# Lesley University DigitalCommons@Lesley

**Expressive Therapies Capstone Theses** 

Graduate School of Arts and Social Sciences (GSASS)

Spring 5-21-2022

# Utilizing Collage to Address Disenfranchised Grief Amongst Older Adults Living with Dementia: A Method

Isabelle A. Olsson Lesley University, iolsson@lesley.edu

Follow this and additional works at: https://digitalcommons.lesley.edu/expressive\_theses

Part of the Social and Behavioral Sciences Commons

# **Recommended Citation**

Olsson, Isabelle A., "Utilizing Collage to Address Disenfranchised Grief Amongst Older Adults Living with Dementia: A Method" (2022). *Expressive Therapies Capstone Theses*. 611. https://digitalcommons.lesley.edu/expressive\_theses/611

This Thesis is brought to you for free and open access by the Graduate School of Arts and Social Sciences (GSASS) at DigitalCommons@Lesley. It has been accepted for inclusion in Expressive Therapies Capstone Theses by an authorized administrator of DigitalCommons@Lesley. For more information, please contact digitalcommons@lesley.edu, cvrattos@lesley.edu.

# Utilizing Collage to Address Disenfranchised Grief Amongst

# Older Adults Living with Dementia: A Method

Capstone Thesis

Lesley University

May 5, 2022

Isabelle Olsson

Art Therapy

Denise Malis, PhD, LMHC, ATR-BC

#### Abstract

Grief is an inevitable part of the human experience as everyone encounters loss across the lifespan. However, some forms of grief go unrecognized or unvalidated leading to the disenfranchisement of the griever's experience. Existing literature captures numerous experiences and approaches to addressing the grief of families and caretakers living with an individual diagnosed with dementia. However, little literature details the grief experiences of individuals diagnosed with dementia. Grief can go unrecognized amongst those living with dementia as they are often thought to be incapable of grief as a result of their memory loss and shift in cognition. This thesis explored the use of collage interventions to address disenfranchised grief amongst older adults living with dementia and in working with grief and loss. A method was developed to carry out three individual art therapy collage interventions with 5 older adults living with dementia in a memory care community within an assisted living facility in the Greater Boston area. Results demonstrated an increase in positive mood amongst residents, increased self-esteem in the creative process, and appreciation for the space to process loss and mourn.

*Keywords:* grief, disenfranchised grief, dementia, collage, art therapy

*Author Identity Statement:* The author identifies as a white, queer, cisgender woman from New England of mixed European ancestry. The author acknowledges the ways in which her identity, location, and experiences influence the presented research and method.

#### Utilizing Collage to Address Disenfranchised Grief Amongst

Older Adults Living with Dementia: A Method

## Introduction

Collage has been a key art material for my growth as an individual and artist allowing for symbolic exploration of themes as I transform and repurpose images and objects. Collage has always offered an inviting ability to connect with visual images and create arrangements or narratives with personal meaning. Through my internship working with older adults, I came to witness this population engage authentically with collage materials as they connected to memories and emotions across their life stories. While collage sparked joy amongst this population, it also became clear to see the natural ways in which collage elicited memories or emotions associated with disenfranchised grief for clients living with dementia. According to Alzheimer's Disease International, there were over 55 million people in the world living with dementia in 2020, and this number is expected to double every 20 years as we live longer lives (World Health Organization, 2021). Dementia exacerbates and adds to forms of loss associated with aging including loss of independence, health, loved ones, identity, and more. This thesis will explore the use of collage to address disenfranchised grief as experienced by those living with dementia in a memory care facility through a series of individual collage interventions. Anticipated outcomes include seeing an increase in positive art-making experiences and an increase in positive mood amongst residents due to the increased recognition and validation of residents' disenfranchised grief. The anticipated outcome will challenge the stigmatization of dementia and misconceptions about those with dementia's ability to experience grief. By

challenging these misconceptions, those living with dementia can access care that acknowledges their personhood and experiences of grief with a progressive condition.

# Literature Review

# **Defining Grief and Loss**

The American Psychiatric Association (2013) defines grief as the agony following a significant loss that is distinguished from bereavement or mourning; grief can present in many forms including anxiety, yearning, and physiological distress among other symptoms. Grief is not exclusive to death losses and the intensity of grief can vary over time and amongst individuals. Grief is a part of the human life experience with everyone experiencing grief as a result of loss at some point in their lifetime. According to MacWilliam (2017), loss can be defined as an experience that leads to feelings of grief. Examples may include death, moving, changes in health, ending of a friendship, divorce, changes in financial security, and so on. MacWilliam (2017) stated, "Typically, what qualifies a loss event is that it negatively impacts our sense of emotional and mental wellbeing, and may even threaten our sense of self-efficacy and identity" (p.31). As shown above, a loss may look different across individuals but can greatly impact our overall well-being and sense of self.

In understanding grief, there are distinctions among different types of grief. Clinicians often refer to typical or normal grief as uncomplicated grief, this form of grief encompasses behavioral, physical, emotional, and cognitive experiences and changes that occur following a loss (Worden, 2018). Grief is considered complex or complicated when it severely impacts the functioning and quality of life of the individual and symptoms persist longer than six months (MacWilliam, 2017). While grief itself is not a diagnosis within the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5), "Complex Persistent Bereavement Disorder" is included as a condition for further study (American Psychiatric Association, 2013). The third type of grief coined by Kenneth Doka is referred to as disenfranchised grief, this occurs when an individual is not afforded the opportunity or right to grieve (2002). The grief is still experienced by the individual but it is not publicly or socially acknowledged, validated, or politically observed. Disenfranchised grief can occur following varying types of loss such as divorce, a stigmatized death, moving, infertility, loss of a pet, abortion, loss of employment, dementia, loss of health, and more. The lack of acknowledgment, validation, and support furthers the grief experience of those living with disenfranchised grief. Disenfranchisement of grief is a failure that interferes with the grieving process by dismissing and delegitimizing the experience of the griever's loss and pain (Attig, 2004).

A multitude of causes can lead to disenfranchised grief, these include societal attitudes, organizational rules, political policies, stigmatization, misunderstanding, and more. Societal norms apply to grieving and therefore determine rules and preconceived notions of how individuals should grieve and what is considered a loss, this includes ideas regarding the duration of grief, display of grief, who is capable of grieving, and more. These norms can be observed in workplace bereavement policies, hospital and insurance policies, availability of grief resources, media representation, and more. Doka (1989) initially described three reasons for the disenfranchisement of grief; a relationship that is not recognized, a loss that is not recognized, and a griever who is not recognized. Through further consideration, Doka (2002) added two additional categories of disenfranchisement including circumstances of death and ways individuals grieve.

#### **Defining Older Adults**

In the United States, older adults are commonly understood to be aged 65 and older. Adults over the age of 65 may also be referred to as elderly, aging, or geriatric but the term older adult will be used to describe this population for the duration of this paper. Understanding of human health and well-being continues to expand as does the lifespan of Americans with the average life expectancy estimated to be 77 years old (CDC, 2020). According to data from the U.S. Census Bureau, 14.5% of the United States Population was over the age of 65 in 2014 (Colby & Ortman, 2014).

As humans live longer there is a continued investment in improving eldercare and quality of life for older adults. Increased attention has been given to better understanding risk factors for and diagnosis of illnesses and conditions commonly associated with aging. While older adults experience several physical and developmental changes later in life a major concern for aging populations is memory loss. Typical memory loss associated with age begins to occur from middle age onward as a part of normal aging, this is distinguishable from warning signs of health conditions such as dementia.

#### **Understanding Dementia**

Dementia is an umbrella term used to encompass a variety of medical conditions causing changes in the brain that result in memory loss, a decline in cognitive functioning, and emotional and behavioral changes (Alzheimer's Association, n.d.). Dementia is a progressive diagnosis that can begin with mild symptoms and progress gradually to severe impairment of daily living and independent functioning for those diagnosed. Dementia symptoms include increased difficulty in completing tasks, changes in mood and behavior, increased irritability and confusion, disorientation, difficulty communicating, changes in abstract thinking, diminished senses, poor judgment, and more.

In the DSM-5, the American Psychiatric Association categorizes dementia as a neurocognitive disorder (2013). The term neurocognitive disorder is utilized by the American Psychiatric Association as it is widely used to refer to broader conditions that may affect individuals regardless of age whereas dementia is a term commonly associated with degenerative dementias impacting older adults (2013). Alzheimer's disease accounts for an estimated 65-75% of individuals living with dementia in the United States, the remaining percentage of individuals represent multiple types of dementia including Lewy body dementia, vascular dementia, and frontotemporal dementia among others (Plassman & Potter, 2018). Diagnosis of dementia lacks a primary test and instead consists of multiple assessments such as laboratory tests, clinical evaluation, review of medical history, and mental status examination. This leads to challenges in researching and understanding dementia from an epidemiological perspective (Plassman & Potter, 2018). A meta-analysis undertaken by Plassman and Potter estimated that 4.38 million North Americans were living with dementia in 2010, a number expected to increase to 11 million by 2050 (2018).

#### Loss in Older Adulthood & Dementia

Older adults experience a profound amount of loss towards the end of their lifespan as they encounter numerous changes to their physical health, cognition, environment, and social circle among other things. This grief can feel ever-present as concurrent losses occur. While substantial research has addressed the grief experience of those caring for loved ones with dementia, little research has been devoted to the grief experience of individuals with dementia (Ostwald et al., 2002.) Wyatt and Liggett (2018) advise that a common misconception is that those living with dementia do not experience sustained grief due to their condition; this harmful misconception can lead to grief becoming disenfranchised amongst those living with dementia. However, those living with dementia experience concurrent losses of employment, control, environment, cognition, memories, and health. While those living with dementia experience changes in cognition, their ability to experience grief remains as they maintain the capability for emotions (Pearce, 2015). Ostwald et al. stress the importance of learning about dementia from individuals living with the disease and centering their narratives (2002). Ostwald et al. undertook a thematic analysis of speech samples and mini mental-status exams (MMSE) of 46 older adults living with dementia (n = 50). The thematic analysis found common themes of loss, feelings, and management strategies. Strikingly, of those interviewed 92% conveyed feelings of loss related to their diagnosis (Ostwald et al, 2002).

Additional factors contributing to disenfranchised grief amongst those living with dementia include stigmatization of dementia, multiple layers of loss, and lack of support. These factors contributing to disenfranchised grief amongst older adults living with dementia align with Doka's (1989, 2002) elements of disenfranchised grievers and disenfranchised styles of grief. Due to the cognitive and behavioral changes experience by those living with dementia, clinicians must take careful time to be mindful of non-verbal cues of grief such as increased confusion, restlessness, elopement, altered sleep, decreased appetite, and isolation (Pearce, 2015.) Working with this population requires clinicians to look beyond and challenge their assumptions and existing knowledge of grief. Symptoms of grief and loss may go unrecognized in those living with dementia for long periods of time as the symptoms are not recognizable in ways that are easily identified (Rentz et al., 2004-2005). Doka (2015) describes that those living with dementia may not cognitively recognize a specific loss but feel a general sense of unease and feeling that something is wrong as evidenced by increased confusion, agitation, or stress.

As those living with dementia experience grief, their ability to understand and communicate information and emotions may lead their grief to vastly differ from traditional expectations of grief and therefore require non-traditional therapeutic support (Pearce, 2015.) The impairment of cognitive abilities may lead to a decline in coping skills, emotional regulation, and self-expression in those further descending into dementia (Fisher et al., 2003 as cited in Rentz et al., 2004). It is important to note that individuals living with dementia may not retain information related to losses and experience grief reactions to past losses that have occurred throughout life as well such as the death of a parent for example.

Enfranchising the grief of older adults living with dementia can be as simple as providing empathetic and compassionate listening and connection. Changes in cognition and memory loss render solution-focused therapeutic work difficult with this population. Current models of grief and mourning do not adequately address the unique needs of this population and more research would greatly benefit interventions and approaches. Doka (2015) emphasizes the importance of offering validation and control in supporting the grief of those living with dementia. As can be seen, those living with dementia possess the potential to experience grief despite their diagnosis; such experiences should be supported and validated to ensure the well-being of this population addressing their capability for resiliency.

#### **Art Therapy & Dementia**

Art therapy has been proven as an effective intervention in working with a variety of populations. For many years, art therapy has continued to demonstrate efficacy in working with those living with dementia to boost mood, improve cognition, and promote engagement and attention (Lee et al., 2019). Chancellor et al. (2014) suggest that the use of art therapy provides three main benefits to those living with dementia including reliance on preserved abilities,

allowance to express emotions, and the potential to generate a creative flow that can improve well-being. While the use of art therapy promotes physiological and cognitive well-being amongst those living with dementia, it also offers a unique ability to address mental health and emotional well-being. As a visual approach, art therapy can serve as a vehicle for those living with dementia to express themselves non-verbally enabling further communication, validation, and understanding with caretakers and family (Camartin, 2012 as cited in Guseva, 2018). Lee et al. (2019) suggest that the exploration of the conscious and subconscious through art therapy allows for the resolution of inner conflicts. Craig and Killick (2011) note the natural use of the arts with those living with dementia, "Because intellectual capacity may have diminished, they may be thrown back on emotion, and so the arts can be a natural outlet for their reaction to all the experiences they are going through." (p. 19). Overall, art therapy is a practical way to address the emotional and behavioral changes that are commonly associated with dementia (Lee et al., 2019).

#### **Art Therapy & Grief**

While traditional grief therapy did not always include expressive modalities, expressive arts therapies have increasingly been incorporated into grief therapy practices with a rise in art therapists specializing in grief and bereavement work (Weiskittle & Gramling, 2018). Weiskittle & Gramling (2018) noted the natural fit of art therapy within grief counseling theory, "Echoing the dual-process model's oscillating conceptualization of grief, theoretical models of art therapy posit that creativity is both a restorative and assertive act" (p.11). Theoretical approaches within both art therapy and grief counseling stress the importance of meaning-making as a restorative process for clients leading to change. Weiskittle and Gramling (2018) conducted a meta-analysis of 27 sources on art therapy and bereavement work. The results demonstrated that the use of art

therapy with bereaved populations led to moderate improvements in meaning-making and positive skill development to adapt to loss (p.18).

Lister et al., (2008) explored current theories in bereavement work and the implications for art therapists working with the bereaved and noted the natural ability of the arts to address narratives of loss. Lister et al. assert that art therapists must work to meet the client in times of both positive and negative emotions associated with memories of the deceased and the adaptability of the arts uniquely positions the art therapist to do so (2008). Art interventions offer an alternative way for clients to explore and express a variety of emotions in the grieving process. The author's exploration of current theories in bereavement work identified three implications for art therapists: there is no linear path in bereavement, the importance of meaning-making, and the life-long impact of loss. Furthermore, their research highlighted the importance of two current bereavement theories, the Dual-Process Model and the Meaning-Reconstruction Model, in utilizing art therapy to address loss as these models move past previous notions such as stages or linear paths that restrict our understanding of grief (Lister et al., 2008). They suggest examples of arts interventions such as journaling, comic books, and sculpture activities in working with bereaved populations.

#### Art Therapy to Address Grief and Dementia

Wyatt and Ligget (2019) utilized qualitative and arts-based research to understand the potential of painting in unlocking disenfranchised grief amongst people living with dementia. Participants each engaged in a one-hour one-on-one art-making session in which the researcher conducted a semi-structured interview while painting side by side with the participant. Researchers broke down the feedback and analysis into the three main areas of disenfranchised grief: the grief that is not openly acknowledged, grief that is not socially sanctioned, and grief

that is not publicly mourned. The research found that all four participants felt some form of disenfranchised grief that was exhibited while painting through "negative emotions of anxiety, frustration, crying, and an awareness of their own difficulties." (Wyatt & Ligget, 2019). It is important to note that researchers did not measure how or if participants felt disenfranchised grief but utilized art-making to provide alternative findings on the impact of disenfranchised grief amongst those living with dementia. Overall, the research demonstrated the efficacy of the arts as a tool for communicating with those living with dementia. The arts provide a way for us to understand the way loss and grief are experienced amongst those living with dementia

## **Benefits of Collage**

Collage is a rich visual medium within the expressive therapies often utilized as an approachable way to engage clients in the artwork. Buchhalter (2011) notes that collage can be a non-threatening and structured way for clients to express themselves as it is a process that does not have a right or wrong way to work and the images provide a simple way to represent emotions and ideas. However, limited research exists on the successful use of collage with older adults living with dementia (Stallings, 2011). Despite the lacking research, those involved in the care of older adults know the power of images and creativity in this population. There are a variety of benefits to the use of collage for older adults living with dementia. Traditional therapies with an emphasis on verbal approaches may become unsuitable for older adults experiencing progressive dementia as their cognitive abilities and memory change over time. The use of existing images enables older adults living with dementia an additional way of communicating and sharing their stories with the therapist that may not be otherwise achievable (Stallings, 2011). Equally, the use of images promotes remembrance and triggers memories for older adults in the visual arts process (Johnson & Sullivan-Marx, 2006 as cited in Stallings, 2011). Utilizing pre-cut collage images provides choice and control for this population which

they may be lacking in their daily lives. Yet the use of precut images provides a structure for the choice and activity to meet the cognitive and physical needs of the population. Stallings (2011) implemented and analyzed a method based upon Langarten's Magazine Photo Collage assessment (1993) with three older adults living with dementia and identified the following themes amongst the results; collage allowed an opportunity for organization and control, it evoked reminiscence in verbal and non-verbal ways, and differences in willingness to participate that may or may not relate to the individuals cognitive functioning.

# Method

In this method, I discuss the use of collage as a tool for working with older adults living with dementia to address disenfranchised grief. The method took place over two and a half months with 6 residents in a memory-care community of an assisted living facility. The use of collage was selected as a welcoming and effective way to invite residents to share stories and express emotions through their creativity. Images used for collage provide those living with dementia a structured way to engage in meaningful artmaking and process emotions related to grief and loss through scaffolded collage interventions. Interventions were designed around themes related to reminiscence, grief, and loss associated with the aging process with the intention that these themes would create a container for residents to safely express and process feelings of grief.

# Setting

This thesis method was set within a memory-care community within a not-for-profit assisted living facility located in the greater Boston area. The memory-care community is a secured unit providing round-the-clock memory support for up to forty four residents in a community living setting with residents maintaining private and shared apartments. The community is split into two separate floors with separate staff to best meet the needs of residents and facilitate a neighborhood-like environment. The facility itself is designed to meet the needs of the residents with accessible layouts, calming colors, bright lighting, and more. This setting differs from a nursing home or rehabilitation facility as the nursing staff does not provide medically complex care.

Residents vary in age and diagnosis across the communities; most residents were above age 65 and living with some form of dementia or brain changes that progressed to a point in which living independently was no longer possible. The site provides compassionate care for residents intending to promote the well-being of older adults to maintain active lives while addressing symptoms of their diagnosis with evidence-based practices to slow the progression of dementia.

Residents benefit from structured group programming throughout the day in addition to individualized support to maintain connection, sense of purpose, and safety. Staff are trained in Teepa Snow's Positive Approach to Care (PAC) to best support and engage residents living with dementia. Group programming includes art therapy, music therapy, dance/movement therapy, educational topics, gardening, trivia, art history, performances, mindfulness practice, physical activity, and more. Many residents participate in individual art therapy with an on-staff clinician or intern.

#### **Participants and Format**

The series of individual interventions were carried out across a period of two and a half months in sessions ranging in length from 30 to 90 minutes. The variation of length between and duration of sessions demonstrates the often-unpredictable nature of working with older adults living with dementia as their needs and participation often shift depending upon physical health, visits from family, and shifts in cognition associated with their condition. The individual format allowed for flexibility based on their needs and permitted additional privacy while exploring difficult or emotional subjects associated with grief. Lastly, the individual format as a more intimate space allowed me as the art therapist to provide more individualized support, adaptations, and authentic witnessing to the resident's stories (Stephenson, 2021).

Five residents (N = 5) participated in the four interventions. Residents were approached for participation based on their level of independence and ability to engage with collage materials; in addition to any known experiences or factors that may have suggested the resident was experiencing grief such as a recent transition to assisted living, bereavement, or isolation. All five residents identified as female and ranged in age from 70 to 90 years old. The residents selected were split between the 1st floor (n = 3) and 2nd floor (n = 2) of the community. Residents met individually with me in the private art studio or within a common room in the facility and participation was voluntary with residents guiding the length of the intervention. Each intervention was structured with an introduction to the activity with guided discussion, the main art intervention, and a closing discussion and review of the artwork.

# Materials

The primary material used for this series of interventions was images for collaging. Collage images were pre-cut and selected based on the interventions and resident backgrounds. The use of pre-cut collage images was an important adaptation as those living with dementia may struggle with complex tasks such as finding representational images in a magazine (Stephenson, 2021). Stephenson (2021) notes that with the use of adaptations and the third hand even those living with dementia can work within the cognitive/symbolic level of the expressive therapies continuum (ETC). Collage images were selected from a variety of magazines, catalogs, and books to ensure a diverse representation of images that allowed residents an equal array of choices. Additional collage materials included scissors, glue, colored and textured paper, and cardstock. Furthermore, residents were offered additional materials for each intervention including acrylic paint, watercolor, markers, colored pencils, and tempera paint sticks. Additional materials were selected to allow residents to build upon their collage product while offering an array of options to meet their needs and location within the expressive therapies continuum (etc). Adaptations were made as necessary for materials with each resident. Where therapeutically appropriate the third hand of the art therapist-assisted with the cutting and gluing to best support the residents' artistic process. The third hand describes the process in art therapy when the clinician aids in the creative process to assist the resident's vision in a non-intrusive and empathetic manner (Kramer, 2000).

#### Procedure

To begin each intervention, I collected a resident who agreed to join me for individual art-making and then brought them to the art studio or community room where materials were set up ahead of time to align with the steps of the intervention. Interventions will be referred to as the following 1). Plateful of Memories, 2). Special Place, and 3). No Place like Home. The themes were selected as they can elicit positive memories from the past while touching on components of loss tied to location, ability, mobility, cognition, family, independence, and more.

For Intervention 1, residents worked to create a plate of collaged food that represented significant foods in their life. This activity was designed to address the personal memories associated with food and family in addition to the loss of independence and resulting emotions that may arise when residents no longer have the ability to cook for themselves living in the memory care community. Each resident initially received a standard-size white paper plate,

liquid glue, a paintbrush, scissors, and access to collage images. Collage images of various foods were laid out on a cafeteria tray for access. To introduce the activity and serve as a warm-up, residents engaged in discussion about their favorite food, memories associated with cooking and eating, family and cultural culinary traditions, and more through the use of predetermined discussion questions with each resident. The resident was then introduced to the main art activity and shown an example. Residents were offered collage images of different foods and ingredients to reminisce on foods they would want to add to their plate to create a meaningful meal. Following this, residents were offered acrylic paint to decorate the edge of their plate with a memorable China pattern or color. To conclude, residents reviewed their art piece and engaged in discussion about the final product answering questions about how the piece made them feel, how it felt to create the piece, and who they would share their plate of food with.

For Intervention 2, residents worked to create a postcard that represented a significant vacation or location in their life. This activity was designed to address the personal memories associated with travel and family in addition to the loss of independence and resulting emotions that may arise when residents lose the ability to travel or move about upon moving into a memory care community. The theme of travel was especially salient during the ongoing covid-19 pandemic which limited residents' ability to travel from the community and receive visitors. Each resident initially received a 5"x7"-piece of white cardstock cut into a rectangle with scalloped edges, a glue stick, scissors, and access to collage images. As an introduction and warmup, residents discussed questions related to travel and vacations that I predetermined to fit the activity. Residents were then introduced to the main art activity and shown an example. Residents were offered different travel-related images sorted on a cafeteria tray by images of the United States, other countries, maps, transportation, and activities. Residents were invited to

choose a variety of images to represent their location on the postcard. After images were selected they were offered markers, acrylic paint, and colored pencils to add color, text, and design elements if they wished. As a final step, residents were invited to write a message on the back of the postcard to a recipient. To conclude, residents reviewed their art piece and engaged in discussion about the final product answering questions about how the piece made them feel, how it felt to create the piece, and to whom they may send the postcard.

For Intervention 3, residents worked to create a collage representation of a significant home from their lifetime. This activity was designed to address the personal memories associated with homes residents have lived in addition to the loss of identity and independence that arises when residents leave home to transition into a memory care community. As an introduction and warmup, residents discussed questions related to homes throughout their lifetime which then were predetermined to fit the activity. Residents were then introduced to the main art activity and shown an example. Residents were presented with a 14"x12" inch piece of white poster board with a simple black outline of a house with two windows and a door on a horizon line. The residents were first offered different colored, textured, and printed papers to fill in the house and provided scissors and a glue stick. Sorted on a cafeteria tray were collage images of interior scenes, family scenes, pets, landscape features, and decorative elements. Residents chose from these images to fill in the windows, embellish the home, and create a scene in the yard. Finally, residents were offered markers or tempera paint sticks to add color or draw as they wish. To conclude, residents reviewed their art piece and engaged in discussion about the final product answering questions about how the piece made them feel, how it felt to create the piece, and if they would like to visit the home they created.

#### Tracking

Per the site requirements, process notes were not required while working with individual residents. I chose not to take notes during the series of interventions to be thoroughly present for residents to witness their stories and creativity while offering assistance with the third hand as needed. Following each intervention, time was taken to create a collaged response image that was maintained throughout the thesis process. These collaged images responded to my experiences with residents using magazine imagery, text, poetry, and markers. Furthermore, I wrote a corresponding journal entry of notes, important moments, and quotes from each intervention after the activity.

# **Ethical Considerations**

The structure and implementation of this method were designed considering materials, adaptations, and space to ensure accessibility and safety. Art materials selected should be certified non-toxic to create a safe work environment for someone experiencing changes in cognition. Adaptations such as pencil grips, varying lengths of paintbrushes, and more may be appropriate. Additionally, the workspace selected should allow ample space for walkers, wheelchairs, and rollators to maneuver. Lastly, precut collage images should be selected to provide a diverse array of imagery representative of residents' identities and lived experiences.

#### Results

The following results are from individual sessions utilizing the three interventions described in the method section of this paper. It should be noted that there were 15 sessions in total. Due to a large number of sessions, the results will highlight the experience of working with four residents in addition to describing overarching themes from all participants.

# **Intervention 1**

As residents entered the art studio for individual sessions, a plain paper plate was set out on the left side of the table as all residents were right-handed and this allowed the art therapist to be positioned to easily assist with cutting and gluing if necessary. In the center of the table was a cafeteria tray arranged with precut images of food, a glue stick and white school glue, scissors, and a foam brush. In the far-right corner of the table was a palette of pre-poured acrylic paints (red, orange, yellow, green, blue, purple, silver, and gold) along with thin paint brushes and varying size foam daubers for the second step of the intervention. These additional materials were kept off to the side to prevent confusion and minimize clutter during the art-making process to ensure the steps were clear to the residents. For this intervention, residents were shown a completed example to illustrate the way the paper plate would be used as a canvas. Figure 1.

Clinician Example for Intervention 1



# **Resident 1**

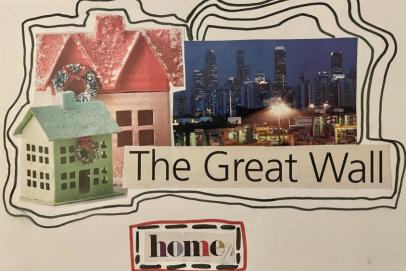
As Resident 1 entered the studio, she immediately was drawn to the collage images and began picking them up while jokingly asking if we would be cooking which allowed a smooth transition to introduce the topic and warm-up questions. Her body language was relaxed as she sat down and quickly began sharing food-related memories in great detail while sorting through the images. Through warm-up questions, the resident shared that she was not often the cook in her home but instead enjoyed her mother or husband's food, "I didn't learn to cook as a kid and was terrible at it as a wife!" An image of cherry cheesecake elicited a sense of connection with her recently deceased husband as she recalled eating this dessert as a family; she shared that while her husband would mostly cook the meals she would wash all the dishes in a team effort allowing them to spend time together in the kitchen. The resident was also drawn to images that explored her identity and culture as a first-generation immigrant. Upon seeing an image of spaghetti, she shared and often repeated a story throughout our time together about enjoying spaghetti in grade school; when she heard the phrase "you are what you eat" she remembered wondering if she ate more spaghetti would she fit in and be American? While viewing the finished artwork, the resident became emotional and shed tears as she described an incongruous story about the loss of her husband and the following loss of her home as she moved into assisted living. The resident reported that the art activity helped her to share memories of her husband as she encountered difficulty expressing these emotions and memories in the community with fellow residents.

Following the session, time was spent documenting the process in a collage-based art journal. I chose to engage with collage materials to mirror the resident's experience selecting representational images while reflecting on and capturing the narratives shared within the resident's artistic process. In Figure 2, I selected images of homes and a city as I reflected on the ways in which the resident's sense of home shifted as she moved into the community. I chose to separate these images with the phrase, "the great wall", as I recalled the resident's experiences adjusting to a new community where she struggled to balance the space, independence, and identity that she associated with her home. While making I thought of the upper area of this collage as fragmented and disjointed from the word "home" at the bottom representing the incongruence the resident and many others face when transitioning to assisted living and redefining their sense of home and safety.

Figure 2.



Response Art, "The Great Wall"



# **Resident 2**

Resident 2 entered the art studio and was immediately intrigued by the images of food although her body language was tense and she expressed doubt about her artistic ability. Warmup questions such as "who were the cooks in your family?" and "do you have foods unique to your culture and heritage?" particularly appeared to resonate with the resident as she relaxed into her seat and her body language became animated while describing Armenian foods. She chose images on her plate that represented her family's Armenian cooking, sharing memories of how her sister would cook elaborate holiday meals, and added a decorative border to the plate. When

asked if she missed cooking, she was quick to say "absolutely not! I was a lousy cook. I worked full time so my sister did the cooking for us." although she did not miss cooking she indicated the connection and joy she felt in helping her mother and sister in the kitchen before holidays. She stated that she would enjoy being able to cook Armenian food within the community to bring back those memories of her family and would welcome doing so with the clinician.

In working with all five residents, similar themes and sentiments arose across sessions although there was a diversity of emotions expressed. The images of food elicited themes of family, culture, identity, independence, and domesticity across art-making. The majority of the conversation in the sessions centered on memories of family associated with the theme of food and cooking.

#### **Intervention 2**

For the second intervention, the art studio was arranged with a plain cardstock postcard set out on the left side of the table for the aforementioned reasons in intervention one. In the center of the table was a cafeteria tray arranged with pre-cut images related to travel sorted by domestic locations, international locations, modes of transportation, and activities. In addition to a glue stick and white school glue, scissors, and a foam brush was included. In the far-right corner of the table were markers and colored pencils for the second step of the intervention. These additional materials were kept off to the side to prevent confusion and minimize clutter during the art-making process to ensure the steps were clear to the residents. Like the first intervention, residents were shown a completed example to illustrate the activity.

# Figure 3.

# Clinician Example for Intervention 2



# **Resident 3**

For Resident 3, the theme of travel provided an instant connection to when her family visited Israel. She described in moderate detail the highlights of the trip, capturing the importance of her family's presence and expressing gratitude that they were fortunate enough to travel internationally together. Throughout the session, she repeated some of these details emphasizing the importance of her family on the trip. She selected images of Israel stating a desire to show the breadth of the country's city and rural scenery. After selecting landscape imagery, the resident asked for a photograph of a family and selected a simple cartoon drawing of parents and children waving. She reported choosing this image as it reminded her of her husband and children while being a simple drawing that allowed anyone to imagine their own family, "to help you see yourself traveling there." The resident continued sharing stories of her and her husband's experience on the trip often using his name many times in one story. This was notable as the resident had never before referred to her deceased husband by name or in detail in session. To finish the artwork, she used short brushstrokes of acrylic paint to add decorative dots

throughout while expressing her desire to create a postcard that people would want to buy in a gift shop or airport. She reported that this was because she wanted to show how important it is to travel as a family. When reviewing the finished artwork, the resident conveyed how meaningful it was to reflect on her trip but noted that she would not wish to return or travel again as "it would be without the others." While expressing this the resident's body language was shrunken and she began to tear up. Before ending the session, she stated a final time that if one can, they should travel with their families. She reported satisfaction with the image as it showed the beauty of Israel encouraging others to travel.

Afterward, I once again engaged in collage journaling to reflect on the session that transpired with Resident 3. Throughout Resident 3's narrative and art-making, I was struck by the strong connection this prompt held to family. I anticipated that this intervention would address independence and mobility but the main theme of this session was the resident's connection to her family and memories built through travel. In Figure 4, I selected a family of meerkats to feature in the collage as I reflected on the importance the resident stressed of traveling with your loved ones; I found the phrase "do I have to travel for what I need?" which brought about a connection for me to the sense of family and comfort that can be brought about by travel. I considered the resident's narrative journey and mirrored this through the imagery of a home and an open road considering how our family memories are built through travel and are carried forward with us as we age.

Figure 4.

Response Art, "Traveling Home"



# **Resident 4**

Resident 4 came to the session and reported that she was looking forward to making art. She was relaxed and inquisitive about what we would be creating. The session began with an introduction of the theme of travel and the goal of creating a postcard which was well received by the resident who put a hand over her heart and stated, "Oh wow that's nice!" In deciding a location to feature for her postcard, the resident reminisced about family trips to a lake house in the Midwest and selected images that represented the scenery and activities of summer vacation on a rural lake. The resident took her time selecting collage images remaining quiet and focused only talking when she found an image, she wished to use sharing a memory associated with each image. The resident seemed reserved, sharing brief positive memories of her vacation with little detail. After choosing a group of images she carefully arranged the clippings exhibiting creative problem solving as she determined how to fit the images together, angling some and creating a focal point in the center of the postcard with a clipping that read, "Midwest". Upon the introduction of colored pencils and markers, the resident communicated that she planned to use green and brown to look like "the farmland in Wisconsin" as she used these colors to fill in all the negative space on the postcard creating a border and frame for the collaged images.

Overall, comparable themes arose for most residents as they participated in intervention two. A large number of the conversations centered on experiences traveling with family and the importance of family bonding for the residents. Secondary themes included exploration, culture, mobility, and independence. It was anticipated to see increased discussion related to feelings of grief surrounding loss of independence and mobility as they connected to travel and transportation. However, general discussion and reflections from residents largely centered on familial connections with little to no mention of their sense of independence. Altogether, intervention two elicited less conversation and saw residents work quicker suggesting a lesser connection to the theme of travel.

## **Intervention 3**

For the final intervention, the art studio was arranged with an 11"x14" poster board set out on the left side of the table for the aforementioned reasons in interventions one and two. In the center of the table was a cafeteria tray arranged with precut images related to home sorted by interior scenes, people, landscape details, and exterior details. Colored paper along with printed brick and wood paper was made available. In addition to a glue stick and white school glue, scissors, and a foam brush. In the far-right corner of the table were tempera paint sticks and watercolor paints for the second step of the intervention. These additional materials were kept off to the side to prevent confusion and minimize clutter during the art-making process to ensure the steps were clear to the residents. Residents were not shown a completed example.

#### **Resident 1**

For Resident 1, this activity connected to many notions of home. She discussed memories of a childhood apartment and the eventual home her parents purchased in great detail sharing memories of the cobblestone sidewalks outside the apartment. She went on to share what it was like when she and her husband purchased their first home and the safe space for exploring this provided their children in the suburbs; this was reflected in the lush yard and gardens she collaged along the house. The home she created in session blended elements from these three important homes she lived in throughout her lifetime, choosing brick paper and a cobblestone path to represent the apartment building, red and green shutters for her parent's home, and the front yard of her family's home. The resident appeared calm and focused throughout the session as she diligently worked to fill in the home with expressive details. While focused, the resident reminisced on the homes from her life throughout the art-making process with little pause. In reviewing the final artwork, the resident smiled while beginning to cry as she expressed gratitude to the house that raised her children. She discussed the difficulty she faced in transitioning to assisted living while grieving her husband. She remarked that this art experience allowed her to feel connected to her husband and reminded her of the hope she feels knowing her home is now raising another family.

#### **Resident 3**

For Resident 3, this intervention provided a connection between her childhood home and her social life in assisted living. She shared memories of a childhood farm in which she lived with her parents selecting an array of colorful plants to depict her mother's avid gardening. Two dogs and a cat represent childhood pets that she reminisced about playing with, in the front yard until dinner. She expressed saddened emotions that pets are no longer a part of her life describing that although it has been a long time she still misses these pets dearly. Upon seeing an image of an older couple walking, the resident quickly chose to add this image as a representation of her current-day self and a friend within the memory care community. She conveyed that she wished she could show her special friend the home that she grew up in and walk the property. She positioned the couple directly in front of the door to the house noting that this way they could go freely through the doors of the home to different locations and walk anywhere they wish. This reflected the locked doors within the community and the inability of residents to freely travel. The resident expressed great joy and pride with the final image remarking on the image's likeness to her childhood home and the joy she saw in the couple walking.

Subsequently, I reflected on resident three's session in my collage journal (Figure 5). I was drawn to the image of a door due to the importance this everyday object had to the resident, while I can travel freely through doors every day a door is a symbol of the outside world, freedom, and independence to a resident living within a locked community. Positioning a door in the center of the collage I utilized natural imagery and maps to consider the possibilities beyond the door and found myself making connections to resident three's experience during intervention two describing the importance of traveling with loved ones.

# Figure 5.



Response Art, "The Insider"

Generally, the completed artwork and concurrent discussion echoed themes of family, independence, comfort, and identity which corresponded with themes witnessed in interventions

1 and 2. This intervention exhibited a higher level of detail and technical craft across all residents' completed artwork in comparison to the previous interventions which could relate to the sense of importance and identity associated with notions of home. In addition, residents spent longer completing this intervention likely due to the large format. Residents unanimously exhibited a strong sense of pride in their completed homes.

Altogether, there were numerous similarities in the themes, use of dominant colors, and resident affect across the three collage interventions as demonstrated below in Table 1. These commonalities speak to the range of emotions and grief expressed by residents. The associations/themes and affect provide information on the efficacy of the interventions suggesting where connections may have been most salient for residents.

Table 1.

Interventions	Associations/Themes	Affect	Dominant Color
Intervention 1	- Family	- Happy	- Red
	- Marriage	- Relaxed	-Gold/Yellow
	- Holidays	- Nostalgic	- Silver
	- Culture	- Teary	- Green
	- Religion	- Mournful	
	- Transition	- Curious	
Intervention 2	- Family	- Happy	- Red
	- Children	- Relaxed	- Green
	- Summer	- Indifferent	- Blue
	- Transportation	- Flat	
	- Culture	- Teary	
	- Color	- Nostalgic	
Intervention 3	- Family	- Happy	- Green
	- Parents	- Relaxed	- Black
	- Home	- Focused	- White
	- Pets	- Nostalgic	- Magenta
	- Loss of Independence	- Teary	- Red
	- Transition	2	

## Commonality Across Interventions.

# Discussion

This thesis explored the use of collage to address disenfranchised grief amongst older adults living with dementia. In implementing this method, the experiences working with residents provided great insight into the potential of collage and the experience of grief amongst this population. This discussion will detail the experience of implementing the method, the successes and limitations of the method, and considerations for future research.

An overarching goal for this thesis was to see an increase in positive art-making experiences and a boost in positive mood amongst residents due to the increased recognition and validation of residents' disenfranchised grief. This was successful in many ways throughout the interventions and was reflected in resident reports that the art process allowed space to reminisce and express emotions in addition to residents' positive reactions to the finished artwork they created. This supports the assertion that art therapy is capable of boosting mood, improving cognition, and promoting engagement for those living with dementia (Lee et al., 2019).

The individual format of the interventions presented residents with the opportunity to express emotions and share memories in a private space outside of the group milieu that encompasses the daily format of the assisted living program. One resident expressed that she usually is not comfortable sharing memories of her late husband "around all the others" and acknowledged that it felt good to cry while remembering what she referred to as happy times. Another resident echoed a similar sentiment reporting that she does not often cry around "the group". The individual format allowed the clinician a greater opportunity to witness and attune to residents' stories and emotions in a more intimate way than group work. While groups have tremendous social and cognitive benefits, it can be difficult to meet the conversational and emotional needs of those living with dementia in a group art setting as cognition and memory vary greatly across members.

During the artmaking process, many discussions centered around memories of deceased family members, memories of home, and loss of independence. These conversations and

emotions experienced by residents in session support Wyatt and Liggett's (2018) assertion that older adults living with dementia do experience grief and lack of acknowledgment leads to the disenfranchisement of their grief. Therefore, a simple success of this method is just the acknowledgment and validation of residents' loss and grief by allowing for creative expression. The art interventions were scaffolded in a way that supported residents by offering validation and control as noted by Doka (2015) as necessary in enfranchising the grief of those living with dementia. As residents continued through the art interventions, they demonstrated increased vulnerability, artistic mastery, and exploration of positive memories that suggest the validation of grief positively impacted their well-being.

The themes chosen for the interventions elicited memories and stories amongst residents allowing for positive reminisce in the artistic process. All residents created artwork that connected to family and positive memories. A beautiful part of the process was the laughter, tears, joy, sorrow, appreciation, and nostalgia that emerged through residents' stories and reminiscence. The range of emotions expressed through the artistic process demonstrated the depth of the topics. The completion of the artwork left residents feeling proud, happy, and content with their finished products as they could connect their experiences with the imagery and felt accomplished utilizing the art materials.

While the method had successes there were also limitations. The method was conducted with a limited selection of individuals in a homogenous setting; implementation of the method with a broader population may highlight cultural and gendered differences in the presentation of grief amongst older adults living with dementia that could influence the effectiveness of the interventions created. Additionally, while beneficial the individual format of the interventions does not foster social interaction, connection, and discovery of shared experiences amongst residents. Exploring the use of collage to address disenfranchised grief amongst this population in a group setting could further social support and develop connections for residents while combating the risk of social isolation amongst older adults in which grief can be a risk factor.

All considered the experiences and results from implementing this method support the literature review highlighting the effectiveness of collage as a medium in art therapy with older adults experiencing dementia and evidence of the tangible grief experienced by this population. Therefore, the use of collage can be a powerful way to address and validate grief amongst older adults experiencing dementia that may otherwise go disenfranchised. Experiences to express and process grief and loss through the creative arts offer a tangible way for art therapists and dementia practitioners to improve the well-being of those living with dementia while acknowledging their personhood. Within the fields of art therapy and dementia care, there is much attention and focus given to supporting loved ones of those with dementia; future research could provide more insight into the experience of grief amongst those living with dementia to prevent disenfranchisement. Additionally, further arts-based research could evidence the ability of collage to foster positive reminiscence and work to resolve negative emotions and behaviors related to inner feelings tied to disenfranchised grief. Witnessing residents' creation, stories, joy, and grief was a dynamic and influential experience that informed my practice as an art therapist. Collage images offered a powerful tool for residents to express their emotions, reminisce, and testify about their experiences through the creative process.

#### References

- Alzheimer's Association. (n.d.). *What is dementia? Alzheimer's Disease and dementia*. Retrieved December 10, 2021, from <u>https://www.alz.org/alzheimers-dementia/what-is-dementia</u>
- Alzheimer's Disease International. (n.d.). *Adi dementia statistics*. Alzheimer's Disease International (ADI). Retrieved February 14, 2022, from https://www.alzint.org/about/dementia-facts-figures/dementia-statistics/
- American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). <u>https://doi.org/10.1176/appi.books.9780890425596</u>
- American Psychological Association. (n.d.). *APA dictionary of psychology Grief*. American Psychological Association. Retrieved February 14, 2022, from <u>https://dictionary.apa.org/grief</u>
- Attig, T. (2004). Disenfranchised grief revisited: Discounting hope and love. *OMEGA Journal of Death and Dying*, 49(3), 197–215. https://doi.org/10.2190/p4tt-j3bf-kfdr-5jb1
- Beaumont, S. L. (2013). Art therapy for complicated grief: A focus on meaning-making approaches. *Canadian Art Therapy Association Journal*, 26(2), 1–7. <u>https://doi.org/10.1080/08322473.2013.11415582</u>
- Bat-Or, M., & Garti, D. (2019). Art therapist's perceptions of the role of the art medium in the treatment of bereaved clients in art therapy. *Death Studies*, 43(3), 193–203. <u>https://doi-org.ezproxyles.flo.org/10.1080/07481187.2018.1445138</u>

- Centers for Disease Control and Prevention. (2022). *FastStats life expectancy*. Centers for Disease Control and Prevention. Retrieved February 14, 2022, from https://www.cdc.gov/nchs/fastats/life-expectancy.html
- Colby, S., & Ortman, J. (2021, October 8). Projections of the size and composition of the U.S. population: 2014 to 2060. Census.gov. Retrieved May 4, 2022, from <u>https://www.census.gov/library/publications/2015/demo/p25-1143.html</u>
- Chancellor, B., Duncan, A., & Chatterjee, A. (2014). Art therapy for Alzheimer's disease and other dementias. *Journal of Alzheimer's Disease: JAD*, 39(1), 1–11. <u>https://doi.org/10.3233/JAD-131295</u>
- Chapin Stephenson, R. (2013). Promoting well-being and Gerotranscendence in an art therapy program for older adults. *Art Therapy: Journal of the American Art Therapy Association*, 30(4), 151–158. https://doi.org/10.1080/07421656.2014.846206
- Doka, K. J. (2002). *Disenfranchised grief: New Directions, Challenges, and strategies for practice.* Research Press.
- Doka, K. J., & Tucci, A. S. (2015). *The longest loss: Alzheimer's disease and dementia*. Hospice Foundation of America.
- Guseva, E. (2018). Bridging art therapy and neuroscience: Emotional expression and communication in an individual with late-stage Alzheimer's. Art Therapy: Journal of the American Art Therapy Association, 35(3), 138–147. https://doi.org/10.1080/07421656.2018.1524260

Kramer, E. (2000). *Art as therapy: Collected papers* [eBook edition]. Jessica Kingsley Publishers.

https://ezproxyles.flo.org/login?url=https://search.ebscohost.com/login.aspx?direct=true &AuthType=cookie,ip&db=cat05473a&AN=les.1434429&site=eds-live&scope=site

- Lee, R., Wong, J., Lit Shoon, W., Gandhi, M., Lei, F., EH, K., Rawtaer, I., & Mahendran, R.
  (2019). Art therapy for the prevention of cognitive decline. *The Arts in Psychotherapy*, 64(20). Page #'s <u>https://doiorg.ezproxyles.flo.org/10.1016/j.aip.2018.12.003</u>
- Lister, S., Pushkar, D., & Connolly, K. (2008). Current bereavement theory: Implications for art therapy practice. *The Arts in Psychotherapy*, 35(4), 245–250. https://doi.org/10.1016/j.aip.2008.06.006
- MacWilliam, B. (2017). Complicated grief, attachment, & art therapy: Theory, treatment, and 14 ready-to-use protocols. Jessica Kingsley Publishers.
- Office of Disease Prevention and Health Promotion. (n.d.). *Older adults*. Older Adults | Healthy People 2020. Retrieved February 14, 2022, from https://www.healthypeople.gov/2020/topics-objectives/topic/older-adults
- Ostwald, S. K., Duggleby, W., & Hepburn, K. W. (2002). The stress of dementia: View from the inside. American Journal of Alzheimer's Disease & Other Dementias, 17(5), 303–312. https://doi.org/10.1177/153331750201700511
- Plassman, B. L., & Potter, G. G. (2018). Epidemiology of dementia and mild cognitive impairment. *APA Handbook of Dementia*, 15–39. <u>https://doi.org/10.1037/0000076-002</u>

- Rentz, C., Krikorian, R., & Keys, M. (2005). Grief and mourning from the perspective of the person with a dementing illness: Beginning the dialogue. *OMEGA - Journal of Death and Dying*, 50(3), 165–179. https://doi.org/10.2190/xbh0-0xr1-h2ka-h0jt
- Stallings, J. W. (2010). Collage as a therapeutic modality for reminiscence in patients with dementia. Art Therapy: Journal of the American Art Therapy Association, 27(3), 136– 140. https://doi.org/10.1080/07421656.2010.10129667
- Weiskittle, R., & Gramling, S. (2018). The therapeutic effectiveness of using visual art modalities with the bereaved: A systematic review. *Psychology Research and Behavior Management*, 11, 9–24. <u>https://doi.org/10.2147/prbm.s131993</u>
- Worden, J. W. (2018). *Grief counseling and grief therapy: A handbook for the mental health practitioner*. Springer Publishing Company, LLC.
- Wyatt, M., & Liggett, S. (2018). The potential of painting: Unlocking disenfranchised grief for people living with dementia. *Illness, Crisis & Loss*, 27(1), 51–67. https://doi.org/10.1177/1054137318780577
- Zizzo, G., Mackenzie, C., Irizarry, C., & Goodwin-Smith, I. (2020). Loss and grief: The experience of transition to residential aged care. *Australian Journal of Social Issues*, 55(4), 474–491. https://doi.org/10.1002/ajs4.105