provided feedback on tool development and administration. The information gathered can be used to aid in the future use of the tool. All participants were drawn from a small geographic area, limiting generalization. It also had a direct effect on responses to the on-site housing survey item. Individuals living outside of the immediate Bowling Green area may feel that on-site housing is more of a priority.

Future Research Implications

Future research should focus on utilizing a larger sample to increase generalizability of results. This would aid in accommodating needs of a broader sample as we develop an ICAP program at WKU.

Further studies should also look at modifying the needs assessment tool for use in other communities in the United States in order to continue development and implementation of intensive aphasia therapy.

Future research should focus on development of evidence based communicative support to enable PWAs to contribute to treatment planning and provide their opinions for increased self-efficacy and autonomy. A research study examining the effects of the

needs assessment tool on PWAs' input on their treatment plans would provide evidence for the use of communicative support for PWA.

Conclusion

This study reviewed the efficacy of intensive aphasia therapy, the use of self-report measure for PWAs, and current ICAP programs. Evidence suggests that more intensive treatment results in positive outcomes for PWAs. PWAs are capable of reporting their own ideas and preferences through carefully constructed measures of self-report when provided with appropriate communicative support. A needs assessment tool was developed and administered to contribute to a better understanding of self-report for PWAs and ICAP development.

Administration revealed the great importance of flexible administration and the use of multi-modal communicative support for PWAs. The needs assessment tool was an effective means of self-report for PWA when paired with skilled administration to provide communicative support to each individual with aphasia. Responses from the needs assessment indicated a high general interest in an ICAP program. Responses also indicated interest in inclusion of physical therapy, individual therapy, and community outings within an ICAP program. Pre-morbid interest and individual need greatly affected responses for items including art therapy, music therapy, computer therapy, on-site housing. Based on this study, no therapeutic offering should be excluded from ICAP development at this time. However, the inclusion of program elements such as art and music therapy as additional optional components should be considered.

The results of this study may assist PWAs in having a voice in their rehabilitation treatment. Results will assist clinicians as they attempt to determine and include patient

preferences in treatment. Providing PWAs the opportunity to contribute to their treatment planning may have the positive impact of increased autonomy, heightened communicative confidence, and improved quality of life.

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APPENDIX A

Institutional Review Board Approval



INSTITUTIONAL REVIEW BOARD OFFICE OF RESEARCH INTEGRITY

DATE: September 15, 2015

TO: Dalana Henson, B.S. Communication Disorders FROM: Western Kentucky University (WKU) IRB

PROJECT TITLE: [802129-1] Intensive Aphasia Needs Assessment

REFERENCE #: IRB 16-061 SUBMISSION TYPE: New Project

ACTION: APPROVED
APPROVAL DATE: September 15, 2015
EXPIRATION DATE: June 30, 2016
REVIEW TYPE: Expedited Review

Thank you for your submission of New Project materials for this project. The Western Kentucky University (WKU) IRB has APPROVED your submission. This approval is based on an appropriate risk/benefit ratio and a project design wherein the risks have been minimized. All research must be conducted in accordance with this approved submission.

This submission has received Expedited Review based on the applicable federal regulation.

Please remember that informed consent is a process beginning with a description of the project and insurance of participant understanding followed by a *signed* consent form. Informed consent must continue throughout the project via a dialogue between the researcher and research participant. Federal regulations require each participant receive a copy of the consent document.

Please note that any revision to previously approved materials must be approved by this office prior to initiation. Please use the appropriate revision forms for this procedure.

All UNANTICIPATED PROBLEMS involving risks to subjects or others and SERIOUS and UNEXPECTED adverse events must be reported promptly to this office. Please use the appropriate reporting forms for this procedure. All FDA and sponsor reporting requirements should also be followed.

All NON-COMPLIANCE issues or COMPLAINTS regarding this project must be reported promptly to this office.

This project has been determined to be a Minimal Risk project. Based on the risks, this project requires continuing review by this committee on an annual basis. Please use the appropriate forms for this procedure. Your documentation for continuing review must be received with sufficient time for review and continued approval before the expiration date of June 30, 2016.

Please note that all research records must be retained for a minimum of three years after the completion of the project.

If you have any questions, please contact Paul Mooney at (270) 745-2129 or irb@wku.edu. Please include your project title and reference number in all correspondence with this committee.

APPENDIX B

Consent Form

INFORMED CONSENT DOCUMENT

Project Title: INTENSIVE APHASIA NEEDS ASSESSMENT TOOL

Investigator: Dalana Henson, Department of Communication Sciences and Disorders,

859-462-1287 dalana.henson309@topper.wku.edu

You are being asked to participate in a project conducted through Western Kentucky University. The University requires that you give your signed agreement to participate in this project.

The investigator will explain to you in detail the purpose of the project, the procedures to be used, and the potential benefits and possible risks of participation. You may ask questions to help you understand the project. If you choose to participate in the project, please sign this form. You will be given a copy to keep.

- Nature and Purpose of the Project: The purpose of this survey is to learn about your interest in an intensive aphasia program and your treatment preferences. This information will help therapists develop better treatment programs for individuals with aphasia.
- Explanation of Procedures: This survey uses visual analog scales to record your interest in various program elements. There are twelve questions and with a scale from 0-5. The survey will take approximately 15 to 20 minutes.
- Discomfort and Risks: No discomfort/risk is expected.
- Benefits: Your responses on the survey will help determine treatment preferences of individuals
 with aphasia and contribute to development of an aphasia treatment program.
- Confidentiality: You will be identified by a personal identification number. Your name will not be recorded on any databases. Data will be kept on a password protected computer and printed documents will be kept in a locked office.
- Refusal/Withdrawal: Refusal to participate in this study will have no effect on any future services you may be entitled to from the University. Anyone who agrees to participate in this study is free to withdraw from the study at any time with no penalty.

You understand also that it is not possible to identify all potential risks in an experimental procedure, and you believe that reasonable safeguards have been taken to minimize both the known and potential but unknown risks

Signature of Participant	Date
Power of Attorney	Date
Witness	Date

THE DATED APPROVAL ON THIS CONSENT FORM INDICATES THAT
THIS PROJECT HAS BEEN REVIEWED AND APPROVED BY
THE WESTERN KENTUCKY UNIVERSITY INSTITUTIONAL REVIEW BOARD
Paul Mooney, Human Protections Administrator
TELEPHONE: (270) 745-2129

APPENDIX C

Needs Assessment Tool

Needs Assessment Intensive Aphasia Program Western Kentucky University

Id	lent	if	ying	In	forn	1at	<u>ion</u>
		_					

Age:

Gender:

PIN:

Instructions

Please rate your interest on the following components of an aphasia treatment program.

0 is not interested at all

5 is very interested

Mark your rating on the scale.

Note: Caregiver/interviewer may read each item and record the rating on the scale. A respondent may reply by pointing to the appropriate number, verbally identifying the number, or by marking the number on the scale.

July S M T W T F S 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 31

4-6 week long Program in the Summer

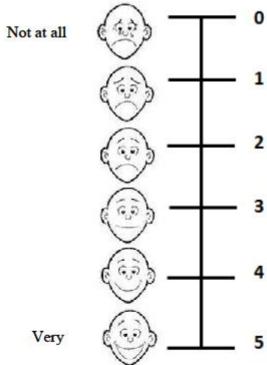
At

Western Kentucky University



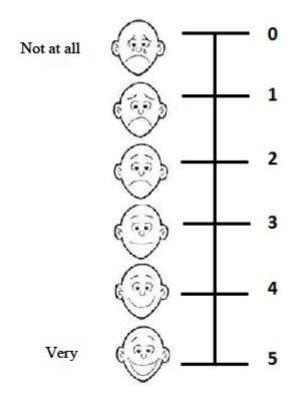
Are you interested in attending a 4-6 week long program to help with your aphasia?





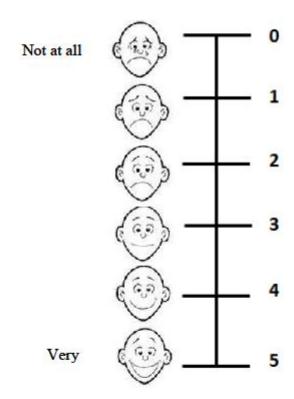
Are you interested in individual therapy?





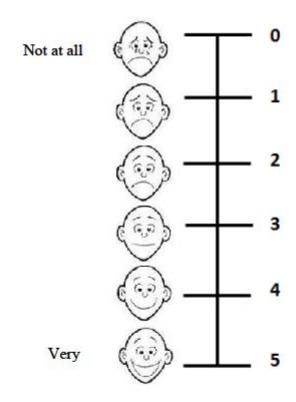
Are you interested in **group** therapy?





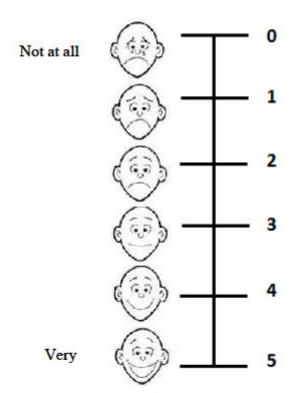
Are you interested in **computer** therapy?





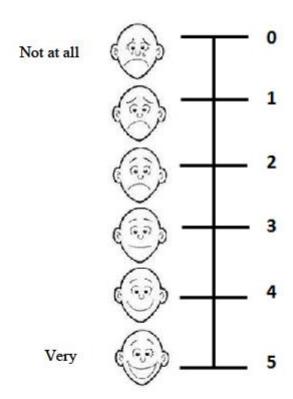
Are you interested in physical therapy?





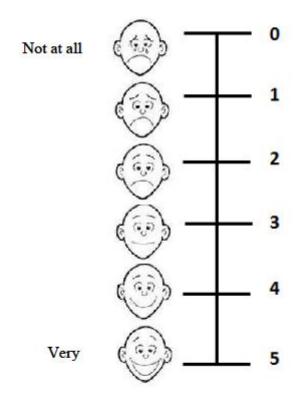
Are you interested in **nursing** assistance?





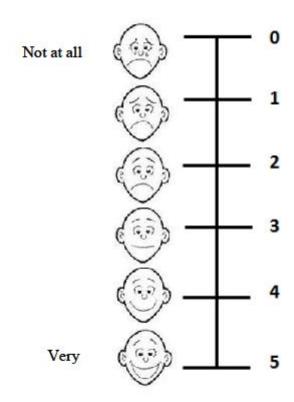
Are you interested in dietary services?





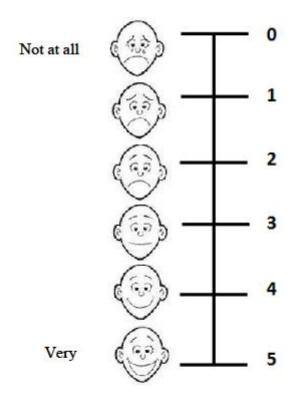
Are you interested in art therapy?



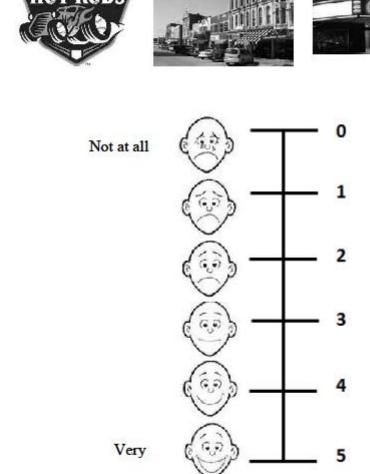


Are you interested in music therapy?



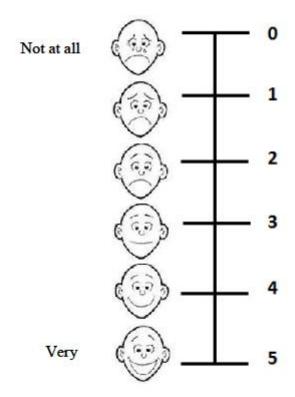


Are you interested in **community outings**?



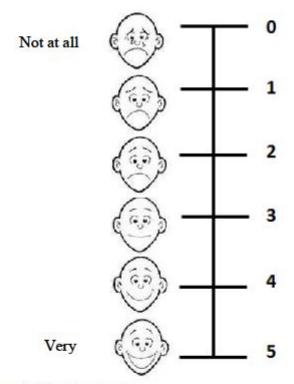
Are you interested in on-site housing?





Are you interested in transportation?





Additional Comments: