

Eastern Kentucky University

Encompass

Occupational Therapy Doctorate Capstone
Projects

Occupational Science and Occupational
Therapy

2017

Opening Minds Through Art: Engaging Art Agencies To Foster Community Participation and Commitment

Ashlyn Cunningham

Eastern Kentucky University, acunningham@maryville.edu

Follow this and additional works at: <https://encompass.eku.edu/otdcapstones>



Part of the [Mental and Social Health Commons](#), and the [Occupational Therapy Commons](#)

Recommended Citation

Cunningham, Ashlyn, "Opening Minds Through Art: Engaging Art Agencies To Foster Community Participation and Commitment" (2017). *Occupational Therapy Doctorate Capstone Projects*. 20. <https://encompass.eku.edu/otdcapstones/20>

This Open Access Capstone is brought to you for free and open access by the Occupational Science and Occupational Therapy at Encompass. It has been accepted for inclusion in Occupational Therapy Doctorate Capstone Projects by an authorized administrator of Encompass. For more information, please contact Linda.Sizemore@eku.edu.

OPENING MINDS THROUGH ART: ENGAGING ART AGENCIES TO FOSTER COMMUNITY
PARTICIPATION AND COMMITMENT

Presented in Partial Fulfillment of the
Requirements for the Degree of
Doctor of Occupational Therapy

Eastern Kentucky University
College of Health Sciences
Department of Occupational Science and Occupational Therapy


Ashlyn Cunningham
2017

EASTERN KENTUCKY UNIVERSITY
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY

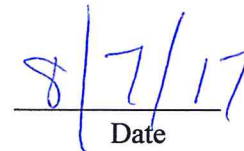
This project, written by Ashlyn Cunningham under direction of Shirley O'Brien, Faculty Mentor, and approved by members of the project committee, has been presented and accepted in partial fulfillment of requirements for the degree of

DOCTOR OF OCCUPATIONAL THERAPY

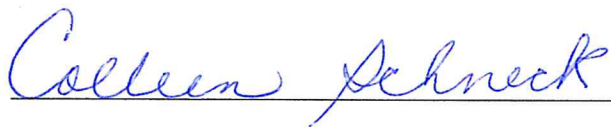
CAPSTONE COMMITTEE



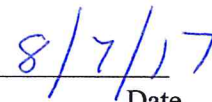
Faculty Mentor



Date



Committee Member



Date

**EASTERN KENTUCKY UNIVERSITY
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY**

Certification

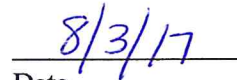
We hereby certify that this Capstone project, submitted by Ashlyn Cunningham, conforms to acceptable standards and is fully adequate in scope and quality to fulfill the project requirement for the Doctor of Occupational Therapy degree.

Approved:



Dana Howell, PhD, OTD, OTR/L, FAOTA

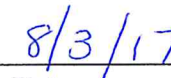
Program Coordinator, Doctor of Occupational Therapy


Date



Colleen Schneck, ScD, OTR/L, FAOTA

Chair, Department of Occupational Science and Occupational Therapy


Date

Copyright by Ashlyn Cunningham, 2017

All Rights Reserved

Executive Summary

Opening Minds through Art [OMA] is a visual arts program for individuals with dementia which aims to enhance the quality of life for individuals living with dementia, as well as their caregivers, through a creative opportunity held within their own community. Despite many venues and arts opportunities in the St. Louis area, there are few agencies that are actively seeking to expand their services to individuals with dementia. The intent of this project was for community art agencies and galleries to participate in dementia-specific training to develop programming for individuals with dementia so that clients with memory needs can actively engage in the creative arts in St. Louis. The theoretical and philosophical framing for this project stems from Person Centered Care which not only cares for the individual with dementia but includes an actual awareness of the individual needs of each person at each stage of the disease.

This project used a pre-post design to analyze perceptions regarding arts based programming with people who have memory loss. Prior to and immediately following an informational training session on creativity and memory loss, participants completed the Dementia Attitudes Scale as well as 4 open-ended questions regarding their experience with the training program and if they would host a program like OMA at their agency. Although no community agencies fully committed to implementing OMA at this time, inroads into the process were made and this training project served as an introduction to the opportunities present through OMA. In addition, perceptions and attitudes of participants in the training did change, and in particular, the perception about people with dementia having creative capacity was increased. Although the goal of this project was to educate and equip those in the arts community with knowledge and strategies to help foster participation with individuals who have dementia, there was limited participation from the invited art agencies. Future programming and research should aim to target art agencies, with a

stronger connection to involving those individuals who are key decision makers in the agency in order to make such programmatic changes happen.

Acknowledgements

I would like to thank Dr. Shirley O'Brien for her guidance and support throughout my online doctoral degree process as well as for her constant advice and feedback regarding my capstone project. Additionally, I would like to acknowledge Katherine Nicholas for her expertise regarding older adults with dementia and I appreciate her encouragement as I pursued this rather large task. I would also like to recognize Dr. Charles Gulas, Dean of the Walker College of Health Professions at Maryville University, for his encouragement in my returning to school to complete this degree. As with any endeavor of this magnitude, I realize the impact that this has had on my family, and I would like to thank my mother, Judy, and my children, Callum and Adeline, for bearing with me over the last year and a half as I worked evenings, weekends, and summers in order to move forward. And finally, it is with the deepest appreciation that I acknowledge my husband and Maryville University Occupational Therapy Program Director, Dr. Robert Cunningham, for motivating me to complete this degree, helping me manage my time, covering for many parenting responsibilities, and thinking that I am smart.

**EASTERN KENTUCKY UNIVERSITY
COLLEGE OF HEALTH SCIENCES
DEPARTMENT OF OCCUPATIONAL SCIENCE AND OCCUPATIONAL THERAPY**

CERTIFICATION OF AUTHORSHIP

Submitted to: Shirley O'Brien

Student's Name: Ashlyn Cunningham

Title of Submission: Opening Minds through Art: Engaging Art Agencies to Foster Community Participation and Commitment

Certification of Authorship: I hereby certify that I am the author of this document and that any assistance I received in its preparation is fully acknowledged and disclosed in the document. I have also cited all sources from which I obtained data, ideas, or words that are copied directly or paraphrased in the document. Sources are properly credited according to accepted standards for professional publications. I also certify that this paper was prepared by me for this purpose.

Student's Signature:

A handwritten signature in black ink, appearing to read 'Ashlyn Cunningham', written over a horizontal line.

Date of Submission: July 9, 2017

Table of Contents

Introduction.....	2
Problem, Purpose and Objectives	2
Problem	2
Purpose.....	3
Objectives.....	5
Theoretical Framework.....	5
Significance of the Project.....	6
Literature Review.....	7
Dementia – Overview.....	7
Stigma.....	8
Occupational Impact	8
Current Support Opportunities	9
Creativity as an Option.....	10
Future Needs – Access	12
Methods.....	13
Project Design	13
Setting.....	13
Participant Recruitment.....	14
Procedure.....	14
Results.....	15
Figure 1: Significant Results of Dementia Attitudes Scale.....	16
Discussion.....	18
Conclusions.....	21
Ethical Considerations and Limitations	22

Future Directions	22
Summary	23
References	25
Appendix A.....	29
Appendix B	32
Appendix C	34
Appendix D.....	55
Appendix E	56

List of Figures

Figure 1: Significant Results of Dementia Attitudes Scale	16
---	----

Opening Minds through Art: Engaging Art Agencies to Foster Community Participation and
Commitment

Ashlyn Cunningham

Eastern Kentucky University

Introduction

Opening Minds through Art [OMA] is a visual arts program for individuals with dementia (Lokon, Kinney & Kunkel 2012). The program's purpose is to build relationships across ages while instilling a sense of autonomy and choice for individuals with Alzheimer's disease and related dementias, thus combating some of the negative symptoms associated with this debilitating disease process. The Office of Disease Prevention and Health Promotion (U.S. Department of Health and Human Services, 2014) is addressing Alzheimer's disease and dementia as one of the 2020 topics and objectives for improving health amongst Americans, with a specific emphasis on early detection, disease management, cost of care/resource management (including caregiving) and enhancing quality of life. As the occupational therapy profession looks to 2025 in its new vision statement (American Occupational Therapy Association, 2016) it is encouraging to note that this direction also includes quality of life, not only for individuals, but also for communities, so that everyone has a chance to participate in the things they want to do. The Opening Minds through Art program aims to enhance the quality of life for individuals living with dementia, as well as their caregivers, through a creative opportunity held within their own community. By focusing on community agencies that already support art programming, it is hoped that the OMA program will be included as an offering of these agencies as a way to support inclusion despite memory loss.

Problem, Purpose and Objectives

Problem

According to the Diagnostic and Statistical Manual of Mental Disorders (DSM 5), dementia is considered a major neurocognitive disorder because of its impact both on an individual's cognition as well as daily functioning (American Psychiatric Association, 2013).

The associated features and symptoms of this disease include confusion with time/place, decreased judgement, mood and personality changes, memory loss that disrupts daily life, difficulty completing rote/familiar tasks, difficulty problem solving, visual/spatial perception changes, and withdrawal from social and work activities (Alzheimer's Association, 2016).

Individuals and family caregivers have a great need for community opportunities in which to participate despite the debilitation that comes with having Alzheimer's disease. The majority of unpaid caregivers (66 percent) live with their loved one with dementia within the community, not in a nursing home or supported/assisted living facility (Alzheimer's Association, 2016). Because of the progressive nature of dementia, as well as the often long hours associated with caregiving, there is a marked association of "burden" amongst those who care for individuals with Alzheimer's disease (Yu, Wang, He, Liang & Zhou, 2015). Although resilience has been found to be a protective factor in caregiver burden (Scott, 2013), the majority of caregivers experience increased stress, stigma associated with a family member with mental illness and general health concerns of their own (Alzheimer's Association, 2016; Navab, Negarandeh, Peyrovi, & Navab, 2013).

Purpose

The purpose of this project was to enhance the quality of life for individuals living with dementia, as well as their caregivers, through a creative opportunity held within their own community. The program, Opening Minds through Art [OMA], is an intergenerational visual art experience for student volunteers and people with dementia (Lokon, Kinney, & Kunkel, 2012). The program was initially developed within a long-term care setting, and involves college age students from a variety of disciplines who become one-on-one friends with people with dementia, while engaged in failure free art projects. In addition to providing a creative experience for the person with dementia, the artwork allows caregivers to connect with the OMA

artist, providing a positive talking point which focuses on ability and creativity. Furthermore, the informal connections amongst caregivers who have a loved one participating in OMA fosters a sense of support and companionship which is critical to caregiver health and well-being.

Maryville University's Walker College of Health Professions has partnered with the Alzheimer's Association (St. Louis Chapter) in an endeavor to build relationships between our agencies and to connect Maryville students with individuals who have dementia. Maryville's OMA program began in the fall of 2015 and to date has served 23 individuals with dementia and their families. The OMA program at Maryville specifically serves individuals who are still living in the community (not residing in a nursing home or assisted living facility). These individuals typically are in the early-mid stages of Alzheimer's disease and a family member is typically the primary caregiver for this individual. Because of the disease process, these individuals and their families often experience social isolation and decreased opportunities for community engagement. By providing a community-based program on Maryville's campus, the OMA program not only impacts the well-being of the person with dementia, but also supports the well-being of the spouse/caregiver and provides a positive learning experience for the student volunteers.

At the moment, the OMA program serves nine artists with dementia each semester on the campus of Maryville University (western suburb of the St. Louis metropolitan area). Knowing the propensity of community dwelling older adults with dementia, where approximately 70 percent of those diagnosed reside with a loved one and not in a care facility (Johns Hopkins, 2013), there is a marked need for resources and services for many individuals with this diagnosis within their communities. It is therefore a goal to expand the OMA program to the St. Louis

metropolitan area to serve more individuals and their families who might not otherwise have opportunities for social engagement, creativity and general community participation.

Objectives

Expanding the OMA program will use an already established partnership with the Alzheimer's Association – St. Louis Chapter. The objectives for implementation were as follows:

Objective 1: Identify art community concerns (broad/overarching and individual) which impact occupational engagement of people with dementia in the arts in St. Louis.

Objective 2: Differentiate community resources with an arts focus available for people with dementia in the Metro St. Louis area.

Objective 3: Educate staff from local arts agencies and community volunteers in a dementia specific creative arts process, to demonstrate the potential for individuals with dementia to be creative and socially participatory.

Objective 4: Develop and implement a training program to teach local art agency representatives about the potential for individuals with dementia to participate in the community in arts-based programming.

Theoretical Framework

The theoretical and philosophical framing for this project stems from Person Centered Care (Kitwood, 1993). Kitwood's work was formulated out of the need to provide more than just a philosophy and process of caring for people with dementia, but an actual awareness of the individual needs of each person at each stage of the disease. Opening Minds through Art utilized

Kitwood's model as a means for participation in the creative process by people with dementia at each stage of the illness. The premise of "personhood despite failing mental powers" is the core of the program and philosophy of relationship and care within the program. It is within this scope that OMA relates to occupational therapy as a client centered approach to individuals with dementia. By providing training and an understanding of person centered care to individuals in the arts community who may be hosting events for people with dementia, there will hopefully be a transformation of culture and a movement towards enablement and affirmation of the person with dementia.

Significance of the Project

An unfortunate reality of dementia is that there is no cure for this debilitating disease and individuals will acquire this illness at an alarming rate as our population ages. Current estimates state that every 66 seconds, someone in the United States develops Alzheimer's disease, and by 2050, the number of people with Alzheimer's disease (over the age of 65) will be 13.8 million – nearly triple what it is today (Alzheimer's Association, 2016). To that end, there will be a continuous need for resources and services, such as this arts-based program, for these individuals and their families' in order to promote independence and social participation for as long as possible and to promote quality of life, even if just for the moment. It is therefore imperative that individuals within the arts community be made more aware of the needs of individuals with memory loss and to develop strategies for supporting these artists in order to better foster participation at community art venues and provide an inclusionary model of service for individuals with dementia.

Literature Review

Dementia – Overview

As the population of Baby Boomers age, the prevalence of Alzheimer's disease and related dementias also rises. In 2016, it was estimated that one in nine Americans who are 65 or older has Alzheimer's disease/related dementia (Alzheimer's Association, 2016). There is a marked increase in this diagnosis as one ages, where the prevalence increases to one in three people having the disease if they are 85 or older. As mentioned earlier, dementia is considered a major neurocognitive disorder because of its impact both on an individual's cognition as well as daily functioning (American Psychiatric Association, 2013). Alzheimer's disease is one form of dementia and is the 6th leading cause of death in the United States; killing more than breast and prostate cancer combined and is the only cause of death in the United States that cannot be prevented, cured or slowed (Alzheimer's Association, 2016).

Along with increase in diagnoses, there is a proportionate increase in the number of caregivers needed for individuals with dementia (Edwards, 2015). These caregivers are not professionals, as only thirty three percent of individuals with Alzheimer's disease live in a residential facility; the remaining sixty-six percent are cared for in their home, typically by a spouse or family member (Alzheimer's Association, 2016). In 2015, more than 15 million unpaid family caregivers provided 18.1 billion hours of unpaid care to their loved one with dementia. Two thirds of these caregivers are women and 35% are older than sixty-five (Alzheimer's Association, 2016). The overarching health impact of dementia not only includes the person with the disease, but also the caregiver, who is most often a family member (spouse or adult child) who often has limited skills and resources for dealing with such a progressive and degenerative disorder (Alzheimer's Association, 2016).

Stigma

Because dementia is a mental health disorder, the overarching stigma of mental illness is the foremost concern for individuals diagnosed with this disease. This complex disease process can overwhelm individuals and make understanding and personal/family acceptance of the illness highly challenging. Mitchell, McCollum and Monaghan's (2013) research highlights the perceived stigma by the client and family members, and shares the client's feelings of shame and increased anxiety and worry over what is to come with the progression of the disease. Those already in the caregiving role for a person with dementia are especially prone to lower acceptance of screening and diagnosis and also perceive that the individual with dementia's suffering would be greater if the individual was made aware of the dementia (Boustani et al, 2011). In a same manner, Weeks, Wilkinson and McLeod (2015) suggest that although clients and families recognize the need to share their diagnosis with others, the emotional connection of having a debilitating mental illness was too much to manage for many clients, so they subsequently put off or never told others about their dementia.

Occupational Impact

Dementia is a progressive illness that follows a pattern of decline in all aspects of life. Initial warning signs of the disease include changes in planning and problem solving abilities, and general difficulty in completing once familiar tasks (i.e. driving, remembering the rules to a favorite game, using a TV remote). Most markedly noticed by others is memory loss that disrupts daily life - forgetting important dates and names that were once known, or forgetting recently learned information (Alzheimer's Association, 2016). Socially, a diagnosis of Alzheimer's disease or dementia leads clients and their families down a path of isolation and one

of limited support. Because of the inherent behaviors of a person with dementia (i.e. repeating the same story over and over, forgetting of familiar names) outsiders do not know or understand how to relate to the individual. This lack of communication and understanding causes past social relationships to wane. Without additional social supports, caregivers are alone with the individual with dementia more and more, resulting in increased caregiver stress and resentment. Social isolation is of particular concern to those living in rural environments where there is limited access to social opportunities which support individuals with memory loss (Forbes et al. 2001).

Current Support Opportunities

Despite advances in diagnostics for dementia as well as support through national organizations on memory loss, community dwelling older adults with dementia and their caregivers often are hesitant to reach out to agencies and engage in opportunities which promote positive well-being for both involved parties (Alzheimer's Association, 2016). These known symptoms and issues with participation are being addressed by the Office of Disease Prevention and Health Promotion (U.S. Department of Health and Human Services, 2014) through the identification of dementias, including Alzheimer's disease, as one of the 2020 topics and objectives for improving health amongst Americans. Specifically, this topic places an emphasis on early detection, disease management, cost of care/resource management (including caregiving) and enhancing quality of life. As the occupational therapy profession looks to 2025 in its new vision statement (American Occupational Therapy Association, 2016) it is encouraging to note that this direction also includes quality of life, not only for individuals, but also for communities, so that everyone has a chance to participate in the things they want to do.

The Alzheimer's Association is a national health organization which focuses on Alzheimer's disease and dementia (www.alz.org). The overarching purpose of the Alzheimer's Association is to provide support, education and research about dementia related disorders and to assist individuals and families who have this disease with various resources and services to best manage their illness experience. The Association is supported by chapters to better serve communities and regions throughout the United States. The St. Louis Chapter of the Alzheimer's Association serves 38 counties in Eastern Missouri and Western Central Illinois where they provide a 24/7 helpline, respite resources, early stage initiatives, and care programs.

Creativity as an Option

Several research studies have investigated the use of creative media and arts based initiatives as positive supports and interventions on the dementia journey (Fornazzari, 2005; MacPherson, Bird, Anderson, Davis & Blair, 2009; McLaren, LaMantia, & Callahan, 2013; Rylatt, 2012). Of particular note was the concept of enhancing the quality of life for individuals with memory loss, even for a brief moment, through the use of creative media. The creative part of the brain may not be impacted as early as some of the other cognitive functions, so health care providers should not rule out these types of creative opportunities as options for intervention (Palmiero, DiGiacomo & Passafiume. 2012). By allowing people with memory loss the chance to be creative and engaged with the arts, there is a greater opportunity that there is part of the brain that still responds to the inner drive for creating something unique and beautiful.

In 2014, the St. Louis Chapter of the Alzheimer's Association committed to strategically increase the impact of early stage Alzheimer's social engagement and enrichment programs through expanded collaboration with local arts and cultural institutions. The resulting

commitment from this initiative is the Arts & Alzheimer's Collaborative Task Force (2014). The purpose of the Arts & Alzheimer's Collaborative Task Force is *to increase the access to, availability and impact of social engagement and enrichment programs for people with early memory loss and their care partners through expanded collaboration with artists and arts / cultural institutions* (Alzheimer's Association, 2014).

Maryville University's Walker College of Health Professions has partnered with the Alzheimer's Association (St. Louis Chapter) in an endeavor to build relationships between our agencies and to connect Maryville students with individuals who have dementia. Opening Minds through Art [OMA], is an intergenerational visual art experience for student volunteers and people with dementia (Lokon, Kinney, & Kunkel, 2012). The program was initially developed within a long-term care setting, and involved college age students from a variety of disciplines who become one-on-one friends with people with dementia, while engaged in failure free art projects. In addition to providing a creative experience for the person with dementia, the artwork allows caregivers to connect with the OMA artist, providing a positive talking point which focuses on ability and creativity. Furthermore, the informal connections amongst caregivers who have a loved one participating in OMA fosters a sense of support and companionship which is critical to caregiver health and well-being.

Maryville's OMA program began in the fall of 2015 and to date has served 23 individuals with dementia and their families. The OMA program at Maryville specifically serves individuals who are still living in the community (not residing in a nursing home or assisted living facility). These individuals typically are in the early-mid stages of Alzheimer's disease and a family member is typically the primary caregiver for this individual. Because of the disease process, these individuals and their families often experience social isolation and decreased opportunities

for community engagement. By providing a community-based program on Maryville's campus, the OMA program not only impacts the well-being of the person with dementia, but also supports the well-being of the spouse/caregiver and provides a positive learning experience for the student volunteers.

Future Needs – Access

Knowing the propensity of community dwelling older adults with dementia, where approximately 70 percent of those diagnosed reside with a loved one and not in a care facility (Johns Hopkins, 2013), there is a marked need for resources and services for many individuals with this diagnosis within their communities. There are over forty art venues in the city of St. Louis and surrounding county (City of St. Louis, 2016; Art St. Louis, 2016) and the city/county has approximately twelve larger public art venues which include museums, galleries and sculpture parks. Despite many venues and arts opportunities, there are few agencies that are actively seeking to expand their services to individuals with dementia and only one venue which describes itself as a place for individuals of varying abilities to participate in art (Artists First STL, 2016). It may not be direct opposition to serving these individuals but rather a lack of understanding the needs of the community dwelling older adult with dementia and how the art agency can connect with this person and their family.

Bartlett (2014) suggests that those with dementia who take time to connect with others who also have dementia can protect against decline and maintain a greater sense of well-being, despite their disease process. This provides a sense of empowerment and a “strength in numbers” philosophy for those looking for social and participation opportunities. The purpose of this project therefore, was to broaden the range of opportunities for individuals with dementia to engage in arts-based programming within their home communities. The intent of the program

was for community art agencies and galleries to participate in dementia-specific training to develop programming for individuals with dementia so that clients with memory needs can actively engage in the creative arts in St. Louis.

Methods

Project Design

This study followed preliminary work which was part of my Applied Leadership Experience (ALE). After completing Objectives 1, 2, and 3 for the ALE that were outlined above, staff from targeted community agencies were the focus of this research. This study focused on Objective 4 and used a pre-post mixed method design (Creswell, 2014) to evaluate the effect of training on the art program staff who were interested in exploring the Opening Minds through Art program as an option for programming at their respective agencies. The pre-post design allowed for analysis of participant perceptions regarding arts based programming with people who have memory loss comparing responses before and after the intervention of an informational session on creativity and memory loss with an overview of the Opening Minds through Art (OMA) program.

Setting

The training program was held at the Alzheimer's Association - St. Louis Chapter main office on March 13, 2017. This was a central location for the participants in the study and also allowed for the environmental needs for the training (i.e. space with tables and a sink for practicing an OMA art project). An additional rationale for choosing this space was that the Alzheimer's Association did not charge a fee for its use. The Association also had technology available which supported the training, via PowerPoint presentation.

Participant Recruitment

The participants in this study were a result of convenience sampling. After receiving approval from Eastern Kentucky University's Institutional Review Board, an email was sent to identified community art agencies from my prior ALE work. The Alzheimer's Association also solicited participants from their volunteer base. The content of the solicitation invited people who had a desire to have additional programming for community dwelling older adults with memory loss as well as any individual desiring more information about the Opening Minds through Art program to attend a 2 hour training session during the evening of March 13, 2017. Anyone who was 18-89 years of age and who could communicate and understand verbal and written English was included in this study. Fifteen individuals registered to participate for the March 13 session.

Procedure

This study was approved by the Institutional Review Board of Eastern Kentucky University. Twelve individuals agreed to participate that evening and three individuals still participated in the arts based training without being part of the research project. Once informed consent (Appendix A) was obtained, participants were assigned a random number for all data collection procedures in order to protect their identity. Then, participants shared basic demographic data and completed the Dementia Attitudes Scale (DAS) (O'Connor & McFadden, 2010), a 20 item Likert formatted instrument which measures personal perceptions and feelings about individuals with dementia (Appendix B). Internal consistency of the DAS, as derived by Cronbach's alpha's, was strong at 0.83-0.85. Additionally, this tool is a fair match for this study

since it has significant correlation with other scales that measure ageism and general attitude towards individuals with disabling conditions (correlation 0.50)(O'Connor & McFadden, 2010).

The training session consisted of a 2 hour experience focusing on the creative arts for individuals with memory loss. Content for the session included an overview of dementia, aspects of creativity for individuals with memory loss, principles of the Opening Minds through Art (OMA) program and a practical experience of an OMA project (tie dye Sharpie coaster). The PowerPoint presentation was interactive and encouraged participation and questioning throughout (Appendix C).

Following the training, participants completed the Dementia Attitudes Scale again. Additionally, participants were asked to respond in writing to 4 open-ended questions regarding their experience with the training program in which they participated (Appendix D). These questions were specifically focused on the concepts of the OMA program and asked the participants' perceptions regarding implementation of the OMA program. A final question asked whether or not the participants would or would not implement the program if given the opportunity to do so. Four weeks after the training session, participants were telephoned about following up with OMA training (Appendix E). Two of the twelve participants responded to this survey, thus providing limited information.

Results

Because of the small sample size and limited analysis needed with the data set, Excel was used as the statistical analysis software for this project. Fifteen individuals attended on the evening of the scheduled training. After reviewing the criteria and informed consent, 12 agreed to take part in the study. All participants communicated in English and ranged in age from 21 to

58 with a mean age of 41.8 years. Two individuals who identified as male, eight individuals who identified as female, and two chose not to identify gender consented to participate. All participants who agreed to participate in this study identified as white/Caucasian. Of those participating, four individuals were from the Alzheimer's Association (either staff or volunteers with the agency), one was from a community arts agency (the target population for this project), two were associated with Edward Jones Financial Investment Firm, and five were from long term care communities.

Results of the Dementia Attitudes Scale pre and post training were compared using a paired t-test. Of the twenty items identified, seven items showed a significant difference pre/post intervention ($p < .05$). Of particular note was question 3, which stated "People with ADRD [Alzheimer's disease and Related Dementias] can be creative". The change in perception for this question was .0379 ($p < .05$).

Figure 1: Significant Results of Dementia Attitudes Scale

Question Number	Question Content	p Value < .05
3	People with ADRD can be creative.	.0379
9	I would avoid an agitated person with ADRD.	.0455
10	People with ADRD like having familiar things nearby.	.0162
11	It is important to know the past history of people with ADRD.	.0251
13	I feel relaxed around people with ADRD	.0379

16	I feel frustrated because I do not know how to help people with ADRD.	.0200
18	I admire the coping skills of people with ADRD	.0251

The qualitative data were analyzed for themes about the participants' perceptions of the OMA program and the creative capacity of individuals with memory loss. A constant comparative method was used to associate applicable incidents for each question (Glaser, 1965). When analyzing the question regarding the possibilities for people with memory loss as they participate in arts-based activities, the constant comparative method yielded recurring themes of socialization, joy and pride. Responses to the question involving concerns about working with individuals with memory loss in an arts based activity produced five responses of little or no concern for those participating. Remaining responses focused on the volunteers needed to effectively implement such a program, and the need to adequately train these volunteers. Overall, participants shared a positive response for opportunities to implement an arts based program at their respective facilities, with limited barriers to this process. Finally, three participants indicated that they would implement an OMA program at his/her facility and three were "not sure yet". The remaining participants indicated that they did not have the power at their facility to make this decision.

The 4 week telephone follow up yielded limited results. Only two of the twelve participants responded (17% response rate). An additional message was left for the remaining 10 participants with no response. Of the two that did respond, there was continued interest and support for the OMA program. Both participants had registered to become OMA facilitators at

the next available training in Ohio. Also, both participants indicated that their agencies and administration supported OMA at their facilities, which were long term care facilities.

Discussion

This Capstone Project had four major objectives which were addressed. Each one was explored and met. Objectives 1-3 were:

- Identify art community concerns (broad/overarching and individual) which impact occupational engagement of people with dementia in the arts in St. Louis.
- Differentiate community resources with an arts focus available for people with dementia in the Metro St. Louis area.
- Educate staff from local arts agencies in a dementia specific creative arts process, to demonstrate the potential for individuals with dementia to be creative and socially participatory.

The above objectives were met as part of the Applied Leadership Experience which took place during the fall of 2016. The process took into consideration the desires of the Alzheimer's Association's "Arts and Alzheimer's Collaborative Task Force Summary" which was to identify community agencies that would be willing to partner with the Association for community art initiatives. The underlying plan was that the OMA program would be one of these initiatives. Inroads were made with addressing these agencies and discussing the potential for their respective facilities to be host sites for creative opportunities for people with dementia. All agencies contacted during this phase were invited to participate in the training experience which was the focal point of this study. To that end, one of the identified agencies did participate.

This project concentrated on the fourth objective. After completing the preliminary work for the Applied Leadership Experience, the following objective was addressed:

-Develop and implement a training program to teach local art agency representatives about the potential for individuals with dementia to participate in the community in arts-based programming.

Statistical analysis of the Dementia Attitudes Scale indicated a change in perception by participants for seven of the 20 items. Of particular note relating to this study, is the change in attitude of training participants regarding the creative capabilities of people with Alzheimer's disease and related dementias. Connecting this participant belief to the research by Fornazzari (2005) further illustrates the creative capacity of people with memory loss and should be capitalized upon to promote greater quality of life for these individuals (McLaren, LaMantia, & Callahan, 2013). This finding reinforces and expands on the value of art offerings for occupational engagement.

The remaining questions which demonstrated statistical significant were indicative of perception changes about Alzheimer's disease in general. Identifying perceptions of frustration, uncertainty with agitation, and relaxation around people with dementia elude to reducing the thoughts of shamefulness in having this disease and illustrates the need to reduce negative views of this mental illness. Through education, such as that offered in this training program, myths were dispelled with the potential for occupational engagement of those with dementia. The hope is that by allowing individuals with dementia to participate in an arts-based program, this stigma will be lessened (Mitchell, McCollum and Monaghan, 2013). The findings of this Capstone Project support this desire.

Qualitative responses to this training reiterated the purpose of the intervention, which was to inform and educate the participants of the potential for enhanced quality of life for individuals with dementia through the use of a visual arts program. Participant responses of “feeling self-worth”, “pride”, and “joy” demonstrate the perception of how visual arts can enhance the self-esteem and confidence of clients with memory loss (Palmiero, DiGiacomo & Passafiume. 2012). Other responses focusing on socialization and connections with others verified the intergenerational aspect of OMA, reaching both the individual with memory loss and the young adult partner who helps the OMA artist engage in the creative process. Participants had few concerns about working with individuals with memory loss – rather, the concern was in the implementation of the OMA program, specifically the need to fully train the 1:1 volunteers who assist the artist partner. The awareness of the need for proper training indicates the participants are visualizing the entire OMA process, not just the creative nature of the program and the end product. Finally, half of the participants that indicated a positive potential for bringing OMA to their agency. This reinforces the beliefs expressed in the literature (MacPherson, Bird, Anderson, Davis & Blair, 2009; Rylatt, 2012) thus changing the perspective of potential of those with Alzheimer’s and other related dementias.

Decision making authority was a consideration in the implementation of OMA programs. Not all who attended the training had decision-making power within their agency (i.e. long term care activities staff or Alzheimer’s Association volunteers). This is a consideration for the future in who attends training and how they then may be able to use the training for future programing changes. It would be advisable to include key stakeholders in this process to gain greater buy in at the beginning.

Although there was a limited response to the follow up phone call, two individuals who did respond remained committed to bringing OMA to their long term care facility and had registered to become OMA facilitators through Miami, OH this August. Although the original intent of this study was to promote OMA in community based settings, these long term care venues will still fulfil the philosophy of OMA which is to “build bridges across age and cognitive barriers through art”. Since thirty-three percent of individuals with dementia reside in long term care environments (Alzheimer’s Association, 2016) these people will still have an opportunity to be creative and have a greater quality of life by participating in OMA, which was the broad intent of my Applied Leadership Experience and this Capstone Project.

Conclusions

The intent of this research was for community art agencies to participate in dementia-specific training to develop programming for individuals with dementia so that clients with memory needs can actively engage in the creative arts in St. Louis. Although no community agencies fully committed to implementing OMA at this time, inroads into the process were made. This training project served as an introduction to the opportunities present through OMA. In addition, perceptions and attitudes of participants in the training did change, and in particular, the perception about people with dementia having creative capacity was increased. In general, this was a first step towards fostering visual arts programming for people with dementia in the St. Louis Metro area. To that end, this project was one example of a continuous need for resources and services, such as this arts-based program, for these individuals and their families’ in order to promote independence and social participation for as long as possible and to promote quality of life, even if just for the moment.

Ethical Considerations and Limitations

Due to the small sample size of this project, limited location for the actual intervention (being the St. Louis metro area), and homogeneity of the participants, there are limitations to generalizability of information gleaned. Also, because of this small sample, the participants could have felt pressured to perform or answer in a manner which is perceived as desirable for the principle investigator. Several of the participants did not have the authority to make the decision whether or not to pursue the Opening Minds through Art program at their agency. Finally, because this project related to individuals with memory loss, there may be an element of pity or feelings of sadness/sorrow for those whom the arts based program is intended. This innate feeling may have influenced the participants' responses and thus impact the results of this study.

Future Directions

Although the majority of participants in this study were not from community arts agencies, the intent to educate the general public about Opening Minds through Art (OMA) was achieved and sparked interest in the for-profit residential sector which deals with individuals who have memory loss. Since OMA was initially developed for residential care communities, these participants have the desire to keep this focus for their elders in their respective communities. By informing more professional caregivers about the benefits of OMA in the hope that these caregivers become trained OMA facilitators, the residents in these communities will have a greater chance at social participation and heightened quality of life.

Additionally, since this study was completed, I have participated in a train-the-trainer program for OMA and will be serving as a practicum site facilitator for the St. Louis metro area in November 2017. This practicum will be the culmination of an online OMA facilitator training

program, which was developed to expand the program and make it more accessible for those wishing to be trained. The Alzheimer's Association of St. Louis is invested in OMA as well, and proposes to financially support one individual from St. Louis, who will then commit to provide OMA at a community art agency in the spring of 2018. This commitment will dovetail with the Arts & Alzheimer's Collaborative Task Force's vision of bringing more creative opportunities to people with memory loss in their own communities (Alzheimer's Association, 2014). I hope to have 20 participants in this practicum experience, and plan to target community art agencies again to foster the idea of bringing OMA into local neighborhoods for older adults who still reside at home.

Summary

The Opening Minds through Art program aims to enhance the quality of life for individuals living with dementia, as well as their caregivers, through a creative opportunities held within their own community. This project served as an informative start for community art agencies and other long term care agencies to think about developing dementia-specific programming to better serve community dwelling older adults with memory loss. By reviewing current arts-based programming in the St. Louis area and investigating the potential for expansion of arts-based services for individuals and families affected by Alzheimer's disease, local art agencies and long term care facilities are better informed of the needs of their constituents and art supporters with memory loss. Although the goal of this program was to educate and equip those in the arts community with knowledge and strategies to help foster participation with individuals who have dementia, there was limited participation from the invited art agencies. Future programming and research should aim to target art agencies, with a

stronger connection to involving those individuals who are key decision makers in the agency in order to make such programmatic changes happen.

References

Alzheimer's Association. www.alz.org

Alzheimer's Association (2014). Arts & Alzheimer's Collaborative Task Force Summary.

Unpublished manuscript.

Alzheimer's Association (2016). 2016 Alzheimer's disease facts and figures. Retrieved on June 18, 2016 from <http://www.alz.org/facts/overview.asp>

American Occupational Therapy Association (2016). AOTA unveils vision 2025. Retrieved on September 5, 2016 from <http://www.aota.org/aboutaota/vision-2025.aspx>

American Psychiatric Association (2013) . Diagnostic and Statistical Manual of Mental Disorders (5th edition). Arlington, Va.: American Psychiatric Publishing.

Art St. Louis (2016). Gallery guide. Retrieved on September 25, 2016 from <http://www.artstlouis.org/index.php/exhibitions/st-louis-gallery-guide>

Artists First STL (2016). Artists First homepage. Retrieved on September 25, 2016 from <http://www.artistsfirststl.org/>

Bartlett, R. (2014). Citizenship in action: The lived experiences of citizens with dementia who campaign for social change. *Disability & Society*, 29, 8, 1291.
doi:10.1080/09687599.2014.924905

Boustani, M., Justiss, M., Frame, A., Austrom, M., Perkins, A., Cai, X., Sachs, G., Monahan, P., & Hendrie, H. (2011). Caregiver and noncaregiver attitudes toward dementia screening. *Journal of the American Geriatrics Society*, 59, 681-686.

City of St. Louis (2016). Art venues. Retrieved on September 25, 2016 from <https://www.stlouis-mo.gov/visit-play/art-venues.cfm>

- Creswell, J. W. (2014). *Research design: Qualitative, quantitative, and mixed methods approaches* (4th ed.). Thousand Oaks, CA: Sage.
- Edwards, M. (2015). Family caregivers for people with dementia and the role of occupational therapy. *Physical and Occupational Therapy in Geriatrics*, 33,(3), 220-232.
- Forbes, D., Ward-Griffin, C., Kloseck, M., Mendelsohn, M., St-Amant, O., DeForge, R., & Clark, K. (2011). "Her world gets smaller and smaller with nothing to look forward to": Dimensions of social inclusion and exclusion among rural dementia care networks. *Online Journal of Rural Nursing and Health Care*, 11, (2), 27-42.
- Fornazzari, L.R. (2005). Preserved painting creativity in an artist with Alzheimer's disease. *European Journal of Neurology*, 12, 419-424.
- Glaser, B. (1965). The constant comparative method of qualitative analysis. *Social Problems*, 12(4), 436-445. doi:10.2307/798843
- Johns Hopkins Medicine (2013). Living at home with dementia. Retrieved on July 31, 2016 from http://www.hopkinsmedicine.org/news/media/releases/living_at_home_with_dementia
- Kitwood, T. (1993). Towards a theory of dementia care: The interpersonal process. *Ageing and Society*, 13, 51-67.
- Lokon, E., Kinney, J., & Kunkel, S. (2012). Building bridges across age and cognitive barriers through art: College students' reflections on an intergenerational program with elders who have dementia. *Journal of Intergenerational Relationships*, 10,(4), 337-354.
- MacPherson, S., Bird, M., Anderson, K., Davis, T., & Blair, A. (2009). An art gallery access programme for people with dementia: 'you do it for the moment'. *Aging & Mental Health*, 13, 5, 744-752. doi:10.1080/13607860902918207

- McLaren, A. N., LaMantia, M. A., & Callahan, C. M. (2013). Systematic review of non-pharmacologic interventions to delay functional decline in community-dwelling patients with dementia. *Aging & Mental Health, 17*,(6), 655-666.
doi:10.1080/13607863.2013.781121
- Mitchell, G., McCollum, P., & Monaghan, C. (2013). The personal impact of disclosure of a dementia diagnosis: A thematic review of the literature. *British Journal of Neuroscience Nursing, 9*, (5), 223-228.
- Navab, E., Negarandeh, R., Peyrovi, H., & Navab, P. (2013). Stigma among Iranian family caregivers of patients with Alzheimer's disease: A hermeneuric study. *Nursing and Health Sciences, 15*, 201-206.
- O'Connor, M. L., & McFadden, S. H. (2010). Development and psychometric validation of the Dementia Attitudes Scale. *International Journal of Alzheimer's Disease, 2010*, 1-10.
doi:10.4061/2010/454218
- Palmiero, M., DiGiacomo, D., & Passafiume, D. (2012). Creativity and dementia: A review. *Cognitive Process, 13*, 193-209.
- Rylatt, P. (2012). The benefits of creative therapy for people with dementia. *Nursing Standard, 26*,(33), 42-47.
- Scott, C. (2013). Alzheimer's disease caregiver burden: Does resilience matter? *Journal of Human Behavior in the Social Environment, 23*, 879-892.
- U.S. Department of Health and Human Services. (2014). Healthy People 2020. Retrieved from <http://www.healthypeople.gov/2020/default.aspx>

Weeks, D., Wilkinson, H., & McLeod, J. (2015). Daring to tell: The importance of telling others about a diagnosis of dementia. *Aging & Society*, 35, 765-784.

Yu, H., Wang, X., He, R., & Zhou, L (2015). Measuring the caregiver burden of caring for community-residing people with Alzheimer's disease. *Plos ONE*, 10, 7, 1-13.

doi:10.1371/journal.pone.0132168

Appendix A

Informed Consent



Consent to Participate in a Research Study

Opening Minds through Art: Engaging Art Agencies to Foster Community Participation and Commitment

Why am I being asked to participate in this research?

You are being invited to take part in a research study about your perceptions of the creative capacity of individuals with memory loss. You are being invited to participate in this study because you have agreed to participate in a training session regarding arts-based activities and individuals with memory loss. If you take part in this study, you will be one of about 20 people to do so.

Who is doing the study?

The person in charge of this study is Ashlyn Cunningham (Principal Investigator), an Occupational Therapy Doctoral student at Eastern Kentucky University (EKU). She is being guided in this research by Dr. Shirley O'Brien, her advisor, who is a Professor in the Occupational Therapy Program at EKU.

What is the purpose of the study?

This research aims to investigate the perception of individuals regarding the creative capacity of people with memory loss. Specifically, this study desires to measure your perception of individuals with memory loss as they engage in arts-based activities before and after you participate in a training session about creative arts and dementia.

By doing this study, we hope to learn more about the perceptions and ideas of individuals such as yourself regarding working with and engaging people with memory loss in arts based activities.

Where is the study going to take place and how long will it last?

The research procedures will be conducted at the Alzheimer's Association – St. Louis Chapter. You will need to come to the Alzheimer's Association 1 time during the study. This visit will take about 3 hours. The total amount of time you will be asked to volunteer for this study is 3 hours on one day. The study is part of a training session - you will be asked to complete information before and after the training. The amount of time to complete the information is 15 minutes before the training and 15 minutes after the training. Additionally, you will receive a phone call approximately one month after the training to ask you questions about your intent to provide arts based programming at your facility for people with dementia. This phone call will last approximately 5 minutes.

What will I be asked to do?

Prior to the training session, you will be asked to complete a brief demographics sheet as well as the Dementia Attitudes Scale (a 20 item questionnaire) regarding your feelings about individuals with dementia. After the training Session, you will be asked to complete the Dementia Attitudes Scale again, as well as respond to 4 questions (in writing). One month after the training, you will be asked to answer 3 questions via phone about your intent to include arts based programming for people with dementia at your agency.

Are there reasons why I should not take part in this study?

There are no foreseeable reasons for you to not participate in this study.

What are the possible risks and discomforts?

Risks of this study include breach of confidentiality. You will be assigned a random code number to protect your identity. This number will be used on all documentation and assessments. Only the principal investigator will have knowledge of the code number and its corresponding participant. Data collected from participants will be kept on a separate password protected flash drive within a locked office.

To the best of our knowledge, the things you will be doing have no more risk of harm than you would experience in everyday life.

You may, however, experience a previously unknown risk or side effect.

Will I benefit from taking part in this study?

You will not get any personal benefit from taking part in this study.

Do I have to take part in this study?

If you decide to take part in the study, it should be because you really want to volunteer. You will not lose any benefits or rights you would normally have if you choose not to volunteer. You can stop at any time during the study and still keep the benefits and rights you had before volunteering.

If I don't take part in this study, are there other choices?

If you do not want to be in the study, there are no other choices except to not take part in the study. You may still participate in the training session held that day. There will be no consequence to you if you chose not to participate in the research study.

What will it cost me to participate?

There are no costs associated with taking part in this study.

Will I receive any payment or rewards for taking part in the study?

You will not receive any payment or reward for taking part in this study.

Who will see the information I give?

Your information will be combined with information from other people taking part in the study. When we write up the study to share it with other researchers, we will write about this combined information. You will not be identified in these written materials.

We will make every effort to prevent anyone who is not on the research team from knowing that you gave us information, or what that information is. For example, your name will be kept separate from the information you give, and these two things will be stored in different places under lock and key.

However, there are some circumstances in which we may have to show your information to other people. For example, the law may require us to show your information to a court. Also, we may be required to show information that identifies you to people who need to be sure we have done the research correctly; these would be people from such organizations as Eastern Kentucky University.

Can my taking part in the study end early?

If you decide to take part in the study, you still have the right to decide at any time that you no longer want to participate. You will not be treated differently if you decide to stop taking part in the study.

The individuals conducting the study may need to end your participation in the study. They may do this if you are not able to follow the directions they give you, if they find that your being in the study is more risk than benefit to you, or if the agency funding the study decides to stop the study early for a variety of scientific reasons.

What happens if I get hurt or sick during the study?

If you believe you are hurt or if you get sick because of something that is done during the study, you should contact Ashlyn Cunningham who will be present at all times during the study. It is important for you to understand that Eastern Kentucky University will not pay for the cost of any care or treatment that might be necessary because you get hurt or sick while taking part in this study. That cost will be your responsibility. Also, Eastern Kentucky University will not pay for any wages you may lose if you are harmed by this study.

Usually, medical costs that result from research-related harm cannot be included as regular medical costs. Therefore, the costs related to your care and treatment because of something that is done during the study will be your responsibility. You should ask your insurer if you have any questions about your insurer's willingness to pay under these circumstances.

What if I have questions?

Before you decide whether to accept this invitation to take part in the study, please ask any questions that might come to mind now. Later, if you have questions about the study, you can contact the investigator, Ashlyn Cunningham at 314-398-4314. If you have any questions about your rights as a research volunteer, contact the staff in the Division of Sponsored Programs at Eastern Kentucky University at 859-622-3636. We will give you a copy of this consent form to take with you.

What else do I need to know?

This research is supported by the Alzheimer's Association – St. Louis Chapter. The Chapter is providing the facilities for the training purposes today.

You will be told if any new information is learned which may affect your condition or influence your willingness to continue taking part in this study.

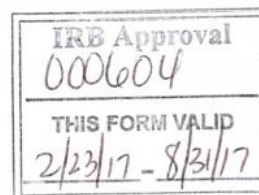
I have thoroughly read this document, understand its contents, have been given an opportunity to have my questions answered, and agree to participate in this research study.

Signature of person agreeing to take part in the study

Date

Printed name of person taking part in the study

Name of person providing information to subject



Appendix B

Dementia Attitudes Scale

The Dementia Attitudes Scale

Melissa O'Connor, Ph.D. and Susan H. McFadden, Ph.D.

Please rate each statement according to how much you agree or disagree with it. Circle 1, 2, 3, 4, 5, 6, or 7 according to how you feel in each case. *Please be honest. There are no right or wrong answers.* The acronym “ADRD” in each question stands for “Alzheimer’s disease and related dementias.”

- | | | | | | | | |
|---|---------------------------|---------------|---------------------------|--------------|------------------------|------------|------------------------|
| 1. It is rewarding to work with people who have ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 2. I am afraid of people with ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 3. People with ADRD can be creative. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 4. I feel confident around people with ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 5. I am comfortable touching people with ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 6. I feel uncomfortable being around people with ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 7. Every person with ADRD has different needs. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 8. I am not very familiar with ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 9. I would avoid an agitated person with ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 10. People with ADRD like having familiar things nearby. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |
| 11. It is important to know the past history of people with ADRD. | 1
Strongly
Disagree | 2
Disagree | 3
Slightly
Disagree | 4
Neutral | 5
Slightly
Agree | 6
Agree | 7
Strongly
Agree |

Turn Page Over

12. It is possible to enjoy interacting with people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

13. I feel relaxed around people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

14. People with ADRD can enjoy life.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

15. People with ADRD can feel when others are kind to them.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

16. I feel frustrated because I do not know how to help people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

17. I cannot imagine taking care of someone with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

18. I admire the coping skills of people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

19. We can do a lot now to improve the lives of people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

20. Difficult behaviors may be a form of communication for people with ADRD.

1	2	3	4	5	6	7
Strongly Disagree	Disagree	Slightly Disagree	Neutral	Slightly Agree	Agree	Strongly Agree

Demographic Information

1. Gender: ☐ Male ☐ Female

2. Age: _____

3. Race: ☐ White ☐ Hispanic ☐ African American ☐ Asian ☐ Native American ☐ Other

4. Have you ever known or worked with someone who has ADRD? ☐ yes ☐ no

If yes, please explain. How long have you known, or did you know, the person or people with ADRD? How close was/is your relationship?

You're done! Thank you for your help!

Appendix C

Training Program PowerPoint

Visual Arts and Memory Loss

Facilitating Creativity Despite Cognitive Decline

Ashlyn Cunningham, MA, OTR/L, CDP, CAPS



Welcome and Introductions

This evening....

Goals for this session

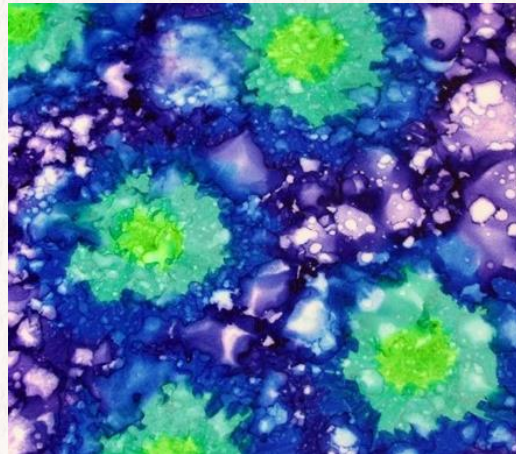
- Participate in a brief creative activity
- Review the potential and challenges of creativity for individuals with dementia
- Discuss the impact of intergenerational and relational opportunities for individuals with dementia on quality of life
- Begin the discussion of creativity for people with dementia in our communities

Assumptions of this session

- You have creative abilities
- You wish to discuss how individuals with memory loss might benefit from creative opportunities

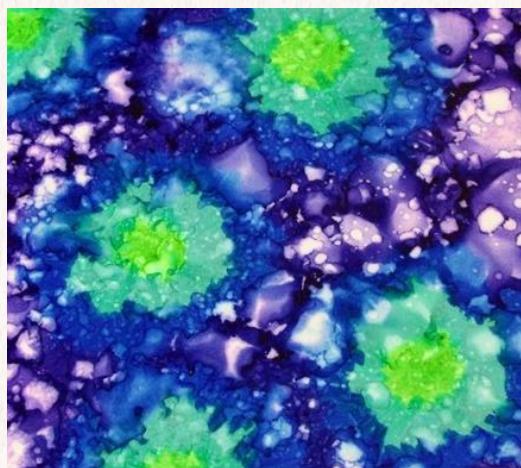
Begin with....

Ink Tile Coasters



Materials needed:

4"x4" ceramic tile
Sharpie markers (various colors)
90% rubbing alcohol
Brush
Pipette
Small cup
Paper towels
Mod Podge Spray
Adhesive felt

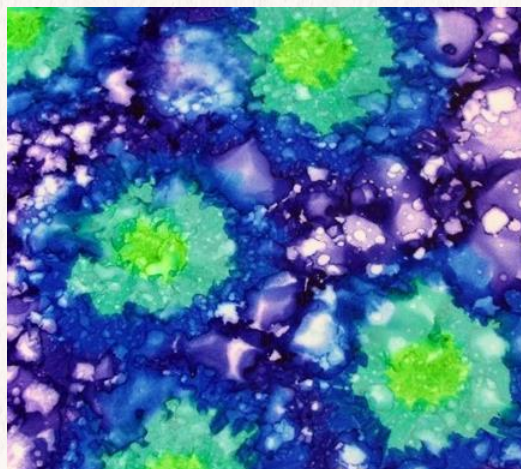


First Step

Gather supplies:

- ceramic tile
- 4 paper towels
- **pipette OR brush**
- small container with ¼" alcohol poured in it
- **Warm OR Cool Sharpie Markers (3-4 complimentary or coordinating colors)**

** Bolded listings indicate personal choice items*



Creativity and Memory Loss

Creativity



- The use of the imagination or original ideas, especially in the production of an artistic work.
- Also can mean originality, individuality or artistry
- Brings something “new” into existence

Do you think of yourself as a creative person? Why or why not?

Second Step

Color tile surface in a random pattern using your selected Sharpies

Project works best if the majority of the surface is colored!



The Dementia Journey

Cognitive loss: memory loss, mental decline, inability to recognize common things

Behavioral changes: irritability, personality changes, restlessness, lack of restraint, wandering

Mood: anxiety, loneliness, mood swings

Psychological: depression, hallucination, or paranoia

Muscular and Perceptual difficulties: inability to combine muscle movements, unsteady movements, inability to perceive items for their use, model demonstrated movements



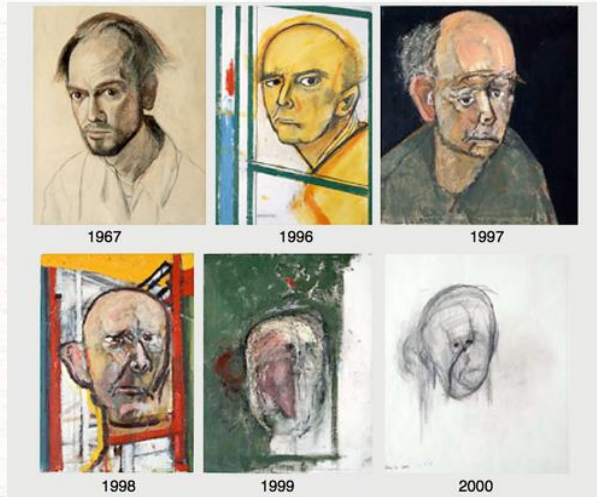
Creative Capacity and Memory Loss (Acosta, 2014)

- Frontotemporal lobe
 - “Bizarre” sketches
 - Perseveration
 - Impulsive
- Alzheimer’s disease
 - Subdued
 - Limited detail
 - Poorly organized
- Parkinson’s disease
 - Dystonia (movement disorder) causes extraneous drawing/painting
 - Impacts “creative drive”
- Lewy body
 - Oversimplification
 - Impaired attention to detail



William Utermohlen (Artist 1933-2007)

Diagnosed with
Alzheimer's
disease in 1995



Research on Creativity
and Memory Loss

Experiences of those with Memory Loss:

Well being vs. Ill Being (Sauer, Fopma-Loy, Kinney, & Lokon, 2014)

Well Being

- Social interest
 - Eye contact, smiling at others, turning towards others, initiates or responds to conversation
- Engagement
 - Sustains attention to task, seeks help/support, engages in task related conversation
- Pleasure
 - Smiles/laughs, verbal/non-verbal expression of pleasure, satisfaction and pride

Ill Being

- Disengagement
 - Sleeping, staring into space, leaving activity area
- Negative affect
 - Anger, verbal/non-verbal expression of anxiety or frustration, signs of agitation
- Sadness
 - Verbalizes feeling sad; crying
- Confusion
 - Shrug shoulders, verbalizes feeling lost; asks what is happening

Activity and Memory Loss (Lokon, Sauer and Li, 2016)

- 67 participants (PWD) and 567 observations
- Activity Types
 - Art Therapy / Music Therapy
 - Opening Minds through Art Program
 - Creative arts and crafts with Regular Staff
 - Non-Creative Activities
 - No Activity
- Results
 - Activity is preferred over no activity
 - Well designed and evidence based programs have higher resultant well-being
 - Having a 1:1 staff/volunteer to PWD achieves the best results

Intergenerational Experiences: Fostering Relationships

- Our society is aging (U.S. Census Bureau, 2010).
- Millennials have negative perceptions and ageist attitudes (Branscum & Sciaraffa, 2013).
- Odds are that the Millennial generation will work with/interact with/care for an older person in their lifetime.
 - Especially concerned with working with older adults with progressive and degenerative diseases
- Opening Minds through Art provides a positive experience and changes young adult perceptions of PWD (Lokon, Li, & Parajuli, 2017).

Importance of Creativity with Older Adults

- Promotes engagement
- May provide emotional relief
- Fosters socialization
- Provides opportunity for self expression
- Can be an alternate means of expression (for those who are non-verbal)



Key Strategies to Promote Creativity

- Make the project complex but easy to manage/complete
 - Provide layers within the activity
 - Opportunity for surprise
- Give choices to promote individual expression (projects should not look like each others)
- Support independence by using artist strengths
 - Be aware of other physical or sensory limitations that impact artistic process (visual deficits, arthritis, etc.)



Key Strategies (continued)



- Provide structure to promote freedom
 - Routines become predictable – less stressful
 - Fixed partners know their artists
 - No background music; minimal visual room distractions
- Use high quality/artist grade materials
 - Benefit: feeling of importance; quality end product
 - Risk: not washable!
- Provide authentic recognition of the artist's creative capacity
 - Praise and sharing during sessions
 - Public venue/showing of work – art show

Third Step

- Using either Pipette or Brush,
- “Load” with rubbing alcohol
- Drop or flick alcohol in spots on ceramic tile.
- **Wait!!!!**
- Repeat application one more time.
- **Wait!!!!**



Opening Minds through Art (Lokon, Kinney, & Kunkel, 2012).

- Visual arts program for individuals with dementia
- Artists are paired with young adult to create failure-free works of art
- Focus is on the process and not the product
 - Making CHOICES
 - Building RELATIONSHIPS
 - Feeling PRODUCTIVE, CREATIVE and IMPORTANT



OMA at Maryville

- Community partnership with Alzheimer's Association
- Presented as a Level I Fieldwork option or a Special Studies course (2 credits)
- Experience allows deep relationships to be built over time
- Focus is on social participation and positive leisure occupations for individuals with a stigmatized disease process



Win –Win Relationship

*Tara, age 22 and
Margarite, age
100*



The Artistic Process

What interests you about this piece of art?



The Artistic Process

- Drawing Interest – inspiration pieces to view and discuss
- Potential for Success – multiple layers; ability to stop and still have an appealing project; is it fun?
- Providing Choice
- Being Surprised - element or step to the process that is unique
- Feeling Proud – the “reveal”



Art Talk

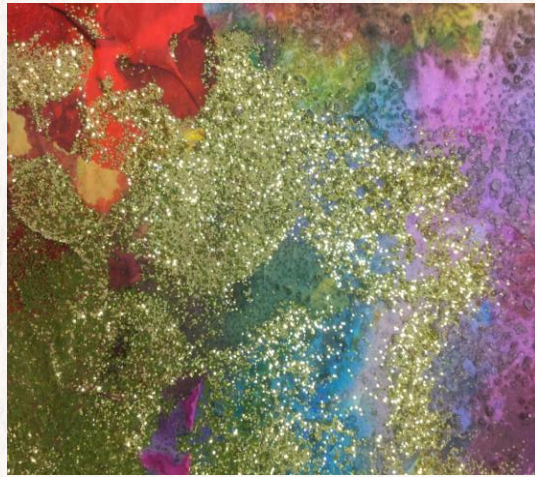
Color: Give examples, red, blue, yellow and point at the color you are talking about.

Contrast: Difference between light and dark

Texture: How something feels, rough, smooth, sharp, soft

Lines: Thick/thin, straight, broken, wavy, etc.

Shapes: Square, rectangle, circle, triangle



Art Talk

Symmetrical: The two halves are the same/similar or mirror image of each other

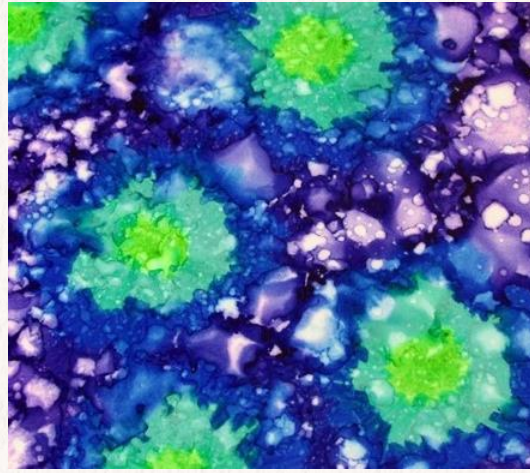
Asymmetrical: The two halves are not the same/similar.

Composition: How things are arranged on the page

The strongest part of the painting: Identify an area that you personally like best in the finished piece and explain to the artist your reasons in clear and simple terms.



Using “Art Talk”
describe your
neighbor’s Ink
Tile Coaster



Leading Creative
Groups for People with
Memory Loss

Responsibilities of Leaders

- Committing to the scheduled art sessions
- Selecting projects and preparing materials
- Setting up art space for session
- Matching partners (and keeping them consistent)
- Providing an overview of project to volunteer partners
- Managing visitors and guests so that artists are not disrupted



Responsibilities of Leaders (Continued)



- Greeting artists as they arrive
- Being an “art waitress”
- Coaching volunteers with strategies for success
- Sharing finished work with others for praise/feedback
- Saying goodbye and making artists feel valued as they leave

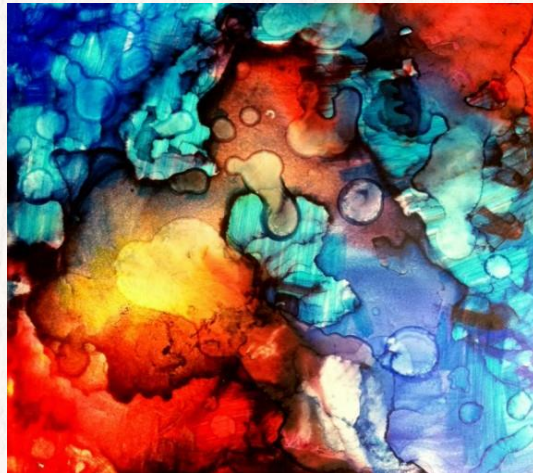
Responsibilities of Volunteers

- Committing to the scheduled art sessions and art show
- Being flexible with the art process
- Being quiet – offering choices but not advice
- Having patience – going slow –wait more than you normally do
- Being in the moment



Final Steps

- Spray with Mod Podge to seal tile surface
- Adhere felt to back of tile.
- Name your project.
- Share your work with others.
- **Enjoy!**

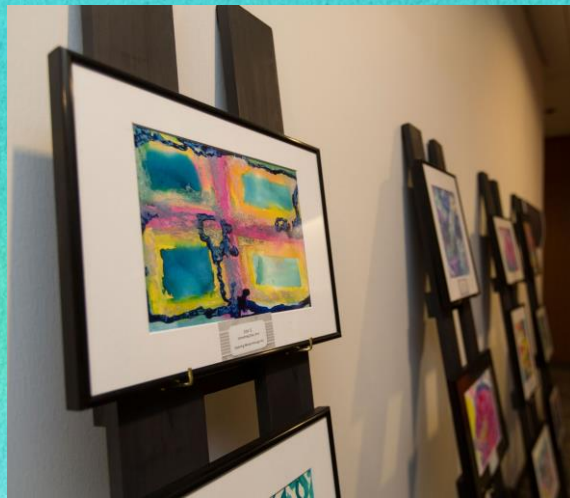


Moving forward...

- What creative opportunities are available in the St. Louis metro area to serve older adults with memory loss?
- How can we “create” creative opportunities?
- Who would be willing to being planning for a pilot opportunity?
- Suggestions from the group

Final thought

It's not about
the product.....





Closing Questions?

Video Examples and Contact Info

- OMA Promo Trailer
 - <https://youtu.be/n1UHR78oX1c>
- OMA
 - <https://youtu.be/Lwz01iQMPX0>

Ashlyn Cunningham, MA, OTR/L, CDP, CAPS
Maryville University - Occupational Therapy Program
acunningham@Maryville.edu
314-529-9533 office
314-398-4314 cell

References

- Branscum, A. Y., & Sciaraffa, M. A., (2013). Changing millennials' attitude toward older adults. *Journal of Family and Consumer Sciences*, 105(1), 18-22.
- Lokon, E., Kinney, J., & Kunkel, S. (2012). Building bridges across age and cognitive barriers through art: College students' reflections on an intergenerational program with elders who have dementia. *Journal of Intergenerational Relationships*, 10,4, 337-354.
- Lokon, E., Li, Y., & Parajuli, J. (2017). Using art in an intergenerational program to improve students' attitudes toward people with dementia. *Journal of Gerontology and Geriatrics Education*. DOI: 10.1080/02701960.2017.1281804
- Lokon, E., Sauer, P.E., & Li, Y. (2016). Activities in dementia care: A comparative assessment of activity types. *Dementia: The International Journal of Social Research and Practice* 0(0), 1-19. DOI: 10.1177/1471301216680890
- O'Connor, M. & McFadden, S. (2010). Development and psychometric validation of the Dementia Attitude Scale. *International Journal of Alzheimer's Disease*, 2010, 1-9.
- United States Census Bureau (2010). The older population:2010. Retrieved on June 24, 2015 from <http://www.census.gov/prod/cen2010/briefs/c2010br-09.pdf>

Photo References

- https://www.google.com/search?biw=1252&bih=604&tbm=isch&sa=1&q=sharpie+marker+tiles+with+brush&oq=sharpie+marker+tiles+with+brush&gs_l=img.3...312200.314314.0.314690.11.11.0.0.0.0.123.950.4j5.9.0....0...1c.1.64.img..2.0.0.aq1Y8ETtjA#imgrc=fQ-7-7x_8suJQM%3A
- https://www.google.com/search?q=sharpie+marker+tiles&source=lnms&tbm=isch&sa=X&ved=0ahUKEwi7zdrwguDMAhXC6SYKHc8vCHgQ_AUICCGC&biw=1252&bih=604#imgrc=bTt0_kidrvT-rM%3A
- https://www.google.com/search?q=sharpie+marker+tiles&source=lnms&tbm=isch&sa=X&ved=0ahUKEwi7zdrwguDMAhXC6SYKHc8vCHgQ_AUICCGC&biw=1252&bih=604#imgdii=hS4WBAbJUZJKM%3A%3BhS4WBAbJUZJKM%3A%3BZWH8QW7YLDzaxM%3A&imgrc=hS4WBAbJUZJKM%3A
- Personal and professional photos courtesy of Maryville University OMA Program

Appendix D

Post Training Questions

1. After being trained today, what do you see as possibilities for people with memory loss as they engage in arts based activities?
2. What still concerns you about working with individuals with memory loss in an arts-based activity?
3. What are the opportunities at your agency to facilitate arts-based programming for individuals with memory loss?
4. What are the barriers at your agency to facilitate arts based programming for individuals with memory loss?
5. Would you implement this program at your facility? YES NO NOT SURE YET

Appendix E

Follow Up Survey

1. Now that you have attended the training regarding the art capabilities of individuals with memory loss, are you planning on implementing such activities at your agency?
2. If yes, what are your plans for this experience (timeframe and general overview of experience)?
3. Are there other questions you might have for me in your planning for this experience?