

Examining the Use of Scrapbooking with Family Members Who Have Lost a Loved One to
Alzheimer's Disease and/or Dementia

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This thesis is dedicated in the memory of my grandmother, Margaret, who passed away from Alzheimer's disease in 2010. It is my hope that this thesis and the research in the years to come not only shines a light on Alzheimer's disease, but that it also aids in finding a cure. To my parents and sister, thank you for the unwavering support and love you have shown me every day. This would not have been possible without your fierce encouragement.

ABSTRACT

This study examined the effect of scrapbooking on memory recall with adults who have lost a loved one to Alzheimer's disease and/or dementia. This was a heuristic study by the researcher who completed a scrapbook in memory of her grandmother who passed away due to Alzheimer's disease and dementia. The results of the study indicated that scrapbooking provides a way to memorialize loved ones while also reflecting back on their life. The scrapbook also served as a means of recall and storytelling among family members.

Keywords: art therapy, memory recall, Alzheimer's disease, dementia, scrapbook

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CHAPTER I

Introduction

Problem Statement

Alzheimer's disease and dementia were serious diseases for which there was no cure. The rates of dementia continued to climb and in a study conducted in 2011, there were 24.3 million people diagnosed with dementia with a predictive increase in numbers to 81.1 million by 2040 (Chien et al., 2011). According to DeFina, Moser, Glenn, Lichtenstein, and Fellus (2013), resources, future plans, and financial planning can be tackled by early detection of the disease. By utilizing art therapy with participants who had lost a loved one due to Alzheimer's disease and/or dementia, this researcher believed that there was hope that this intervention could assist in constructing a reminiscent scrapbook, act as a storytelling tool, and give participants the ability to reflect on the effects of this disease.

Research Questions

This study was guided by the questions, *To what extent does engaging in art interventions impact memory recall? What images convey my grandmother's personality? Does this picture bring up a specific memory? Will I include images of my grandmother with her friends and family or just my grandmother? Would my grandmother be proud of the images I chose? What story does this photograph tell?*

Basic Assumptions

This research study had the following assumptions: a) the scrapbook will be used as a time capsule for the participant; b) creating a scrapbook can allow the participant to remember important times in their lost loved ones' lives; and c) in creating a piece of artwork about their deceased loved one, that would strengthen the relationship between those participating.

Statement of Purpose

The intent of the study was to create a means of creative expression for a granddaughter who experienced the loss of her grandmother due to Alzheimer's disease and dementia. The researcher's goal was to establish an art therapy directive which could be used to strengthen familial relationships, trigger memory reminiscence, and create a time capsule for the participant. Reminiscence, sensory output, and reflection are all ways in which art therapy has helped individuals diagnosed with dementia (Kahn-Denis, 1997). Though accessing a person's cognitive strengths through reminiscence, communication has been shown to increase (Woods, Spector, Jones, Orrell, & Davies, 2009). The results of this study will add to the growing body of literature around this topic.

Hypothesis

This research study hypothesized that having the participant create a scrapbook as a reflective tool would aid the participant in remembering a loved one who has passed, enhance the relationship between family members, and create a tangible piece of creative history for future generations to learn about previous family members.

Definition of Terms

Alzheimer's disease. This disease is a subset of Major or Mild Neurocognitive Disorder in which the Alzheimer's disease genetic mutation was present. The symptoms of Alzheimer's disease included cognitive regression and noticeable deterioration of memory. This diagnosis was made when no other diagnoses was attributable (American Psychiatric Association, 2013).

Dementia. Also known as Major Neurocognitive Disorder, dementia was a disorder in which there had been substantial cognitive regression that affected the individual's daily life (APA, 2013). The regression in cognitive abilities had been noted by a clinician, the individual,

or someone close to the individual as well as cognitive decline on a clinical assessment (APA, 2013).

Scrapbooking. A way of outwardly displaying memories through the use of photographs, journaling, and mementos (Clegg, 2006).

Caregiver. An act which consisted of assisting individuals who are in need and are suffering (Hermanns & Mastel-Smith, 2012).

Justification of the Study

While there were many articles using this population as participants, the researcher felt that this population was still underrepresented in research studies. Similarly, there was a lack of resources on the experiences of family members of those with Alzheimer's disease and dementia. The researcher also found many articles to have a shortage of readily available resources on creative coping techniques that families could use.

This study was important because it could advance the field of art therapy, educate others about the effects of Alzheimer's disease, dementia and memory recall problems, and hopefully provide a way to reminisce and creatively remember loved ones diagnosed with Alzheimer's disease, dementia, or memory recall problems. Secondly, this study could help those affected and their families find alternative ways of coping. Lastly, the researcher had family members who passed away from the effects on Alzheimer's disease and dementia so to assist in finding a way to cope with the disease or aid in finding a cure for caregivers was very important to her.

CHAPTER II

Literature Review**Alzheimer's Disease and Dementia**

Alzheimer's disease is a mental diagnosis that exists along a continuum starting with typical aging and atypical aging such as Alzheimer's disease, mild cognitive impairment, and dementia (DeFina et al., 2013). Four symptoms have to have been present for a diagnosis of Alzheimer's disease to be diagnosed: a genetic mutation stemming from family history, evidence of memory withdrawal, continual progressive cognitive decline, and no other attributable reason (APA, 2013). Variations of these symptoms could lead to a diagnosis of either major or mild neurocognitive disorder due to Alzheimer's disease with the specifications of either probable Alzheimer's disease or possible Alzheimer's disease. Due to the effects of this disease on individuals close to those diagnosed, it was known as the family disease (DeFina et al., 2013).

Potential causes. While there had been no specific cause for Alzheimer's disease, scientists have linked some potential causes. The Mayo Clinic (2015a) stated that one's environment and genes could play a role in being diagnosed. Age was another leading contribution to being diagnosed (APA, 2013). Also, medication was available to help temporarily cope with symptoms and slow the progression of the disease, but no cure for Alzheimer's disease or dementia had been found (Mayo Clinic, 2015b).

For individuals over the age of 65 years, there was a 1 in 20 chance of being affected, and once an individual turns 80-years-old, the risk of being diagnosed rises to a one in five (Bunn et al., 2012). As of 2017, the rate at which the disease occurred was every 66 seconds and 1 in 3 older adults passed away with Alzheimer's disease or some form of it (Alzheimer's Association, 2017). Daily life can become affected with a diagnosis of dementia. Researchers Bunn et al. (2012) found that feeling stigmatized, experiencing changes in relationships, and identity shifts

were all part of a diagnosis of dementia. The National Institute on Aging (2017) recommended to stay empowered and active during one's diagnosis to enhance quality of life by engaging in activities such as gardening, dancing, visiting with children, playing with pets, and eating out.

Vascular dementia or vascular cognitive impairment, was a type of dementia that occurred after strokes (Alzheimer's Association, n.d.). This form of dementia was seen as the second most common type of dementia. Symptoms included misperception, uncertainty, speech impairment, and vision damage (Alzheimer's Association, n.d.). Researchers suggested also looking at vascular elements (i.e. diabetes or hypertension) as a contributing factor or cause for Alzheimer's disease since these factors have not been fully explored (Viswanathan, Rocca, & Tzourio, 2009).

Depression and Isolation. In a study that looked at the correlation between depression and risk of vascular dementia and Alzheimer's disease diagnosis, researchers found that depression that occurred later in life led to an increased risk for vascular dementia, Alzheimer's disease, and dementia (Diniz, Butters, Albert, Dew, & Reynolds, 2013).

Loneliness was something that older adults could experience frequently through the loss of family members, spouses, friends, retirement, or losing their independence by having to live in an assisted living facility. According to Coyle and Dugan (2012), health issues could be attributed to the individual being in an environment where they were sequestered or lonely. Loneliness and Alzheimer's disease were found to have an increased correlation but the researchers found that loneliness was not a leading factor in diagnosis of Alzheimer's disease among the study's participants (Wilson et al., 2007). After having conducted a study over a four-year period, researchers concluded that social isolation and loneliness were connected to lower cognitive performance (Shankar, Hamer, McMunn, & Steptoe, 2013). Gregory (2011) said that dementia could be accompanied by such feelings as distress, anxiety, and isolation.

According to Coyle and Dugan (2012), relationships formed with others could aid in abating feelings of isolation. The researchers suggested engagement in creative expression to help build and maintain relationships. Due to all the life changes that occur when diagnosed with Alzheimer's disease or dementia, support from others was integral to overall well-being (Steeman, Dierckx de Casterlé, Godderis, & Grypdonck, 2006).

Grief and loss. Grief and loss was something that individuals diagnosed with Alzheimer's and dementia also experience. According to Magniant (2004), not only was there the fear of losing someone due to age but there was also the fear of personal death. Family members of those diagnosed with dementia may also feel a sense of loss for their loved one, but how they react towards a family member's diagnosis could be detrimental to promoting a positive transition in the individual's new reality (Steeman et al., 2006). There were many ways to cope with feelings of grief and loss. Researchers stated that rest, relaxation, and nourishment were all ways to deal with grief (Bruce, 2007). Specifically, for mental health professionals, a light atmosphere, treating oneself, and laughing were all ways to help combat grief as well. The way grief was expressed could be determined through the individual's culture (Bruce, 2007).

Caregiver Support

Being a caregiver can be an extreme source of stress. At the time of this research, the Alzheimer's Association website provided local support group information and tips for combating stress as well as signs for recognizing symptoms of burnout in caregivers. According to Chien et al. (2011), support groups were very valuable to caregivers of individuals with dementia. Maintaining one's quality of life as a caregiver was also integral when providing care for others. The Alzheimer Society of Canada (2016) recommended educating oneself on the disease, getting support from others, engaging in self-care, and maintaining one's mental health. Participating in peer support groups with other families who experienced a diagnosis of

Alzheimer's disease helped to comfort fellow group members who shared this commonality (Ponce et al., 2011). Ponce et al. (2011) conducted a prospective study where a psychoeducation intervention was administered to a total of 17 participants which were divided between informal caregivers (spouse, family, or friend) and formal caregivers (nursing staff). The results yielded that this psychoeducational intervention, consisting of participant's opinions on quality of care as well as positive and negative aspects of the caregiver role, was deemed beneficial to caregivers. The study also found that expanding psychoeducational research and interventions enhanced the quality of life in not only the caregiver but also the patient as well (Ponce et al., 2011). A randomized trial study that examined caregiver grief between 188 caregiver dyads (hospice patient and caregiver) one year following patient death, determined that although caregivers had the ability to attend grief and loss services, several caregivers still exhibited stress a year after the loss of a patient (Allen, Haley, Small, Schonwetter, & McMillan, 2013). Researchers also found that the more depressive symptoms exhibited at the beginning of hospice admission by caregivers, the higher likelihood that there would be greater depressive symptoms one year following the patient's death (Allen et al., 2013).

Counseling. Counseling can be an additional outlet for couples who are navigating a dementia diagnosis. Auclair, Epstein, and Mittelman (2009) provided counseling to couples in which one partner was diagnosed with dementia. The study showed two couples how to work together which allowed the participants to realize that they were going through the diagnosis simultaneously (Auclair et al., 2009). Mittelman, Haley, Clay, and Roth (2006) conducted a longitudinal study where participants were provided individual and family counseling, access to support groups, and telephone counseling. The study found that caregivers who participated experienced a decrease in assisted living assignment for those diagnosed with Alzheimer's disease compared to typical controls.

Support and care of the relationship between caregiver and the individual with dementia was viewed as being integral to the success of the relationship and well-being of both individuals in this new reality that they both face (Ablitt, Jones, & Muers, 2009). In addition to their own health problems that caregivers could encounter, a sense of reclamation could arise once the individual who was cared for, passed away (Schulz & Martire, 2004). Interventions which aided both the caregiver and individual with dementia were most likely to produce the best outcome (Schulz & Martire, 2004).

In a study conducted by Hubbard, Cook, Tester and Downs (2002), individuals with dementia used nonverbal behaviors such as affective touch to communicate and it was recommended that facilities which cared for these individuals create a way to communicate with their residents nonverbally. By doing this, it allowed the relationship among caregivers and residents to flourish. Hubbard et al. (2002) acknowledged that when family members or caregivers failed to realize the importance of nonverbal communication among individuals with dementia, communication between caregivers and the individual was jeopardized.

Art Therapy and Alzheimer's/Dementia

Art therapy. Art therapy is a profession in the mental health field where an art therapist facilitates the creative process and counseling techniques to explore a myriad of different issues that a client could experience (AATA, 2013a). Some of the issues explored included emotional well-being, communication, socialization, mental health diagnosis, physical well-being, or self-awareness (AATA, 2013a). Art therapy has been used in an array of settings and populations. According to the AATA (2013a), studies conducted in the field found that art therapy has benefitted individuals who have gone through afflictions, trauma, mental health issues, and those who were looking to better themselves.

With regards to cognitive improvement, Pike (2013) found that art therapy sessions with older adults resulted in an increase in cognitive functioning. Also, Young, Camic, and Tischler's (2016) study found that improved focus, memory stimulation, interaction, and involvement was a result in participants who engaged in art activities. This finding provided some evidence for art therapy as an intervention for memory recall. The creation of art lasts long after the client has created it. Spaniol (1997) found that art made by older adults could leave behind a legacy for their relatives to reflect on and cherish. Rusted, Sheppard, and Waller's (2006) randomized control study found that among their 45 participants diagnosed with mild to severe dementia, although both recreational activities and art therapy were seen as positive interventions, art therapy produced greater benefits among participants. At the end of the 40-week study, participants in the art therapy groups exhibited an increase in depression scores which had eventually subsided three months later when researchers conducted a follow up.

Phototherapy. According to Stevens and Spears (2009), the goal of phototherapy was to let individuals creatively express themselves. Glover-Graf (2007) stated that phototherapy allowed clients to become independent in their choice making when it came to stylized expression of images. A study conducted by Takeda and Dimond (2017) taught older adults with Alzheimer's disease how to use a digital camera as well as how to use their voice through image. The study found that the photographs assisted in facilitating reminiscence among participants (Takeda & Dimond, 2017). Likewise, Stevens and Spears (2009) found that photographs served as a communication tool with clients during a session (Stevens & Spears, 2009). Kutac and Miller (2015) allowed individuals with early stage Alzheimer's disease to learn photography techniques as well as the freedom to compose photographs, which were then critiqued by group members and displayed in an art show. Results indicated that photography allowed the participants to nonverbally express themselves and develop a new sense of self distinguishable

from their diagnoses (Kutac & Miller, 2015). Lastly, phototherapy had the ability to allow clients to feel empowered when they had formerly felt helpless (Glover-Graf, 2007).

Benefits of using collage. Collage and scrapbooking were compared in likeness to one another through their organizational and structured qualities (Kohut, 2011). According to Stallings (2010), collage was a beneficial modality to use due to the fact that it is not based on one's drawing ability. During a study examining the use of collage as a therapeutic tool with older adults, it was found that collage served as communication and reminiscence tool among participants (Stallings, 2010). Chilton and Scotti's (2014) study examined the use of collage in art therapy practice and found that the shared collage directive promoted identity growth.

Originally, scrapbooks were used to record one's life and, today, scrapbooks could provide a physical way to cope with grief and loss as well as celebrate one's life (Kohut, 2011). Scrapbooks were a way to preserve the memories of a life forged between people (Kohut, 2011). Through creating life review scrapbooks with older adults, Magniant (2004) found the life review process elevated levels of self-esteem as well as gave participants the opportunity to reflect on the past and resolve any negative experiences or memories. The scrapbook allowed the participants to "stimulate memories, validate one's personal history, enjoy a sense of competence from creating a 'book,' and validate a person's current strengths" (p. 58).

Scrapbooking has been seen as useful art therapy intervention with other diagnoses as well. In a study conducted with women diagnosed with PTSD, researchers wanted to determine the validity of scrapbooking coupled with journaling to combat PTSD (Davidson & Robison, 2008). Researchers hypothesized that journaling techniques and scrapbooking would assist in telling the participant's trauma story (Davidson & Robison, 2008). The study found that the scrapbooking process served as an effective directive in reducing PTSD symptoms (Davidson & Robison, 2008). Schexnaydre (1993) recommended giving participants a safe environment to

create in as well as non-judgmental ears during the life-review process. The varied use of media provided to the client can also assist in triggering memories for the participant (Schexnaydre, 1993). The more and more pages an individual created, the greater their confidence level rose in terms of the challenges they were currently facing (McCarthy & Sebaugh, 2011). Lastly, scrapbooking in a group or with a family supported the family system and could promote emotional well-being as well as a support system for fellow participants (McCarthy & Sebaugh, 2011).

Reminiscing. Reminiscence used to reflect on past experiences with older adults could be used at any time of the day and was most effective when asking clients an open-ended question (Klever, 2013). Having studied individuals who either lived in an assisted living or non-assisted living program, it was found that reminiscence was more beneficial for non-assisted living individuals (Bohlmeijer, Roemer, Phd, & Smit, 2007). According to Bohlmeijer et al. (2007), there were three tenets to reminiscence: self-continuity, guidance, and emotional regulation. This technique was an important tenant of care when helping those who have been diagnosed with Alzheimer's disease or dementia.

Often it is easy to forget that those who we cared for have led lives prior to our taking care of them. By allowing caretakers or family members to collaborate with the participants and witness the recalling of memories, this seemed to illuminate the humanity of the participants. One interesting finding of the study, according to the interviewees, was that through using recall, participants could use intellectual functions that were previously thought to have been missing (Gregory, 2011).

Storytelling. Storytelling can be another way to promote engagement and social interaction in assisted living facilities with dementia residents. Fritsch et al. (2009) used storytelling through TimeSlips to facilitate memory recall. According to the researchers,

TimeSlips “preserved abilities, rather than focusing on participants’ diminishing capacities, by using creative storytelling to engage residents and help them communicate with each other and their caregivers” (Fritsch et al., 2009, p. 119). The study found there to be higher levels of social engagement, positive regard, and an increased level of interaction (i.e. eye contact and touch) between caregivers and participants. In a study that used older adults to recall their personal life stories to students, Chippendale (2013) found that the study produced positive results among participants. Some benefits included witnessing other individual’s life experiences, a changed opinion of older adults, and self-reflection.

The process of narrative therapy used re-authoring one’s own story to overcome cognitive blockages (Payne, 2006). With this form of therapy, narrative therapists assisted their clients to view themselves as “unique histories” (Polkinghorne, 2004, p. 53). In having done this, narrative therapists promoted a deeper understanding in their client and showed them that their own interpretations of events that surround them led to either personal limitation or expansion (Polkinghorne, 2004). Narrative therapy allowed clients to take an objective look at their life, separate themselves from their problem, and then proceed with a therapist to find answers to their problems (McCarthy & Sebaugh, 2011).

Poetry. Directives that allow for creative expression can benefit individuals who have Alzheimer’s disease or dementia. According to Furman (2012), the use of poetry as therapeutic outlet allowed participants to creatively engage and connect with others, and provided an opportunity for self-reflection. Gregory (2011) facilitated a poetry recall program in which participants spoke freely about their lives. The researcher concluded that the poetry recall technique improved communication and could “re-humanize dementia sufferers in the eyes of those who care for them” (Gregory, 2011, p. 160). Through recalling previous memories, caretakers and family members may get a glimpse into a past life which allowed them to

successfully communicate and create meaningful experiences between individual and caregiver (Gregory, 2011). Swinnen (2016) mentioned that in working with individuals diagnosed with dementia, it was important for the poetry intervention facilitator to not just allow poetry to be written orally but to also incorporate collaboration, rhyme, rhythm, call and response, and gestures into the performance to increase discussion among participants.

Art viewing. In a program at the Museum of Modern Art (MoMA), older adults gathered to view and discuss artwork with their caregivers and museum staff (Rosenberg, 2009). According to the MoMA, viewing art with others in the same position gave caregivers and individuals with Alzheimer's disease an opportunity for social engagement, cognitive stimulation, and a mental break for caregivers (Rosenberg, 2009). Eekelaar, Camic, and Springham's (2012) study proposed that viewing and then making art in a gallery increased episodic memory recall in individuals who had dementia. The study also found that caregivers mentioned that there was an increase in mood, confidence, and feelings of loneliness amongst the participants.

Researchers Camic, Tischler, and Pearman (2014) conducted a study examining the effects of viewing art in a gallery then creating art with older adults diagnosed with dementia and their caregivers. The study found that viewing art and then participating in an intervention led to greater feelings of engagement, higher levels of cognition, and inclusion among participants. At the National Gallery of Australia, a group was held to determine the effects of art viewing amongst caregivers and museum staff to determine if the participant's engagement level would change (MacPherson, Bird, Anderson, Davis, & Blair, 2009). The study found that while in the group, engagement was very high, but when participants were removed from this atmosphere the participant's confidence wavered. Participants also reported that they felt their memory recall

increased, experienced an increase in confidence, and were respected and dignified while in the group (MacPherson et al., 2009).

Rehearsal. According to Jonides (2008) music and acting can be a way to assist in memory recall. This study found that implementing rehearsal techniques that are commonly used in acting and music can help lead to better memory recall. Noice, Noice, and Staines (2004) conducted a study which integrated theatre techniques, visual arts, and a no-treatment group with older adults to assess intellectual and emotional performance. The study found that techniques used in acting, specifically recall and problem-solving, produced positive results (Noice et al., 2004). Music therapists used the creative process to assist in behavioral change, gain understanding, and engage in communication and expression with their clients (McFerran & Hunt, 2008).

Fukui, Arai, and Toyoshima (2012) conducted a study measuring whether music therapy could be an effective treatment for Alzheimer's disease. The study found that music therapy increased secretion of the hormones 17β -estradiol and testosterone which aid in slowing the effects of Alzheimer's disease (Fukui et al., 2012).

Challenges

Rausch, Caljouw, and van der Ploeg (2016) found that there was more research conducted with caregivers than those diagnosed with Alzheimer's disease or dementia. Researchers pointed to the possibility that because of the rapid cognitive decline in patients, this could limit studies (Rausch et al., 2016). Enrollment was another issue when conducting studies with individuals diagnosed with Alzheimer's disease. Factors such as time, energy, comorbid diagnoses, travel costs, and participant permission on behalf of their conservators were all factors that lead to issues with participant enrollment (Grill & Karlawish, 2010). Lastly, many studies

that the researcher had researched included small sample sizes which were viewed as a challenge or limitation in some studies (MacPherson et al., 2009).

Summary

The risk of Alzheimer's disease continued to climb once an individual hit a certain age (Bunn et al., 2012). Loneliness as well as grief and loss could also be experienced in an Alzheimer's and/or dementia diagnosis. Providing coping skills, caregiver support, and counseling were all ways to assist in the diagnosis. Quality of life increased for both the patient and caregiver when psychoeducational interventions were provided to the caregiver (Ponce et al., 2001).

Expressive arts such as art therapy, rehearsal, viewing art, and storytelling were also some of the ways to engage the individual diagnosed with Alzheimer's disease and provide support. Pike's (2013) study stated that there was an increase in cognitive functioning among older adults who participated in art therapy. Similarly, creating a scrapbook allowed individuals to celebrate the life they have led and preserve memories (Kohut, 2011). Storytelling was found to produce positive results in older adults (Chippendale, 2013). Lastly, Jonides (2008) stated that enacting rehearsal techniques can assist in memory recall. While there was still no specific cause or cure for Alzheimer's disease at the time of this thesis research, the above options may help an individual and their families cope with this diagnosis.

CHAPTER III

Methodology

Participants

The participant, also the researcher, was a 25-year-old Caucasian female who had lost a family member, her grandmother, to Alzheimer's disease and dementia in 2010. The participant was also an art therapy student working on her Master of Arts in Art Therapy during the completion of this study. The participant also had experience working with Alzheimer's disease and dementia through her Master's internship.

Research Design

The study conducted was a heuristic study using the researcher as a participant as an investigative tool for self-discovery (Moustakas, 2001). The main goal of a heuristic study was to reestablish a previously experienced situation. Moustakas (2001) also stated that in heuristic studies, research material was commonly portrayed in different formats such as stories, metaphors, and analogies.

Heuristic studies were comprised of six steps: initial engagement, immersion, incubation, illumination, explication, and creative synthesis (Moustakas, 2001). The first step, initial engagement, was when the researcher became compelled to a certain topic (Kapitan, 2010; Moustakas, 2001). The researcher-turned-participant engaged in initial engagement by being extremely interested in whether engaging in the scrapbooking process would assist in memory recall.

Immersion, the second step, focused on the researcher-turned-participant completely immersing themselves in the questions surrounding the research topic (Kapitan, 2010). This occurred when the researcher-turned-participant completely absorbed herself in thinking about

her experience and memories from when her grandmother was diagnosed with Alzheimer's disease and dementia.

Incubation occurred when the participant reached the peak point of immersion and looked towards focusing on life outside of the study (Kapitan, 2010). After becoming engrossed in the research topic, the researcher-turned-participant gave herself a few days to conduct self-care and re-focus on her everyday responsibilities, thus engaging in the incubation stage.

Illumination, the fourth step, was when an insight or theme occurred without consciously thinking about the topic (Kaptian, 2010). Illumination occurred when the researcher-turned-participant started to pull images for the scrapbook and subconscious memories started to become realized.

Explication occurred when the researcher-turned-participant started to dissect and discover the meanings behind these findings (Kapitan, 2010). This step was put into effect when the researcher-turned-participant started to compartmentalize the themes, memories, and emotions associated with the image findings.

After having combed through all themes and realizations, the participant engaged in the final step, creative synthesis, which used these times and realizations to engage in a new, creative way to exhibit these findings (Kapitan, 2010). Moustakas (2001) cited this stage as a creation of the creative vision. Lastly, the scrapbook was created and other themes were reported in the creative synthesis stage.

There were many ways to check for validity in this heuristic study. Kapitan (2010) stated that looking at the data and double checking that the data represents its original intent as well as accurately portrays the participant's experience were ways to establish validity. Having clear and concise questions, reasonable scope, and a plan to take on the open-ended and conversational nature of heuristic studies was also recommended (Kapitan, 2010; Moustakas, 2001).

On the other hand, heuristic studies were also not valid or reliable by nature. According to Kapitan (2010), heuristics was not a “quantifiable method of inquiry” (p. 148). Also, the qualitative nature of heuristic studies could affect validity (Djuraskovic & Arthur, 2010). Lastly, small sample sizes found in heuristic studies could affect generalizability (Djuraskovic & Arthur, 2010).

Procedures

The participant first reflected on what she wanted the scrapbook to convey and any feelings associated with the loss of her grandmother. The researcher thought about such questions as *What images convey my grandmother’s personality? Does this picture bring up a specific memory? Will I include images of my grandmother with her friends and family or just my grandmother? Would she be proud of the images I chose?* and *What story does this photograph tell?* Next, the participant chose what pictures the participant felt captured the essence of my grandmother, who passed away from Alzheimer’s disease and dementia. Then, the participant purchased a 12 inch x 12 inch scrapbook, scrapbook paper, and stickers. Next, the participant gathered images and items which represented strongly associated memories to utilize in the scrapbook. Following this step, the participant engaged in the creative process, reflected on the scrapbook, and wrote down feelings associated with the scrapbook.

Image Selection. The participant chose to include certain photos because she wanted to portray a timeline of her grandmother’s life and include certain aspects in which she was proud of. Born in Hungary, the participant’s grandmother was extremely patriotic and taught the participant to love her ancestry. The participant also wanted to include pictures that represented aspects of her grandmother that she instilled in the researcher (i.e. her love of animals). Images that reminded the participant of her grandmother’s death were included because these photographs provided the participant closure. Lastly, the participant’s grandmother and the

participant had a mutual bond for her grandson, also the participant's cousin, so the participant decided to include an image of her and him together to represent the immense amount of loved she showed to her family. Lastly, the participant chose pictures that may not be aesthetically typical of her but this process made the participant realize that she loved her grandmother so deeply and in the end, the participant could not omit any images that were found.

Journaling. The participant kept a journal to write down any realizations, emotions, thoughts, etc. experienced during the study. During the image selection process, the participant wrote one-word associations with the images that she later formed into fully thought out sentences during the scrapbooking process. The participant also wrote down memories associated with the images on the back of the scrapbook pages so she could remember in the future the emotions and memories associated with the scrapbook pages.

Challenges. There were some challenges in creating the scrapbook. First, the participant had to re-experience the fact that her grandmother is no longer present. Secondly, the participant realized that she wished she had conducted an interview with her grandmother about her grandmother's life experiences prior to her death where she could have recorded their most vivid and favorite memories or talked about their love for one another. Also, to not have a tangible recording of her grandmother's voice or something that they created together makes the participant wish she had the opportunity to do so before grandmother's death.

Data Collection

The participant completed at least three scrapbook pages in five one-hour sessions. Photographs were chosen based on availability to the participant and evocation of a certain memory or feeling in the participant. Feelings and memories experienced during the scrapbook completion were recorded in a journal. The participant also created guiding questions to reflect upon prior to image selection as well as use when arranging the scrapbook pages. Upon

completion of the scrapbook, the researcher recorded, transcribed, and coded themes that occurred during the creative and reflective process.

Data Analysis

To begin the data analysis process, the researcher first collected and transcribed all the data. The data, which consisted of journals and responses to the guiding questions, were then hand-coded in relation to any themes that were present and then later identified (Creswell, 2014). Through the codes, themes were discovered and separated to allow for better processing of data. The data was then reviewed and any themes were coded and categorized into overarching themes. Once this process was completed, a summarization was provided for the reader as well as a thematic analysis chart (see Figure 1). Validity was strengthened in thematic analysis by having a peer review the themes established by the researcher (Alhojailan, 2012). Through having obtained valid themes in the first data reduction step, the process of data reduction in the remaining steps becomes more reliable and less likely to produce inaccuracies (Alhojailan, 2012).

Ethical Implications

The American Art Therapy Association has an ethical policy in which the study held its values to. When determining the subject of the research, the researcher asked herself what population would benefit from this research as well as what were the implications in this research (Maxwell, 2005). Since the researcher became the participant, by asking the above questions it allowed the researcher to engage in ethical research. The researcher's supervisor provided a checks and balance system to maintain ethical responsibility with the participant. Above all, the well-being of the participant was the main priority when conducting the immersive study. Lastly, the researcher gained approval for her research through an Institutional Review Board.

Researcher Bias

The researcher had bias in this study. Since a close relative to the researcher had dementia, this was the inspiration behind the study. Much care was taken on behalf of the researcher to not let personal bias influence any of the research findings. The researcher was a graduate student completing her Master's degree in art therapy. Therefore, the researcher's belief in using art as a therapeutic modality could be considered a bias. Through recognizing that there was partial bias in the study, this allowed for greater validity (Creswell, 2014). By acknowledging there were certain biases, this allowed the researcher to identify certain instances that may arise over the course of the study and ensure that the study maintained ethical, authentic, and professional standards.

CHAPTER IV

Results

Through doing this, the researcher was able to create an art piece in memory of her loved one while exploring their relationship and experience with the disease. An analysis of the data indicated three themes (a) emotional experience, (b) relationship growth and storytelling, and (c) time capsule.

Emotional Experience

During this image selection process, I experienced an array of emotions. While the scrapbook pages themselves do not exhibit the emotions I felt, the act of image selection does. I became sad when I remembered she was not here to complete the scrapbook with me. Grandma and I used to engage in creative projects together and as I was creating the scrapbook I found myself thinking “I am despaired that we couldn’t do something like this when she was alive.” I also felt sad that my grandmother, who almost sacrificed her life when she immigrated to America during World War II, died being a prisoner of her own mind.

Anger was another emotion that I experienced. I felt angry about not knowing about resources or having the knowledge to help her cope with this disease when she was alive. While combing through boxes of photographs and having my mother watch which images I chose, we both found ourselves saying, “why was art therapy not a resource for us when we were in the thick of things? It could’ve helped her so much.” I felt shameful for how I acted towards her. My grandmother passed away when I was a teenager and I was always so angry with how she treated me due to the disease. I felt that it robbed her of her humanity and was always questioning why my best friend was treating me so badly. The scrapbook helped me to reflect and realize that she could not help it and that she was frustrated with herself for not being able to remember anything. I remember us both exchanging words with one another in her hospital

room out of frustration and feeling so angry with her. Looking back, I know that this was not her true self. During my journaling process, I wrote, “I wish I could turn back the clock and use what I know now about this disease and advocate for her.” Lastly, I experienced happiness over the images I found because I had not seen some before this moment. The images took me back to a place of nostalgia with remembering how great of a person she was. In my journal I wrote, “Wow, what an incredible and self-sacrificing woman she was. I only hope to be so loving.”

Relationship Growth and Storytelling

The process of image navigating also allowed me to reminisce with my mother, who was her daughter, about my grandmother. We both found ourselves saying, “I wish she was still here. I wish we knew more about this disease to make her life easier.” Having reflected on her death, it made me realize that her death brought my mom and I closer together. We had this shared experience which was unfortunate but it allowed us to appreciate the time we all spent together. During the scrapbooking process, I also noticed my mother telling me stories about my grandmother which I had not previously heard. It seemed as if the images I chose took her back to her childhood. During the image finding process she stated, “This is the only picture I have of when I was younger with my mom. I remember us not having a lot when I was a child but always cherishing what we had.”

Time Capsule

The scrapbook allowed me to create something tangible that is a lost art in today’s world. Since everything can be catalogued on one’s phone, having a physical memory book to flip through and feel was empowering to make. I plan to keep the book around for my future children to keep the story of my grandmother alive. While we don’t have many pictures of my grandmother, my mother and I both agreed that having me complete this scrapbook would be a

good way to have all the pictures we have be in one place that we can always add to the scrapbook should we choose to.

Presentation of Themes

Through the research study, there were three outstanding themes that occurred: emotional experience of the researcher, relationship growth and storytelling experiences, and the scrapbook serving as a time capsule.

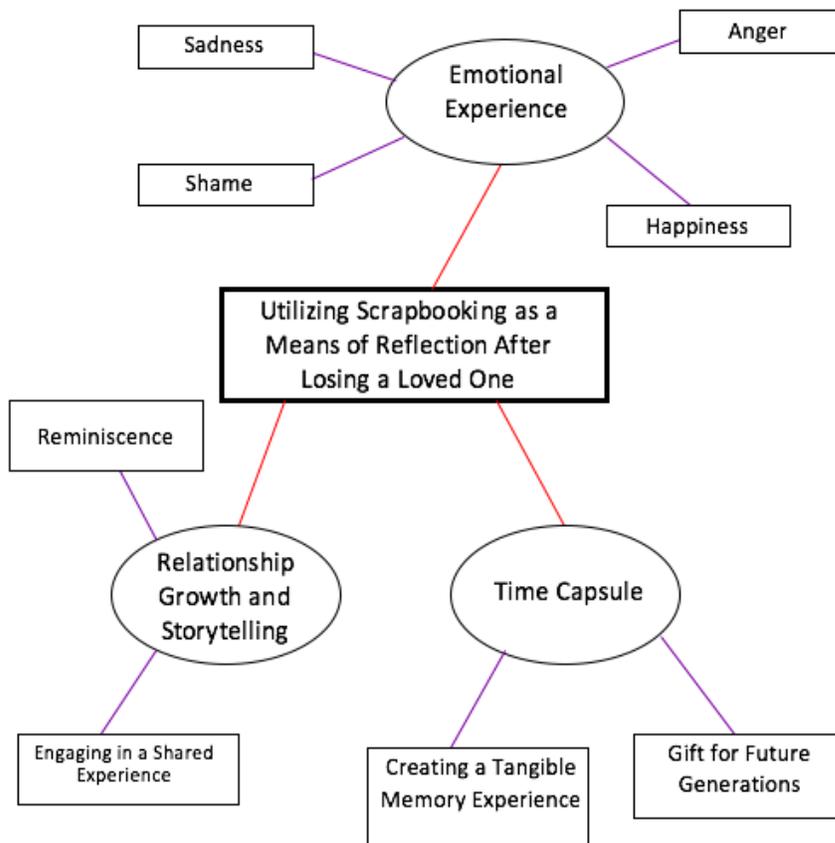
Emotional experience. Creating a scrapbook based on a lost loved one can be an emotional experience. The researcher experienced sub-themes such as sadness, anger, shame, and happiness throughout the image gathering and scrapbook completion. The researcher kept a journal in which she wrote down any thoughts or feelings experienced throughout the study which were then hand-selected and coded by the researcher and a third-party in order to identify themes.

Relationship growth and storytelling. During the scrapbook creation process, the participant and her mother reminisced about photographs and told stories about the deceased. Through the storytelling process, the participant and her mother engaged in a shared experience about their love for the participant's grandmother. The researcher and a third-party hand-coded themes and sub-themes which exemplified any thoughts, memories, or experiences about relationship growth and storytelling.

Time capsule. Through creating a physical scrapbook, this allowed the researcher to create a tangible object to reminisce on and that could be experienced by future generations. The researcher and a third-party hand-selected and coded themes as well as sub-themes from the participant's journal.

The following is a thematic analysis chart (See *Figure 1*) displaying the themes and sub-themes found throughout the study.

Figure 1. Thematic analysis chart



Summary of Findings

Through conducting this study, the researcher found that creating scrapbooks was an emotional experience. The act of picking images, reflecting on them, and creating something which represents the life of a lost loved one was difficult yet rewarding at times. The scrapbook also allowed the researcher a space to reexamine the thoughts and feelings associated with losing a loved one to Alzheimer’s disease. Although the scrapbook was created individually, the researcher’s mother was nearby during the image selection process. This allowed the researcher to ask questions and have a richer reminiscence period as well as strengthen their mother/daughter relationship. Lastly, through having produced an interactive, physical scrapbook, this created an opportunity which future generations could explore.

CHAPTER V

Discussion

The study consisted of the researcher becoming the participant and creating a scrapbook which reflected on the participant's experience of having a family member diagnosed with Alzheimer's disease and dementia. The participant first decided on a topic then immersed herself in the emotions, memories, and experiences of living with a family member who succumbed to Alzheimer's disease. A journal was kept throughout the study for the participant to write down any emotions or notable memories associated with the scrapbooking process. Images were collected and then the scrapbook was created.

Emotional Experience

Reviewing one's life can be a powerful tool used with those who had difficulty with memory recall. Through reflecting on the past, the participant could remember important times and talk about it with their family members or spouses. Young, Camic, and Tischler's (2016) study found that creating art led to improved focus, memory stimulation, interaction, and involvement among participants.

Relationship Growth and Storytelling

By having the researcher select the scrapbook images and then reminisce over them with her mother, this gave the participant and her mother a chance to talk about memories that they may have experienced individually or with one other, thus producing a foundation to bond over. While Fritsch et al.'s (2009) study included caregivers in a nursing facility and not family members or spouses, it was shown that by using a method of creative storytelling, called TimeSlips, interaction and engagement among the participants and their staff was more likely as opposed to other facilities not enacting TimeSlips.

Time capsule

The concept of making art could be likened to a snapshot of time. In Gregory's (2011) study, after having recorded participant's memories and created the memories into poetry, family members were then allowed to read the poetry that was created which evoked previous subconscious memories of their respective participant. Each piece that was created allowed the creator to reflect on how they were feeling, what emotions were evoked, and what brought them to create as they did. By having two individuals tied to one another either by way of familial bond or as a spouse, opened the door to create something together which could serve as a time capsule for both creators. According to Gregory (2011), memory work gave participants the ability to document prior experiences which allowed the memories to be preserved. This scrapbook could be used in the future to reminisce on their loved ones once they have passed and the memories made during the creative process. Spaniol (1997) wrote that in creating art centered around their life, older adults can leave behind a glimpse of their human experience for future generations.

Reflection of Literature Review

The following study reflected several points made in the literature review. First, Takeda and Dimond (2007) found that photographs assisted in reminisce which the researcher found while engaging in the image selection process. During the image gathering, the researcher found photographs that were not previously known about. This facilitated reminisce on behalf of the researcher. Secondly, this study echoed Stevens and Spears' (2009) study where they stated that photographs aided communication. The photographs which were found allowed the researcher and her mother to discuss different memories and times that they had with the deceased as well as provide support for one another. This finding was somewhat similar to McCarthy and Sebaugh's (2011) study where creating a scrapbook with a family member promoted well-being

and created a support system between family members. Lastly, Spaniol (1997) found that art was a way for older adults to leave a physical legacy for loved ones. Also, Kohut (2011) stated that scrapbooks were a way to exemplify the life lived between individuals. This study reflected both of these points in that the scrapbook was a way for the participant to create a physical representation of memories experienced with her grandmother as well as a something for future generations to experience.

Limitations

The participant did the best she could in finding photographs—however, there were some limitations. First, many images were in storage which could not be accessed at the time of image selection. Secondly, although the participant did her best in selecting the best images, this did limit the ability to portray some of the memories she wanted to represent in the scrapbook.

Recommendations and Future Studies

I recommend the process of scrapbooking to manage grief in a grief and loss group. By doing this, it could allow an individual experiencing grief an outlet as well as the ability to create something in remembrance of their loved one. Also, completing a scrapbook in a caregiver support group would be an area of interest as well. Lastly, creating a scrapbook by an individual completing a long stay in a hospital, for example, a chronic illness, would be recommended as a way to document their journey.

Conclusion

Alzheimer's disease affected not only the person diagnosed, but also family members or friends whose lives have changed because of the diagnosis. The reality was that losing one's memory can be a terrifying thing to experience and for loved ones to witness. It was in the researcher's experience that during the time period when her grandmother was alive, there were no resources given to her family to help cope with this disease. Creating the scrapbook allowed

the participant to reflect on previous memories, recall memories previously forgotten, and process the effects of Alzheimer's on families. While some parts of the study were challenging to re-experience, the process provided the participant with an outlet to memorialize her loved one. Current findings indicated there was not a cure for Alzheimer's disease or dementia so it was possible that a future study could contribute to a finding that aids researchers in finding a solution. It was the researcher's hope that this thesis would shed light on the effect that Alzheimer's disease had on those diagnosed as well as family members of these individuals.

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