

Visual Arts for People with Aphasia

Mason Gehring

January 6, 2020

University of Florida

Abstract

Arts in health is a field that offers opportunities for arts engagement in a healthcare setting that can provide improvements to a person's wellbeing (Fancourt, 2017). The purpose of this study is to collect data about the impact of a visual art engagement on people with aphasia. The study will also evaluate people's interest in making art and/or being creative pre- and post-stroke incident. Aphasia is a language disorder that often occurs post stroke that can strongly affect the entirety of a person's quality of life (NAA, 2018). Engagement in structured visual art making activity could provide opportunities to improve the quality of life for PWA by building confidence and improving social engagement.

Methodology: This study collected data from thirteen participants via self-reporting quantitative pre-post surveys evaluating participants desire for art making, their experience with the art activity, and their future interest in creativity.

Results: The results from the collected data showed that participants find it more important now, after their stroke incident, to participate in creative activities. There was no significant change in responses for continuing to be creative or make art alone from pre and post art activity. However, there was an increase in participants wanting to make art as a group after the art activity.

Conclusion: Further research is needed to clearly measure the interest and attitudes of people with aphasia on participating in visual art projects. This population has an interest in being creative but needs more research to properly understand their needs to participate in a visual arts creative process.

Keywords: Aphasia, people with aphasia, quality of life, visual art engagement

VISUAL ARTS FOR APHASIA

Visual Arts for People with Aphasia

Aphasia is a language disorder that can affect the way a person communicates and comprehends information but does not diminish their intellect (CDC, 2018; NAA, 2018; NSA, 2018; Simmons-Mackie, N., 2018). The number one goal for someone living with aphasia is to improve their quality of life and feel as though they are “living successfully” (Grohn et al., 2014). A “successful life” consists of positive meaningful interactions, support in setting goals, and independence and autonomy (Grohn et al., 2014). These successful life indicators differ from stroke survivors because of the overall severity of how aphasia impacts a person’s life (Hilari et al., 2015). Stroke survivors without the onset of aphasia do not have to face the burden of a communication barrier that can limit how a person feels that they are living a fulfilled life (Brandenburg et al., 2015). Stroke survivors have higher rates of returning to living a fulfilled life than those with aphasia (Simmons-Mackie, 2018). Therefore, long term care focusing on meaningful interactions that improve self-confidence and social interactions are of utmost importance.

The field of arts in health can offer artistic experiences in a healthcare setting that provide opportunities for reduced stress levels, distraction from medical issues, increased confidence, and less visits to a primary care physician (Fancourt, 2017). This study proposes that a structured art engagement could provide meaningful interactions, opportunities for autonomy, and an opportunity to set new goals while working in a group creating visual art. This is a new area for the arts in health field to collect data, therefore, the study will focus on foundational information of how a visual art project is experienced by a person with aphasia.

This study collected data from thirteen participants with mild aphasia from the organization Voices of Hope for Aphasia, a local non-profit support group for people with

VISUAL ARTS FOR APHASIA

aphasia and their caregivers. Speech therapists assisted some of the participants to complete the surveys that were administered pre and post the art activity. The surveys focused on measuring participant's attitudes towards being creative and their interest in continuing to be creative after the art experience. With limited literature on how arts in health specifically impacts people with aphasia, the research questions cover a range of concepts for PWA and a visual art experience.

- Is it an enjoyable positive experience to make art for PWA?
- Is being creative too difficult for PWA?
- Does making art with a group improve wellbeing for PWA?
- Does aphasia affect a PWA's interest in making art or being creative?

Ultimately, this research aims to better inform future visual art projects, aphasia community groups, and arts in health research for people with aphasia. More specifically, this research aims to create a better understanding of the PWA's attitudes towards visual arts and how to create an aphasia friendly self-rating survey that could be used successfully for future research and program evaluation.

Background

The leading cause of disability in the United States is by stroke (CDC, 2018; Grohn et al, 2014; NSA, 2108; Simmons-Mackie, N., 2018). A stroke can affect the entirety of a person's life. From mobility and mental health to maintaining independence, stroke is a serious threat to quality of life. Recovery requires multiple types of therapists and a team of caregivers to manage the day-to-day life (NAA, 2018; NSA, 2018). Age, race, gender and other physical factors can also affect recovery, care, and accessibility a patient will experience (Bishop & Bushnell, 2017). A common disorder often occurring because of a stroke is a language disorder called aphasia and

VISUAL ARTS FOR APHASIA

it affects nearly forty percent of stroke survivors (NAA, 2018). Aphasia compounds the effects of stroke with the limitations and isolation of a language disorder that disrupts a person's ability to project a publicly who they are (Simmons-Mackie, 2018). This makes issues of self-confidence, motivation, self-identity, self-expression, mobility, autonomy, goal setting, socialization, and wellbeing significant factors and why aphasia is the largest negative influence on quality of life (Spaccavento et al., 2013).

Quality of life for people living with aphasia

Emotional wellbeing is one of the most important quality of life indicators for those living with stroke and especially aphasia (Alawieh, Zhao, & Feng, 2018; Bishop & Bushnell, 2017). The World Health Organization defines quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." (WHO, 2018, p.1) The need for a more focused quality of life tool resulted from the exclusion of people with aphasia from other QoL scales because of the severe effects of the disorder (Spaccavento et al., 2013). A study done in the United Kingdom, gathered findings from speech therapists across sixteen countries to define quality of life for people living with aphasia. This study found that it is more effective to use a narrowed Quality of Life tool to understand how aphasia affects all aspects of living. This tool is called the Health-related Quality of Life (HRQL). HRQL takes into consideration how the disorder negatively impacts the person's physical, mental, and emotional wellbeing (Hilari et al., 2015). Results showed that aphasia negatively impacts a person's life more so than cancer or Alzheimer's by causing emotional distress with communication issues and limitations (Hilari et al., 2015).

VISUAL ARTS FOR APHASIA

The limitations and negative impacts of aphasia. Due to the above mentioned, strategies for long-term care for PWA are essential to providing quality of life. Current medical care for aphasia can consider it a temporary condition instead of a chronic illness which can lead to people falling through the cracks of the medical system and into isolative behavior and depression (Simmons-Mackie, 2018; Spaccavento et al., 2013). Being diagnosed with aphasia can bring the consequences of decrease in meaningful activities, little to no employment, social isolation, depression, loneliness, negative self-identity, less autonomy, higher medical bills, and higher frequency of readmission to hospital (Simmons-Mackie, 2018). Arts in health activities can be a means to alleviate these consequences and even carry into weekly or daily habits to manage long term quality of life.

Research for the aphasia population focuses mostly on improving physical limitations. When improvements are gained, the wellbeing of the individual is indirectly improved. This can be effective but, more research could focus on finding long term strategies for maintaining wellbeing for the aphasia population. Therefore, from the literature, most arts-based aphasia research has been developed for therapeutic use involving creative arts therapists. Creative arts therapists engage with patients using arts-based methods to alleviate or improve health issues in a therapeutic setting (NCCATA, 2019). This differs from artists in health professionals who offer artistic experiences in a healthcare setting. There is a gap in the literature pertaining to the arts in health field using arts engagements with people with aphasia. However, information can be drawn from literature of arts in health engagements in stroke recovery along with the creative arts therapies to synthesize effective arts in health engagements for people with aphasia for long term care in improving and maintaining wellbeing.

Creative art therapies for aphasia

VISUAL ARTS FOR APHASIA

Exploring what arts in health professionals can learn from creative arts therapists to create safe and meaningful arts engagements for PWA, a study on traumatic brain injury and art therapy reveals that a high degree of tailoring to the therapy process is needed for each patients' individual needs (Kline, 2016). Kline (2016) found that aside from the positive impacts of art therapy that improve cognitive, emotional, psychological, and behavior needs, that the art making process can provide motivation in their lives to reestablishing a mind/body connection. Group art therapies were also highly regarded as providing benefits to verbalization, socialization, problem solving, and peer supports (Kline, 2016). Therefore, these results could be used to inform the foundation of knowledge on how an arts in health professional could create a positive art making experience for PWA without needing to engage the participant a therapeutic treatment.

Other disciplines for creative art therapies are also a promising therapy strategy for PWA and other speech disorders. Drawing has been used as a way to improve motor skills and create new means for communication (Farias, 2006; Sacchett, 1999) Music therapy is available for PWA but generally is focused around improvement of word recall or speech. There is less of a focus on psychosocial or emotional needs that other art therapies or a visual art intervention could provide (Stahl & Kotz, 2014; Hurkmans et al., 2015; Leonradi et al., 2018). Physical improvements can typically have an indirect impact on the wellbeing of a PWA but are not the center of the research available.

While the creative arts therapies give parameters on creating safe creative spaces, customization requirements, and allowing for mind/body connections for PWA, the arts in health field currently has research being used in stroke recovery but does not generally include people with aphasia. The exclusion of PWA in the arts in health research centers on the difficulty of

VISUAL ARTS FOR APHASIA

measuring QoL for PWA and general lack of knowledge by medical staff on aphasia (Hilari, 2016; White, 2014; Beesley, 2011).

Arts for stroke recovery

Arts in health interventions and creative arts therapies have been used in stroke recovery research as a new holistic approach to recovery. The following studies find that this benefits the recovery process by providing social engagement and at times a spiritual experience (Lo et al., 2018). There is substantial evidence of the impacts of the arts improving wellbeing and QoL in stroke recovery (Beesley, 2011; Morris, 2014; Sit, 2014; Baumann, 2014). Using these studies to understand how arts in health interventions could guide arts in health professionals in engaging long-term care for PWA could find solutions to maintaining wellbeing for life.

Review of arts-based therapies for stroke. Creative arts therapies have been used in both short-term and long-term care for people living with stroke. Lo (2018) created a qualitative systematic review of literature on creative arts-based therapies for stroke survivors. She reviewed the positive impacts and challenges faced with creative arts-based therapies on psychosocial needs for those living with stroke (Lo et al., 2018). This review thoroughly looks at the research to see what types such as physical, speech, and occupational therapies that are part of the current structures of usual care and where art has been used to supplement a more holistic approach to recovery (Lo et al., 2018). Across the disciplines for arts-based interventions, their goal was to “cultivate a safe environment for self-exploration, encourage self-expression, creativity, and imagination through the use of arts” (Lo et al., 2018, p.2). This review helps guide creative arts therapists and artists in healthcare professionals in ways to provide meaningful art activities for stroke survivors.

VISUAL ARTS FOR APHASIA

The review specifically highlighted that the use of visual arts showed an enhancement in communication abilities, opportunities for self-expression, increased self-esteem, and an infusion of hope as a type of spiritual experience (Lo et al., 2018). The short-comings found in participating in visual arts were relatively common, such as difficulty generating new imagery, struggling with art materials, and unable to take praise (Lo et al., 2018). These are significant results to help frame the possibility of positive impacts to PWA engaging in a visual arts intervention.

Leisure art-based creative engagement art program. In 2014, Sit et. al developed a study that explored the emotional wellbeing of chronic stroke survivors that used a leisure art-based creative engagement (LACE) program. This program was facilitated by a nurse practitioner for two and half hours a week to engage small groups of patients in opportunities for artistic expression, creativity, and reflection (Sit et al., 2014). A variety of artistic methods were explored that included painting, drawing, collage and hand crafts (Sit et al., 2014). The patients experienced an improved sense of self, caring for each other, and a restored sense of harmony between their minds and bodies (Sit et al., 2014). This type of program could lessen depression and isolation commonly experienced in stroke recovery (Alawieh et al., 2018). Art also created a new space for caring between the nurse and patients (Sit et al., 2014). From this study, it can be assumed that art has the ability to add an alternative avenue for recovery that further justifies the need for my research project to add to the existing literature and establish foundational data for the arts in health field.

Tayside creative engagement intervention art program. Morris et al. (2016) developed a study of the psychosocial benefits of art making during stroke rehabilitation. Morris administered the Tayside Creative Engagement Intervention (TCEI), a visual arts program

VISUAL ARTS FOR APHASIA

created by artists and academics that is delivered during stroke rehab. This arts program was more structured and artistically in-depth than that experienced by participants in the other studies (Beesley et al., 2011). In the Morris study, participants met with an artist, who has a minimum of five years' experience working with stroke survivors, to discuss their specific stroke limitations, artistic preferences, and goals for art and recovery during rehab (Morris et al., 2016). Stroke survivors met with artists individually and in group sessions for twelve weeks to create art work that advanced these goals. Extensive efforts were put into the development of the TCEI program between the medical team, research team, and professional artists for the implementation of the study. Positive results from the study included themes of improved mood, self-esteem, and a sense of control (Morris et al., 2016).

The study showed that tailoring the artistic process implemented by the art program helped foster feelings of hope and confidence (Morris et al., 2016). The program also facilitated a safe artistic space for the participants to develop relationships with each other and improve social interactions and self-esteem, even for those with aphasia. These are extremely important improvements for stroke survivors and people with aphasia because depression and low self-esteem is a common side effect (Alawieh, 2018; Bishop, 2017; NSA, 2018). Finally, the engagement from the artists to collaborate during the recovery process gave the participants a revitalizing sense of control (Morris et al., 2016). For these patients, control over preferences in art such as choices in mediums expanded into improved control over limbs impaired by the stroke (Morris et al., 2016). These improvements to the stroke survivors' wellbeing created a bridge from the pre-stroke to post-stroke self as a way to reframe the incident and perceptions of the future by seeing themselves as creative people (Morris et al., 2016). This is noteworthy for the field of arts in health to be used as a significant part of stroke recovery.

VISUAL ARTS FOR APHASIA

Gaps in literature

Art interventions found in stroke recovery like the TCEI or LACE program along with guidance from creative art therapies for aphasia research could lead arts in health engagements to improve the long term wellbeing for PWA. The lack of information in the arts in health field for creating visual art interventions for PWA led to the creation of my study to explore and collect data for future research. From reviewing the literature, there is a need to understand how to measure wellbeing levels for participating in visual art interventions and exploring more evidence based aphasia-friendly interventions to improve their quality of life (Hilari et al., 2015). This study is addressing the need for data on attitudes and satisfaction with creative activities for people with aphasia, creating art in a group setting, and if more access to art activities will increase their interest.

Methods

Methodology

The methodology for this study is a quantitative approach for data collection. A modified Wong-Baker Faces Likert-scale (Wong-Baker FACES Foundation, 2016) allowed the participants to select to what degree they positively or negatively reacted to each question. The pre-intervention survey measured their attitudes on creative activities pre and post their stroke incidents. The post intervention survey measured their satisfaction of the art intervention itself and future interest in continuing to engage in creative activities.

Rationale for methodology

The rationale for a quantitative approach was to measure the attitudes and satisfaction of a visual arts experience for PWA from a single session. The creation and use of a modified Wong-Baker Faces Likert-scale for data collection was developed because of its familiarity for

VISUAL ARTS FOR APHASIA

VOH members. Reducing the amount of stress in learning to use new tools or new forms of measuring was of utmost importance to create a sense of ease for participants. The phrasing and imagery of the survey questions is based on the Stroke and Aphasia Quality of Life -39 tool used in assessing quality of life for post stroke survivors including those with aphasia (Hilari et al., 2003). The number of survey questions was reduced to a limited amount of six (6) per survey because of the risk of mentally exhausting participants for the research process. The use a self-reporting data collection tool and not the assistance of a proxy was purposeful to allow the PWA the opportunity to self-report resulting in a sense of self-sufficiency. There are positive and negative implications for using a self-rating system and those limitations were taken into consideration and will be further addressed in the limitations section of this study. The use of imagery like the Wong-Baker Faces scale was chosen to maximize the participants understanding of the survey questions (Spaccavento et al., 2013). Since these surveys were measuring the attitudes towards creativity and the art intervention, it seemed relevant to use an emotionally centered rating scale.

This research will be new for the arts in health field and could be a foundation for the aphasia population and supportive organizations to understand needs for engaging in a visual arts intervention for people with aphasia. Thus, it was important to administer the study even if the results were small and limited in hopes that more research could be generated from small beginnings.

Recruitment

Voices of Hope for Aphasia members with mild aphasia that included men and women from 45 – 95 years old living were accepted into the study. Members with minimal language comprehension were not enrolled into the study. Although inclusion was of the utmost

VISUAL ARTS FOR APHASIA

importance for this study, not all of the members from VOH were included in collecting data from because of their level of comprehension of the process of the study. The pre and post surveys and art intervention were administered at both locations, the Hale center and Sunshine center, and were completed within 3 hours at each location. A previous relationship and experience had already been established between the primary investigator, VOH staff, and VOH members. All participants have been diagnosed with aphasia and the research project parameters were explained at the start of the study. Waivers of documentation of consent were reviewed and acknowledged prior to the pre-art intervention survey. Participants understood that participating in the survey was giving consent to the research process. The goal was to enroll up to twenty-three (23) PWA in the visual art intervention between the two locations. On the days of data collection, a total of thirteen (13) individuals participated in the study.

Abstract visual art activity

The art activity consisted of the creation of an abstract self-portrait created by each participant using paper and markers giving an opportunity to create abstract expressive imagery within pre-made paper silhouettes of a head to be arranged on a 12" x 12" piece of paper. Participants were instructed to divide the head into four spaces to give them smaller spaces to create in. An example self-portrait was presented by the principal investigator to show that there was no need to focus on creating a realistic self-portrait but rather to use shapes and colors to create an abstract expression of ones-self. Examples of different kinds of shapes and marking making were drawn on a white board for all of the participants to reference. Once completed the portraits were collected and arranged together in a large paper quilt to show the individuality of each member and the community they create. A two-hour time limit is given for the constraints of the art instruction and creation period. This time constraint was created because of

VISUAL ARTS FOR APHASIA

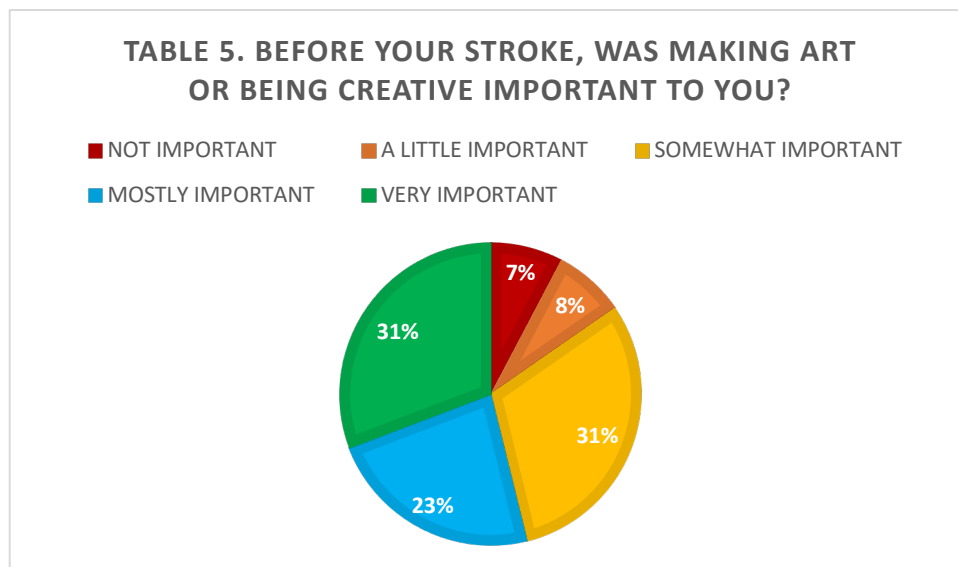
personal knowledge of working with this aphasia organization, that they can easily be exhausted or disinterested by lengthy artistic processes. Art making tools and processes were adapted to be accessible for all VOH members regardless of any mobility issue.

Data analysis plan

All surveys were anonymous and the data was entered into a spreadsheet only accessible by the research investigators. Each participant was given a number that was written on their surveys and art project instead of names or any other identifying information. The data analysis plan reviewed the ordinal information collected from the pre intervention Likert scale survey that measured their pre and post stroke attitudes in being creative. The post intervention survey measured their interest in continuing to engage in creative activities and their experience of the art intervention.

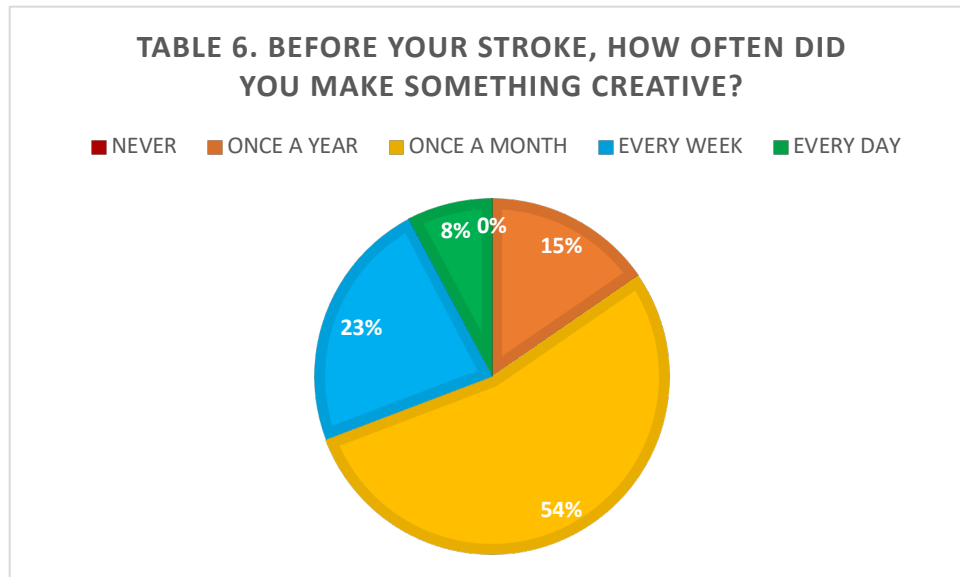
Findings

Results from the pre-art intervention survey show the importance of being creative after their stroke incident decreased, compared to their pre-stroke responses.

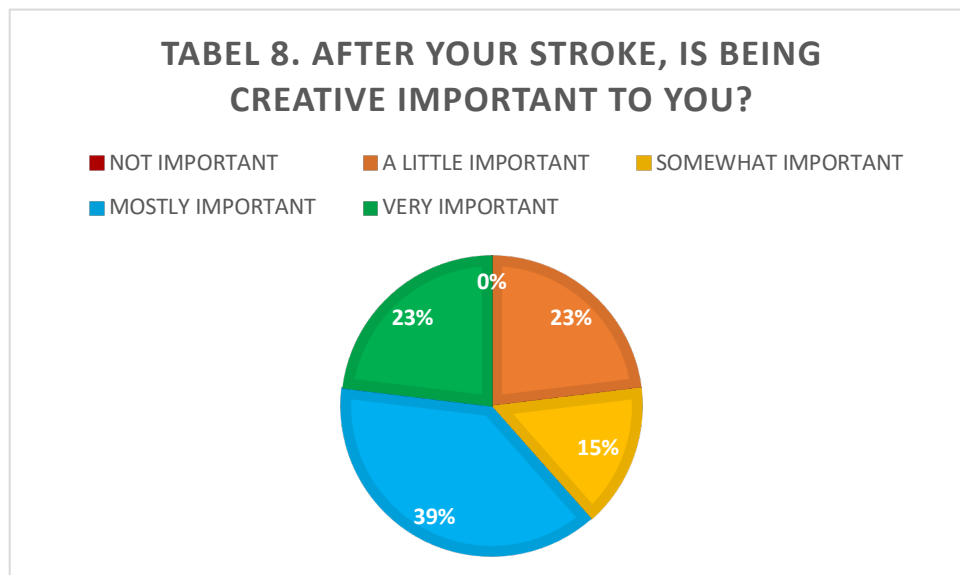


VISUAL ARTS FOR APHASIA

In Table 5, 85% of participants said that it is “somewhat, mostly, or very important” to be creative prior to their stroke incident while in Table 8, 77% feel that it is “somewhat, mostly, or very important” to be creative after their stroke incident. In Table 6 we see that more than 50% of participants claim to be creative “once a month” before their stroke and more than 60% feel as though that being creative was “mostly to very fun” experience before their stroke.

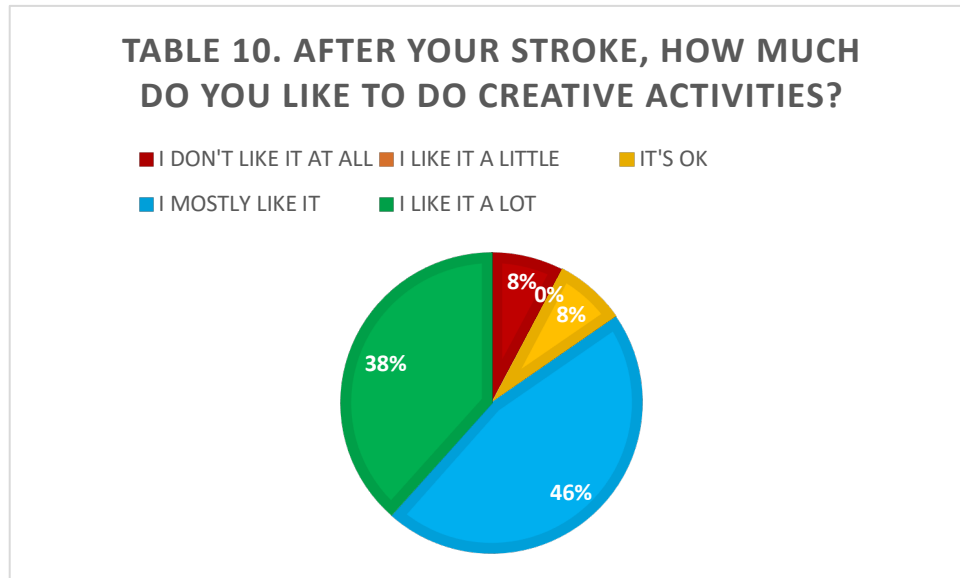


Conversely, in Table 8 it depicts nearly 40% participate in a creative activity once a month after their stroke incident, a decrease of 6% from their pre-stroke incident responses.



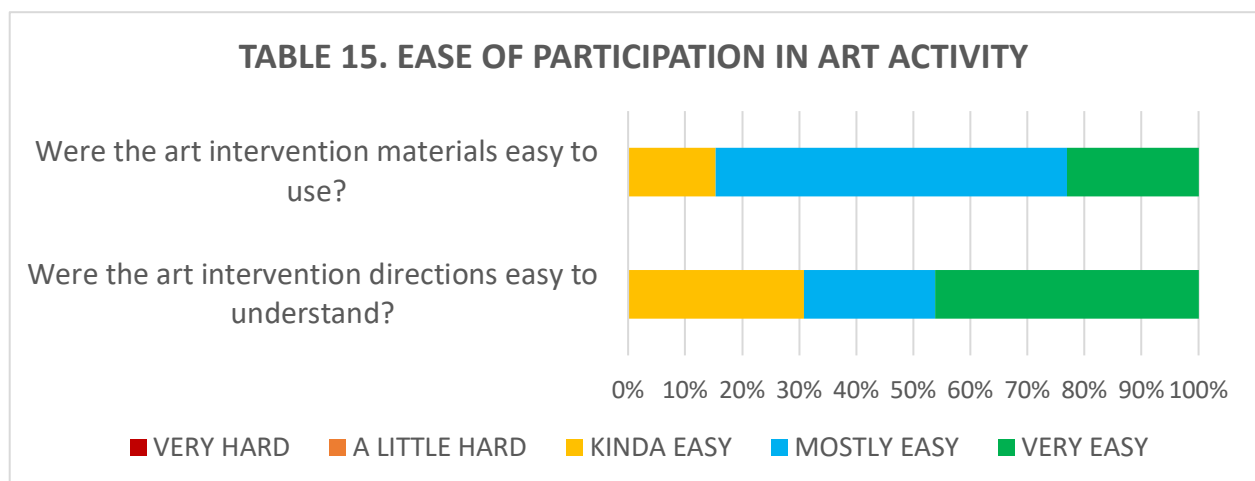
VISUAL ARTS FOR APHASIA

In Table 10, 46% of participants “mostly like” making art or being creative after their stroke incident, followed by 38% “like it a lot”.



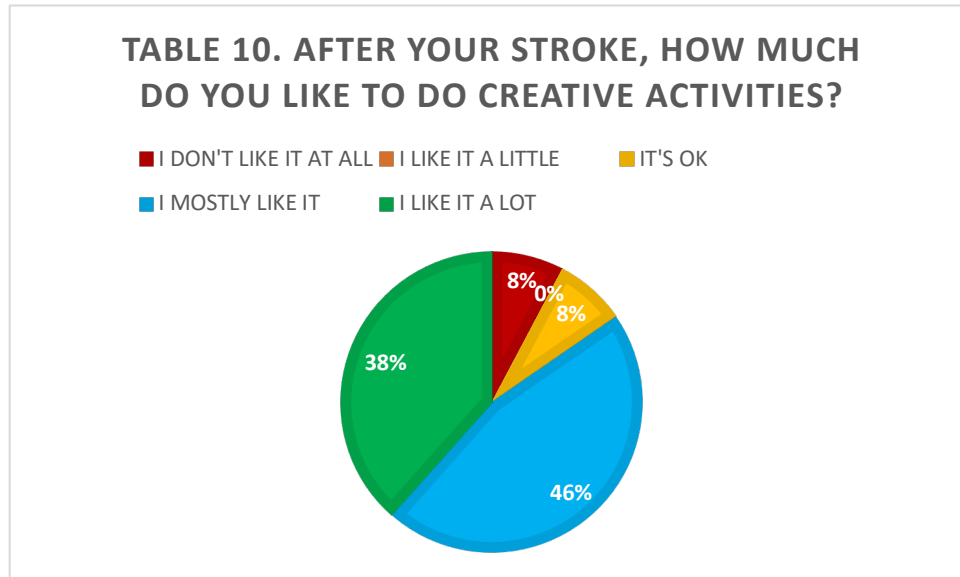
Averages of responses were from 3.23 to 4.08 with a range of 0.85. The standard deviation of the pre-art intervention survey ranged from 0.83 > 1.26.

Results from the post-art intervention survey show that nearly 50% found it “very easy” to participate in the art intervention and over 60% found that the art making materials of paper and markers were “kind of easy” to use. See Table 15, for that no one found the art intervention “very hard” or a “little hard” to understand the directions or access the art materials.

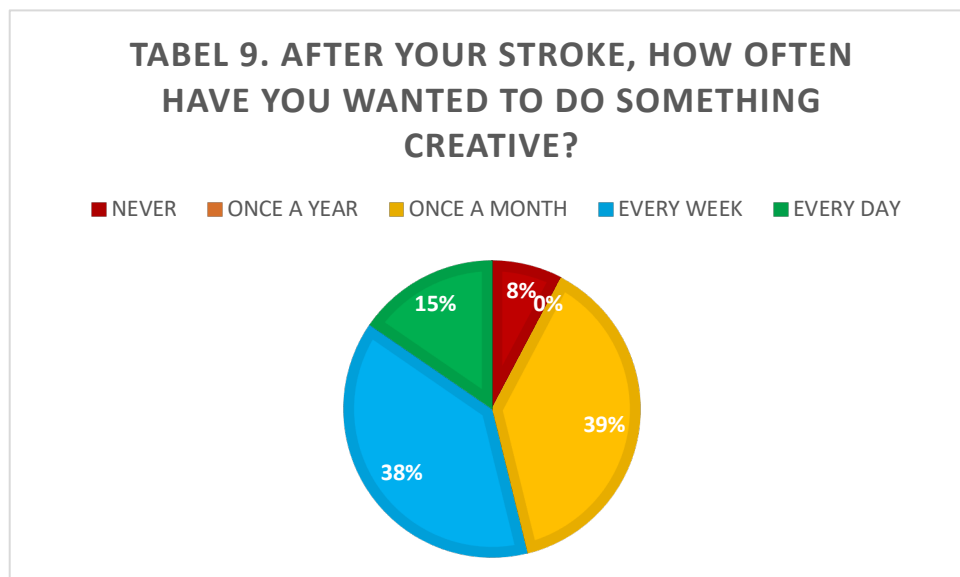


VISUAL ARTS FOR APHASIA

Almost 70% of participants “mostly wanted or definitely wanted” to keep making art but, 30% of participants selected that they would “rather not or did not care” to keep making art. In Table 10 it shows that no one “definitely did not” want to keep making art.



In Table 9, 38% of participants wanted to continue to make art by themselves “once a month” followed by 31% at “once a week”, and 23% at “everyday”.



Making art as a group increased in results for “once a month” engagement of 46% of participants, followed by 38% wanted to make art as a group “everyday”. No one “never wanted

VISUAL ARTS FOR APHASIA

to make art” as a group or by themselves compared to the 8% who “never wanted to make art” after their stroke incident. 100% of the participants responses for engaging in group art participation fell between “once a month” and “everyday”. Averages of responses were from 3.69 to 4.15 with a range of 0.46. The standard deviation of the pre-art intervention survey ranged from 0.64 >1.07.

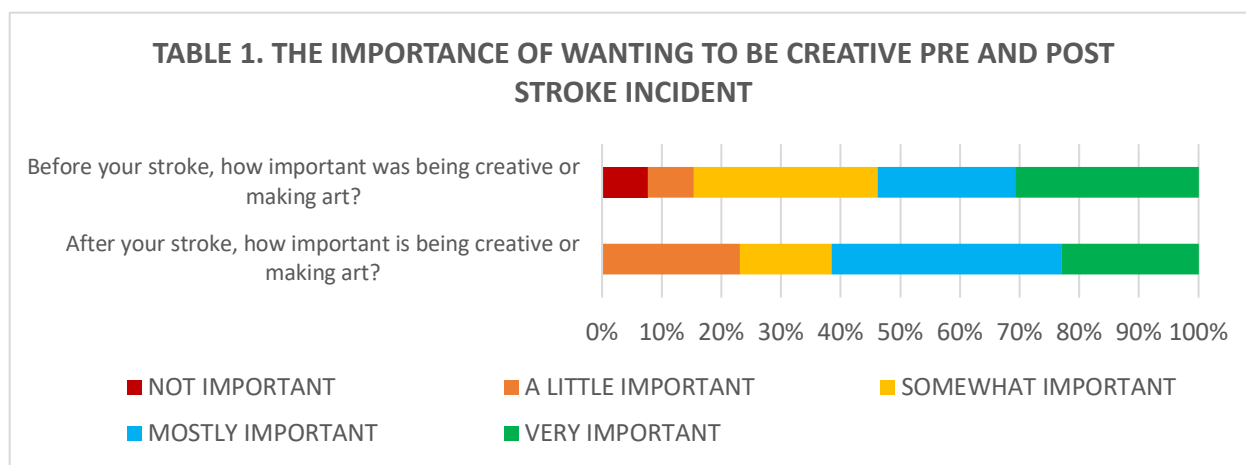
Discussion

This study takes a step for the arts in health field in exploring the experiences of PWA and visual art making. Data collected from this study can direct artists, speech therapists, and future researchers on how to create studies or visual art programming for PWA. The majority of valuable new information gained from this research is derived more from its complications in the development, execution, and analysis of the research than the data itself.

From the results, there is difficulty to compare the pre-art intervention results to the post-art intervention responses. The survey questions were not set up to directly compare in this manner. In general, it is unclear how the art activity directly changed attitudes or interests towards visual arts engagement.

The importance of being creative

With this in mind, summation of the comparison of importance of being creative or making art responses pre and post stroke incident there is a slight increase in finding it “a little important”, “somewhat important”, “mostly important”, and “very important” compares to the before stroke responses (See table 1).



No participant found it “not important” to engage in creative activities after their stroke incident. It is possible that the stroke incident changed their view of their life and they are encouraged to find new ways to communicate and participate in life. From the literature, results from Kline’s (2016) art therapy work with PWA and participants in the TCEI art program (Morris et al., 2016) from stroke recovery said engaging in art activities gave patients new ways to view their body and self-identify. There is a possibility that doctors and caregivers are looking for alternative ways for PWA to practice communication or socially engage and using the arts is a possible mode for improving quality of life as compared to prior their stroke incidents.

Desire to create

More participants positively responded to continuing to “make art as a group” after the art intervention rather than “by themselves” (See Tables 2 & 3). It can be assumed that they enjoyed the art making process together and seeing their work become one piece.

VISUAL ARTS FOR APHASIA

TABLE 2. HOW OFTEN DO YOU WANT TO MAKE ART BY YOURSELF?

■ NEVER ■ ONCE A YEAR ■ ONCE A MONTH ■ EVERY WEEK ■ EVERY DAY

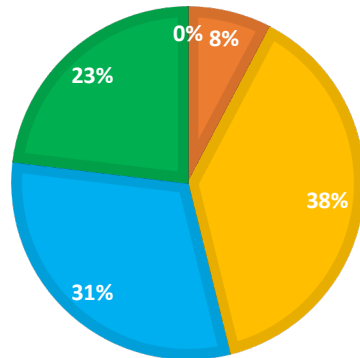
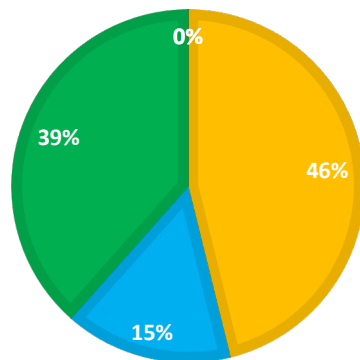
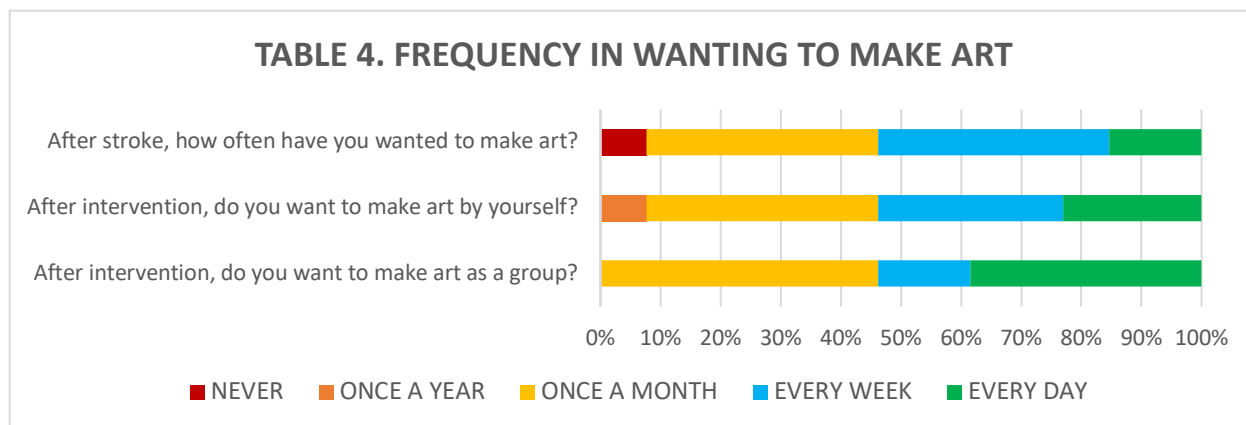


TABLE 3. HOW OFTEN DO YOU WANT TO MAKE ART AS PART OF A GROUP?

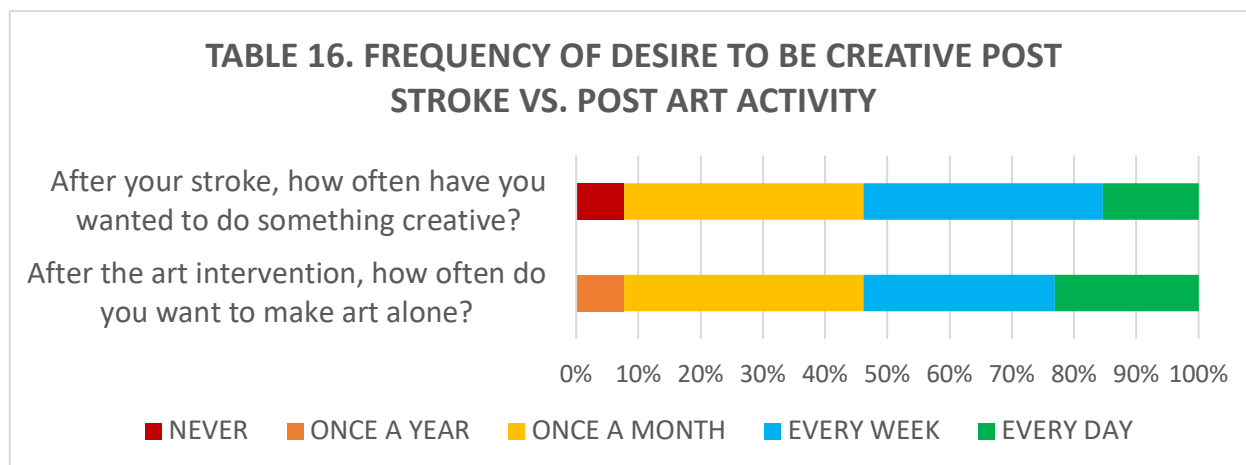
■ NEVER ■ ONCE A YEAR ■ ONCE A MONTH ■ EVERY WEEK ■ EVERY DAY



Nearly half of participants wanted to make art “once a month” by themselves or as a group. This is significant information for the arts in health field to acknowledge and actively pursue engaging the aphasia population in visual arts activities because there is a demand for it (See Table 4).



The desire to create as a group justifies one of the “successful living” indicators of improving social engagement and building confidence (Grohn et al., 2014). Whether engaged in creative activities before or after their stroke incidents, the results show that a need for group engagement in artistic activities. As a group, there is a possibility to have meaningful interactions, improve self-esteem, set goals, and establish independence from caregivers, see Table 16 for increase in desire to participate in art activities.



These are all very important aspects of living a quality of life specific to the aphasia population (Lee et al., 2015). This data is just the beginning of understanding if participating in visual arts interventions is a positive experience for people with aphasia.

Past interactions with VOH members

VISUAL ARTS FOR APHASIA

In the past, the principal investigator spent over one hundred hours working with this organization and its members witnessing first-hand that engaging in art activities has increased socialization, confidence, and opportunities to learn new skills. This study lacked insight into the best ways to gather information from this specific population and their means of interacting with the creative process.

Members engaged in weekly sessions of an aphasia-friendly Pictionary game, where significant improvement in eye-hand coordination, spatial awareness, and creative thinking of the participants that ignited a comradery and encouragement between members that was contagious. Willingness to try new things increased as the members shared more experiences together learning about printmaking or watercolor painting. The realization that being creative was something that could bring joy or improvement to their lives occurred frequently by not only the members but also by their caregivers. The group experiences created a sense of camaraderie amongst the members as they all faced challenges or triumphs with the creative process or maneuvering new art making materials. The opportunity to make jokes and laugh with each other was always part of their creative process.

Creating art with the principal investigator gave the VOH members pride in things they created, new awareness to abilities they did not know they had, and opportunities for new ways to express themselves. This experience was rich in data that could help inform the research community of the impacts of visual art on PWA.

Limitations

Limitations from this study include the following. For example, the limitations on time, funding, and knowledge of research protocol created many obstacles to the design and process of this study.

VISUAL ARTS FOR APHASIA

Time limitations. First, time limitations constricted the mode in which to measure data by limiting it to only using quantitative data and not a mixed method approach that included qualitative focus groups or one-on-one interviews that are more suitable for this population. A schedule that allowed for ample amounts of time for qualitative data collection would give this study richer information on this population. The low physical and mental stamina of PWA created time limitations in the research process with the possibilities of exhausting participants and in turn forcing them to drop out of the study resulting in a poor representation of the aphasia population. More in-depth data could have been collected with more time to collect on a variety of visual art interventions rather than only one session. Because of a restriction of time, the research process was edited to encompass what would be possible for the circumstances and the abilities of the participants that were approved by the institutional review board.

Funding limitations. Additional funding to create more opportunities for engagement and materials to create multiple art interventions for data collection would assist in further exploring this topic. A stronger collection of data could be created with more consecutive instances to expose the same participants to different visual art projects and measure their responses. Within the financial limits of this study, the visual art activity created was what was achievable in these limitations as well as a limited amount of time for the research process.

Knowledge of research processes limitations. Finally, knowledge of research protocol and process limited a large aspect of this study. Knowledge of the best practices in ways to prepare and collect data were lacking to this new researcher. The use of a Likert scale for data collection can create limits to the information collected. Although, they are a common use, Likert scales are not necessarily equal and they cannot determine the distances between

VISUAL ARTS FOR APHASIA

responses (Sullivan & Artino, 2013). This limits the variety of responses that could have been responses from the participants.

The use of self-reporting surveys for the aphasia population limits access to individuals with severe aphasia who would need a proxy to participate. Although it would be more inclusive and more accurate information to use proxies for participants with more severe disorders, there are negative implications of the use of proxies as well. Hilari (2016) states that the use of a proxy for surveys tend to show a significant difference in proxy and self-reporting on functional status and quality of life. Therefore, it can be less reliable than allowing the participant to self-report because the proxy is assuming they know the participants experience. Although giving the opportunity for self-reporting can give a sense of autonomy to the participant, the possibility that the responses are inaccurate because of confusion from understanding the survey questions is high. Testing and retesting of the surveys would have reduced the possibilities of inaccuracy but, lack of time and research protocol leaves this uncertainty available.

The surveys' wording structure was not ideal to collect significant data for the aphasia population. It is unclear how to measure the impact on quality of life or wellbeing post-art intervention because none of the survey questions directly ask this of the participants. These are failures in the research process that the principal investigator lacked experience to better understand how to create questioning to collect significant responses. Great difficulty was found in creating in-depth questions to collect results while using phrasing and wording that is friendly for the aphasia population.

Biases limitations. There is also the possibility that the relationship between the principal investigator and the participants could have skewed responses to be more positive than if there was not a personal relationship with participants and the organization. Participants may

VISUAL ARTS FOR APHASIA

have responded in ways that they are assuming will help the principal investigator rather than a more honest response to each question. However, this familiar relationship between the principal investigator and the participants could play a part in the positive responses to the art making process.

Recommendations for future research

This population has an interest in being creative but needs more time invested in research to properly understand their needs in the visual arts creative process. Studies into specific kinds of visual art activities for people living with aphasia to increase quality of life are waiting to be created. This study could be part of new research for the arts in health field that could facilitate the expansion of knowledge of visual arts for PWA.

Qualitative longitudinal studies using visual arts with PWA during stroke recovery but continued consistently for up to a year or more post stroke could help establish best practices for the arts in health field and the aphasia population. While evidence from creative art therapies and visual art interventions for stroke recovery can inform aspects of visual art activities for PWA, further research is needed to fully understand ways to provide greater access to quality of life activities for long term care. Understanding how to live a great life with aphasia could be a visual art project away.

Conclusion

For those living with aphasia, their subjective needs and ways to measure quality life is still being investigated by the research community. Knowing how to interact with the aphasia community, measure their wellbeing, and to be included in research also needs further development so that this knowledge can easily be used in other fields like arts in health. Further research is needed to clearly measure the interest and attitudes of people with aphasia on

VISUAL ARTS FOR APHASIA

participating in visual art projects. There is work to be done to include a population that has been excluded and unheard, physically and metaphorically, for too long. Allowing people with aphasia to explore their new ways of visually expressing themselves allows for a greater knowledge into how art can heal and bring greater health and awareness to a significant population.

References

- Alawieh, A., Zhao, J., & Feng, W. (2018). Factors affecting post-stroke motor recovery: Implications on neurotherapy after brain injury. *Behavioural Brain Research, 340*, 94–101. <https://doi.org/10.1016/j.bbr.2016.08.029>
- Beesley, K., White, J. H., Alston, M. K., Sweetapple, A. L., & Pollack, M. (2011). Art after stroke: The qualitative experience of community dwelling stroke survivors in a group art programme. *Disability and Rehabilitation, 33*(22–23), 2346–2355. <https://doi.org/10.3109/09638288.2011.571333>
- Bishop, L., & Bushnell, C. (2017). Post Hospital Discharge Care for Complex Chronic Conditions: The Unique Challenges Facing Stroke Patients in their Homes. *Current Cardiovascular Risk Reports, 11*(12), 36. <https://doi.org/10.1007/s12170-017-0560-7>
- Brandenburg, C., Worrall, L., Rodriguez, A., & Bagraith, K. (2015). *Crosswalk of participation self-report measures for aphasia to the ICF: what content is being measured?: Disability and Rehabilitation: Vol 37, No 13.* <https://www.tandfonline.com/doi/full/10.3109/09638288.2014.955132>
- Fancourt, D. (2017). *Arts in Health: Designing and researching interventions.* Oxford University Press.
- Grohn, B., Worrall, L., Simmons-Mackie, N., & Hudson, K. (2014). Living successfully with aphasia during the first year post-stroke: A longitudinal qualitative study. *Aphasiology, 28*(12), 1405–1425. <https://doi.org/10.1080/02687038.2014.935118>

VISUAL ARTS FOR APHASIA

- Hilari, K., Byng, S., Lamping, D. L., & Smith, S. C. (2003). Stroke and Aphasia Quality of Life Scale-39 (SAQOL-39): Evaluation of Acceptability, Reliability, and Validity. *Stroke, 34*(8), 1944–1950. <https://doi.org/10.1161/01.STR.0000081987.46660.ED>
- Hilari, K., Cruice, M., Sorin-Peters, R., & Worrall, L. (2015). Quality of Life in Aphasia: State of the Art. *FOLIA PHONIATRICA ET LOGOPAEDICA, 67*(3), 114–118. <https://doi.org/10.1159/000440997>
- Kline, T. (2016). Art Therapy for Individuals With Traumatic Brain Injury: A Comprehensive Neurorehabilitation-Informed Approach to Treatment. *Art Therapy: Journal of the American Art Therapy Association, 33*(2), 67–73. <https://doi.org/10.1080/07421656.2016.1164002>
- Lee, H., Lee, Y., Choi, H., & Pyun, S.-B. (2015). Community Integration and Quality of Life in Aphasia after Stroke. *Yonsei Medical Journal, 56*(6), 1694–1702. <https://doi.org/10.3349/ymj.2015.56.6.1694>
- Lo, T. L. T., Lee, J. L. C., & Ho, R. T. H. (2018). Creative Arts-Based Therapies for Stroke Survivors: A Qualitative Systematic Review. *Frontiers in Psychology, 9*. <https://doi.org/10.3389/fpsyg.2018.01646>
- Morris, J., Toma, M., Kelly, C., Joice, S., Kroll, T., Mead, G., & Williams, B. (2016). Social context, art making processes and creative output: A qualitative study exploring how psychosocial benefits of art participation during stroke rehabilitation occur. *Disability and Rehabilitation, 38*(7), 661–672. <https://doi.org/10.3109/09638288.2015.1055383>
- NAA. (2018). *National Aphasia Association*. National Aphasia Association. <https://www.aphasia.org/>

VISUAL ARTS FOR APHASIA

NCCATA. (2019). *National Coalition of Creative Arts Therapies Associations, Inc.*. Nccata.

<https://www.nccata.org>

NSA. (2018). *Impact of Stroke*. Stroke.Org. <http://www.stroke.org/understand-stroke/impact-stroke>

Simmons-Mackie, N. (2018). *Aphasia in North America: Frequency, Demographics, Impact of Aphasia, Communication Access, Services and Service Gaps*. Aphasia Access.

<https://www.aphasiaaccess.org/stateofaphasia>

Sit, J. W. H., Chan, A. W. H., So, W. K. W., Chan, C. W. H., Chan, A. W. K., Chan, H. Y. L., Fung, O.

W. M., & Wong, E. M. L. (2014). Promoting Holistic Well-Being in Chronic Stroke Patients Through Leisure Art-Based Creative Engagement. *Rehabilitation Nursing, 0*(0).

<https://doi.org/10.1002/rnj.177>

Spaccavento, S., Craca, A., Del Prete, M., Falcone, R., Colucci, A., Di Palma, A., & Loverre, A.

(2013). Quality of life measurement and outcome in aphasia. *Neuropsychiatric Disease and Treatment, 10*, 27–37. <https://doi.org/10.2147/NDT.S52357>

Stahl, B., & Kotz, S. A. (2014). Facing the music: Three issues in current research on singing and aphasia. *Frontiers in Psychology, 5*. <https://doi.org/10.3389/fpsyg.2014.01033>

Sullivan, G. M., & Artino, A. R. (2013). Analyzing and Interpreting Data From Likert-Type Scales.

Journal of Graduate Medical Education, 5(4), 541–542. <https://doi.org/10.4300/JGME-5-4-18>

WHO. (2018). *WHOQOL: Measuring Quality of Life*. WHO.

<https://www.who.int/healthinfo/survey/whoqol-qualityoflife/en/>

VISUAL ARTS FOR APHASIA

Wong-Baker FACES Foundation. (2016). *History of the Wong-Baker FACES® Pain Rating Scale*.

Wong-Baker FACES Foundation. <https://wongbakerfaces.org/us/wong-baker-faces-history/>

Appendix 1

Data Tables 1-16

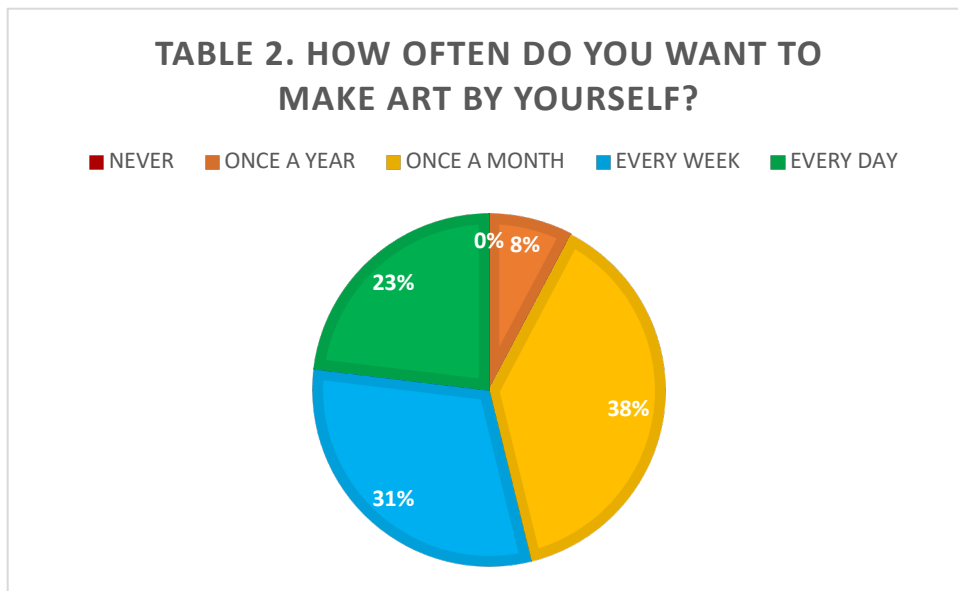
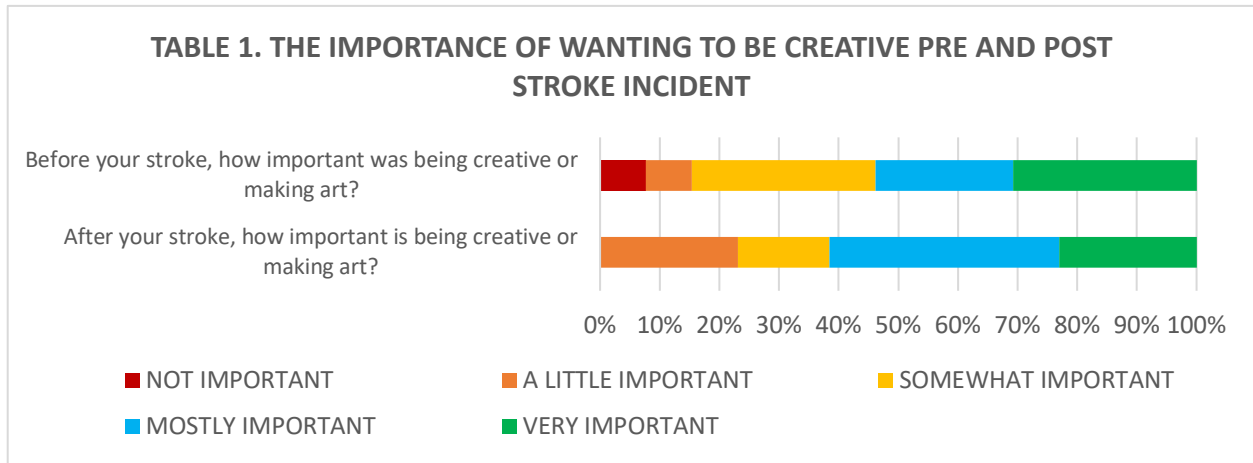


TABLE 3. HOW OFTEN DO YOU WANT TO MAKE ART AS PART OF A GROUP?

■ NEVER ■ ONCE A YEAR ■ ONCE A MONTH ■ EVERY WEEK ■ EVERY DAY

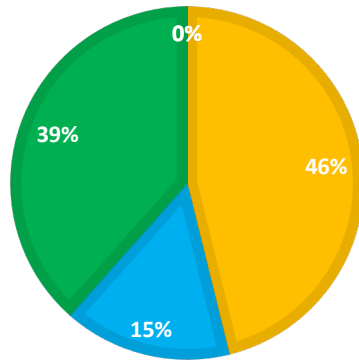


TABLE 4. FREQUENCY IN WANTING TO MAKE ART

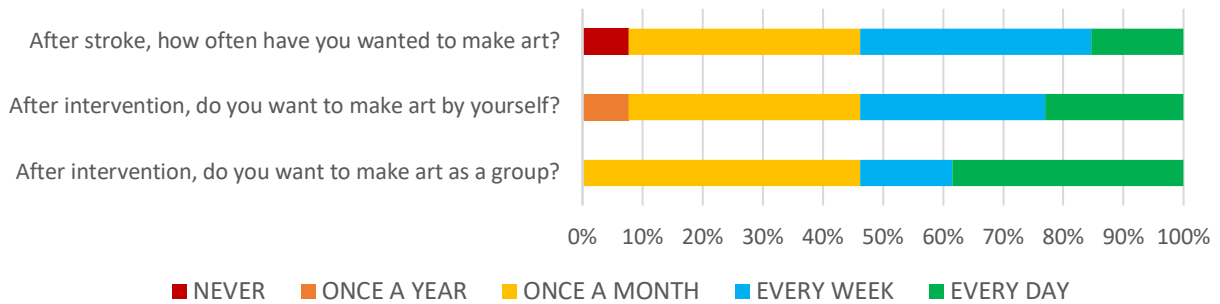


TABLE 5. BEFORE YOUR STROKE, WAS MAKING ART OR BEING CREATIVE IMPORTANT TO YOU?

■ NOT IMPORTANT ■ A LITTLE IMPORTANT ■ SOMEWHAT IMPORTANT
 ■ MOSTLY IMPORTANT ■ VERY IMPORTANT

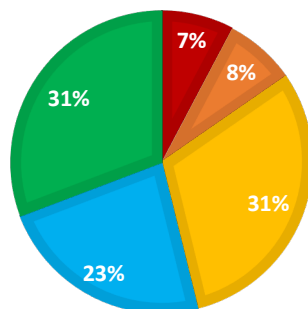


TABLE 6. BEFORE YOUR STROKE, HOW OFTEN DID YOU MAKE SOMETHING CREATIVE?

■ NEVER ■ ONCE A YEAR ■ ONCE A MONTH ■ EVERY WEEK ■ EVERY DAY

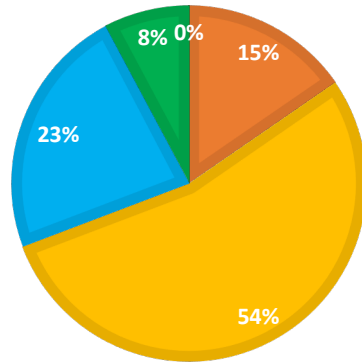
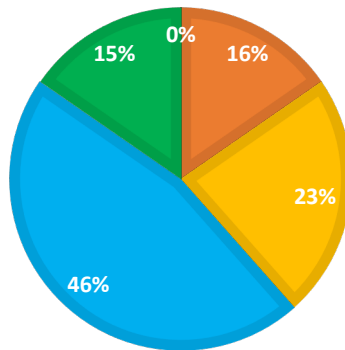


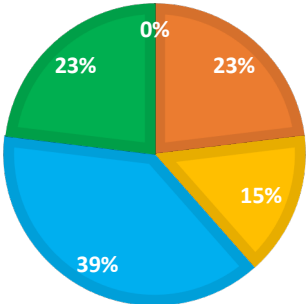
TABLE 7. BEFORE YOUR STROKE, WAS BEING CREATIVE FUN FOR YOU?

■ NOT FUN ■ A LITTLE FUN ■ KINDA FUN ■ MOSTLY FUN ■ VERY FUN



TABEL 8. AFTER YOUR STROKE, IS BEING CREATIVE IMPORTANT TO YOU?

■ NOT IMPORTANT ■ A LITTLE IMPORTANT ■ SOMEWHAT IMPORTANT
■ MOSTLY IMPORTANT ■ VERY IMPORTANT



TABEL 9. AFTER YOUR STROKE, HOW OFTEN HAVE YOU WANTED TO DO SOMETHING CREATIVE?

■ NEVER ■ ONCE A YEAR ■ ONCE A MONTH ■ EVERY WEEK ■ EVERY DAY

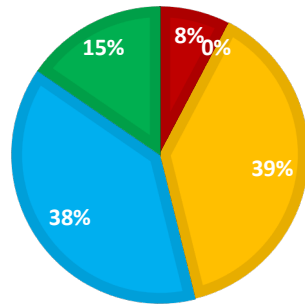
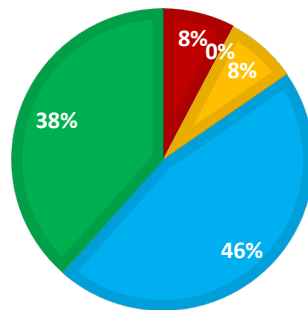


TABLE 10. AFTER YOUR STROKE, HOW MUCH DO YOU LIKE TO DO CREATIVE ACTIVITIES?

■ I DON'T LIKE IT AT ALL ■ I LIKE IT A LITTLE ■ IT'S OK
■ I MOSTLY LIKE IT ■ I LIKE IT A LOT



VISUAL ARTS FOR APHASIA

TABLE 11. WERE THE DIRECTIONS EASY TO UNDERSTAND?

■ VERY HARD ■ A LITTLE HARD ■ KINDA EASY ■ MOSTLY EASY ■ VERY EASY

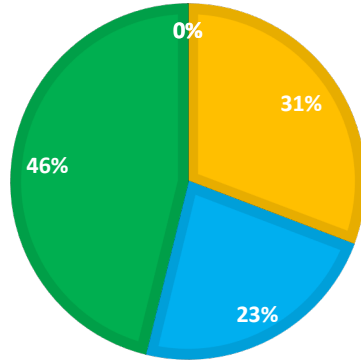


TABLE 12. WAS IT FUN TO MAKE ART TOGETHER?

■ NOT FUN ■ A LITTLE FUN ■ KINDA FUN ■ MOSTLY FUN ■ VERY FUN

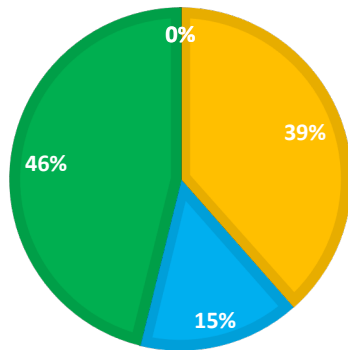


TABLE 13. WERE THE ART MAKING MATERIALS EASY TO USE?

■ VERY HARD ■ A LITTLE HARD ■ KINDA EASY ■ MOSTLY EASY ■ VERY EASY

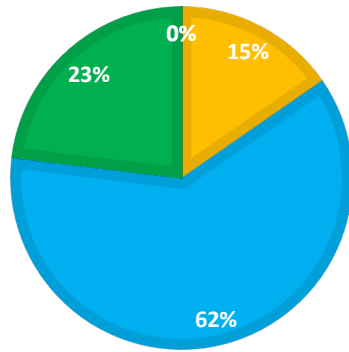


TABLE 14. WOULD YOU LIKE TO KEEP MAKING ART?

■ DEFINITELY NOT ■ I'D RATHER NOT ■ DON'T CARE ■ MOSTLY YES ■ DEFINITELY YES

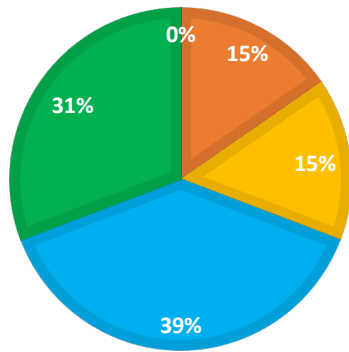
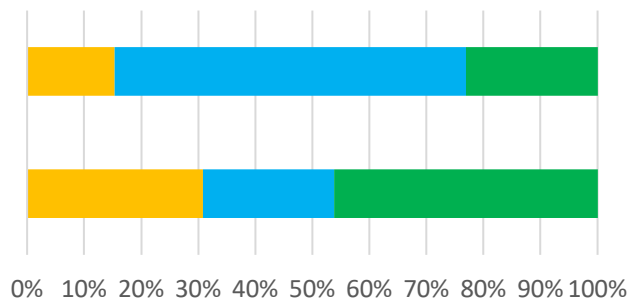


TABLE 15. EASE OF PARTICIPATION IN ART ACTIVITY

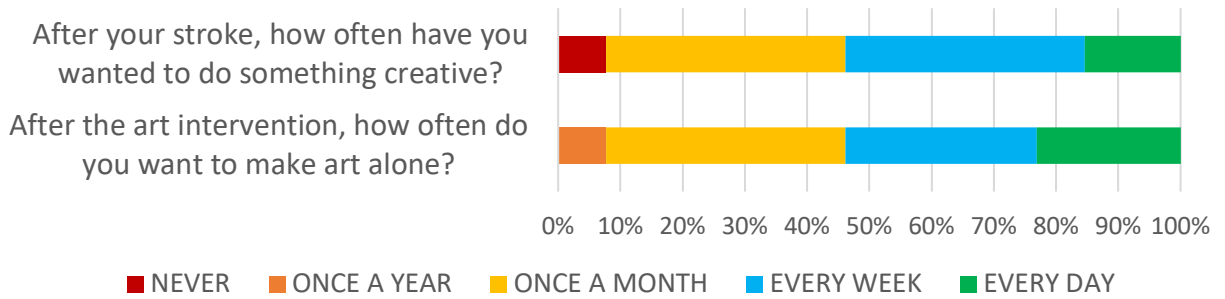
Were the art intervention materials easy to use?

Were the art intervention directions easy to understand?



■ VERY HARD ■ A LITTLE HARD ■ KINDA EASY ■ MOSTLY EASY ■ VERY EASY

TABLE 16. FREQUENCY OF DESIRE TO BE CREATIVE POST STROKE VS. POST ART ACTIVITY



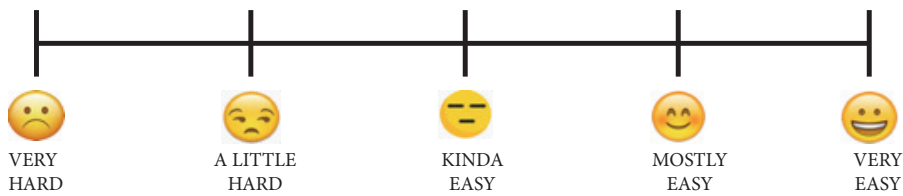
Appendix 2

Sample of study survey

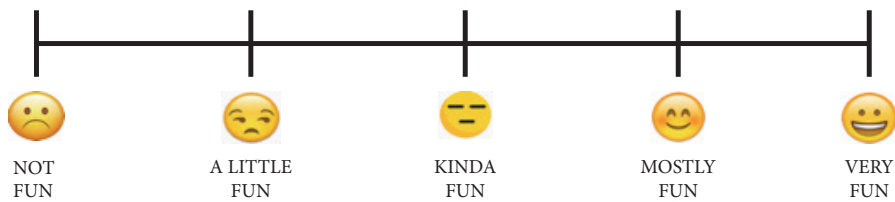
POST - ART SURVEY

Directions: Put an X on your answer to the following questionws.

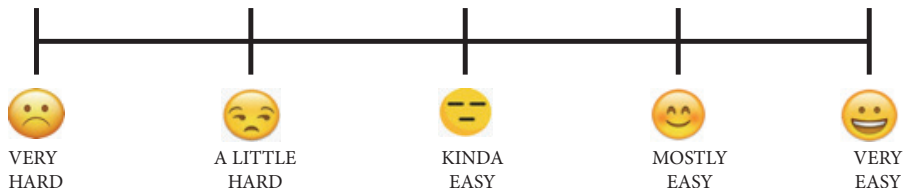
1. Were the directions for the art project easy to understand?



2. Was it fun to make art together?



3. Were the art making materials easy to use?



Appendix 3

Completed art activity

