# DESIGN THINKING

## ADDRESS ANTICIPATORY GRIEF WITH PHOTOGRAPHY & ART CREATION



#### CONNECT

NOW
WITH
YOUR
MEMORIES
BEFORE
YOUR AGING
LOVED ONE
IS GONE

LEARN WHAT AG MEANS

Recognize the signs

LEARN HOW TO ADDRESS IT

Design Thinking methods can help

EXPLORE FIVE HELPFUL STEPS TODAY

See page 2 for stages

# THIS STUDY MAY HELP

#### GRIEF STUDIES BEHIND THE APPROACH & WHY ADDRESSING AG WITH ART CAN HELP

Advanced care planning (ACP) and palliative care practices to address grief have been commonly emphasized in art creation, especially photo collages. Often post-death exploration of photographs of aging loved ones' lives give solace to families left behind---after loss. Many studies show that when aging parents require assistance to function independently, people begin to deal with elements of grief. When the loved ones witness severe or quick decline due to Alzheimer's or Parkinson's Disease they go through the process of grieving, Anticipatory Grief (AG).

This study showed that AG is not exclusive to those family members dealing with serious parental aging decline, but includes those with parents who exhibit natural, diminishing mental and physical decline that comes the age.

#### **PART ONE: RECOGNIZED AG & CONNECTED WITH MEMORIES**



- Completed 20-30 minute Grief Survey to help define AG. [a Likert scale to identify your level of loss & grief].
- Participants gained awareness of AG and how it affects them. They appreciated this stage and shared how this was helpful at the start of the study.
- Wrote & Responded in a journal to identify memories most significant to their relationship with their aging parent [1-2 weeks].
- Participants recognized the need and benefit of recording traits and memories of their aging parent's life. They found this method allowed them to appreciate their relationship more.

Researchers provided **affinity clusters** in response to the completed journals. These clusters influenced the categories suggested for photograph search and collection.

### **PART TWO:** DISCOVERED CONNECTIONS WITH AGING PARENT BY TOUCHING AND SEEING, & TALKING ALOUD

- **Searched** for photographs or images that best represent the themes revealed in their journals. Solo, with siblings or your aging loved one--chose 8-16 photos that became personalized artwork. Returned photos to researchers.
- Participants distinguished this stage as emotionally uplifting with a bit of sadness for what their parent used to do or say. Happiness, feelings of closeness and fulfillment was experienced during this method. The exploring of photos evoked positive feelings.
- Attended a scheduled **Zoom art-reveal session** with the researcher. They were given questions to keep in mind at the start of the interview and shown their personalized artwork comprised of their personal photograph selection.
- Commenced with a Talk-Aloud 30-minute Exit Interview session, the final step in this study.
- Participants viewed their artwork and responded to revealing thoughts, feelings, reactions and epiphanies about each stage of the study and their reactions to their individualized artwork---designed just for them---to represent the connection they have with their aging parent. They were emailed the artwork to keep. They expressed great admiration for the artwork discussed and how important and effective the placement of certain photographs was to the overall aesthetics.
- Participants reflected on all stages of the study and all believe these design thinking strategies and photography art creation can be beneficial to others who have aging parents. Also noted was the enlightenment they felt addressing AG.



#### Photography and Art Creation to Address **Anticipatory Grief:** A Design Thinking Approach

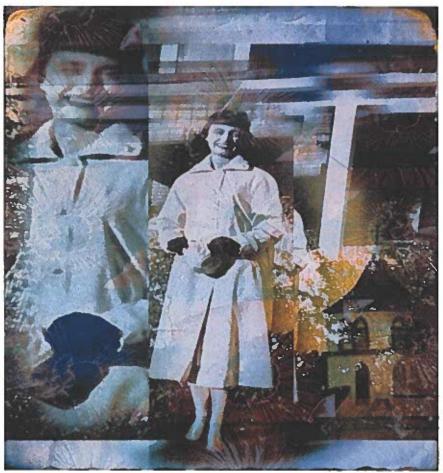


Figure 1. Artwork result of design thinking methods in this study.

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#### **Abstract**

Grieving for loved ones or even strangers throughout the world is commonplace thanks to the emergence of the COVID-19 pandemic and the havoc it has created. In most cases, post-death emotions leave loved ones disconnected, distraught, uncertain, and grieving, and this individual experience is not the same for everyone. While extensive research has examined post-death emotions, research on anticipatory grief (AG), grief prior to death, is lacking, and the few investigations conducted suggest that this condition can affect loved ones' well-being. In this study, we explored anticipatory grief among 6 individuals who have an overall healthy, aging parent 70-90 years of age. Using design thinking strategies such as a grief survey, journaling, affinity clustering, storyboard creation with photos, and think aloud testing, we discovered family members' connection with their loved ones and allowed them to address feelings of grief before great decline.

Another purpose was to provide family members with tools to unveil their knowledge of their most sacred feelings about their aging parents and allow such elements to become artwork. Participants' photographs or graphic illustrations became art and represented new connections that were shown to help them deal emotionally with inevitable losses. Interestingly, the personalized art gave participants positive feelings of a life well lived that may allow them to process their AG while their parents continue to age. The artwork creation gave researchers an increased understanding of how AG affects the personal relationship between loved ones and aging parents and offers insight into the helpfulness of photographic art.

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#### **Chapter 1**

#### Introduction

"Comprehending the nature of grief requires taking into account non-paradigm cases, which do not involve someone dying, and not even the irrevocable loss of another's personhood" (Rando, 2000; Varga & Gallagher, 2020, p. 176).

We live in a time and place where anxiety, conversely results in an "existential vacuum" of the threat of non-being (Gatewood, 2010). The COVID-19 pandemic death count increases by the thousands daily around the world, with no definite end in sight. Families of stricken and hospitalized loved ones are left with "denied opportunities" to say goodbye; phones and videos with desperate feelings that end with uncertainty (Wallace et al., 2020). Their time together is limited with little time to prepare emotionally and physically to the loss. As noted by Shear (2011), bereavement can temporarily render a person a mere shadow of their former self, disoriented and besieged by intensely painful emotions. Shear builds on the beliefs that complicated grief (CG) is prevalent and how grief is an illness that can last a lifetime if not addressed; "grief as a process, not a state" (Parkes, 1996; Shear, 2011).

In this study, we examined how the process of anticipatory grief (AG), i.e., grief that occurs prior to death, affects relationships and how photographic art creation can be used to aid individuals. Grief has always been a concern for the medical profession and for other family members who watch a mourning loved one suffer severe mental or physical deterioration because they are unable to cope. The literature will be used to further address the grieving process family or loved ones endure in the context of advanced care planning (ACP) and AG.

Design-thinking strategies will be implemented to discover how we can utilize existing art therapies using photography to address AG and expand on existing procedures to help plan

for a natural loss of life far in advance of death. With uncertainty looming and grief relief often focused on post-death situations, applied AG solutions are more concentrated on those with lengthy illnesses or those with physical or mental impairments such as terminal cancer or dementia. Having most attention directed to post-death, "complicated grief not addressed can cause substantial distress and functional impairment; knowing when to address it has always been a problem" (Simon, 2013, p. 416). Focused on AG, we may not know for years to come the long-term effects of such sudden loss on family members.

What we can do is recognize AG as a legitimate condition that needs to be addressed in some way to help families prepare for loss. Such recognition is needed more than ever due to the increase of death during the COVID-19 pandemic. Using design-thinking methods, the results from this study revealed how commonplace photography that is used to document lifetimes and art creation increased connectedness between people with aging parents before death. While evaluating palliative care practices and grief, clearly the COVID-19 pandemic has disrupted "usual experiences with grief" (Wallace et al., 2020, p. 70).

Literature shows an increase in clinician care and training for family grief counseling (Morgan et al., 2020). Given the increase in acknowledgement that people do suffer with thoughts of aging family members, there is more discussion among various professionals when it comes to labeling pain and loss for loved ones before death (Shear, 2010). Positive psychologists have shown a keen interest in studying the contributions of spirituality to well-being, including during times of loss and bereavement (Snyder et al., 2015). There exists an opportunity for design thinking and artistic expression to help address AG for families, as they deal with the final years of their aging loved ones. There is also established a distinct usefulness of photography in grief addressment. Therefore, the purpose of this research study was to explore

how design thinking methods can affect family members who utilize photography and art creation to address anticipatory grief and increase connectedness to their aging loved ones.

#### **Definition of Terms**

advanced care planning-making decisions about healthcare people would want to receive if facing a medical crisis. Decisions made based on personal values, preferences, and discussions with loved ones (Kezirian et al., 2018).

<u>affinity cluster method</u>-a design thinking method which can help you gather large amounts of data and organize into groups or themes based on natural relationships or their affinity to one another. Post-it notes and markers, a white board or digital platform are used to analyze and synthesize research findings (LUMA, 2012, p. 40-41).

anticipatory grief (AG)-grief that occurs before death (or another great loss) in contrast to grief after death (conventional grief) (Reynold & Botha, 2006).

<u>bereavement</u>-the action or condition of being bereaved or deprived of something or someone.

<u>cognitive behavior treatment</u> (CBT)-psychotherapy that combines cognitive therapy with behavioral therapy by identifying faulty or maladaptive patterns of thinking, emotional response, or behavior and substituting them with desirable patterns of thinking, emotional response, or behavior (Miller & Rollnick, 2002; Shear, 2018).

<u>complicated grief</u>-uncommon and persistent complex bereavement that involves painful emotions. It involves some or all of the following: inhibited or absent grief, delayed grief, chronic grief, or distorted grief (Shear, 2018).

<u>constructive memory</u>-new memories that emerge based on analysis, synthesis, and evaluation of past events, and emerge as a newly formed memory (Gero, 1999).

<u>design-thinking</u>-an iterative approach to problem solving that intentionally seeks out people with different perspectives, knowledge, skills, and experience. It is a human-centered approach which seeks to understand the user and challenge assumptions in an attempt to identify alternative strategies and solutions that might not be instantly apparent with our initial level of understanding.

<u>dreamscaping</u>-imaginal practice for helping clients at various points on the grief and loss continuum. Grounded in recent empirical research on how the emotional brain encodes new memories, this book describes how to create a resource-rich "prescriptive memory." Application of dreamscaping from a transdisciplinary perspective includes protocols for use with individuals and groups and guidelines for collaboration with therapists and professionals. Illustrations with full-color dreamscape images co-created by clients and therapists (Neimayer, 2016).

grief-deep and poignant distress caused by or as if by bereavement (Wallace et al., 2020).

<u>interpersonal psychotherapy (IPT)</u>-a time-limited, focused, evidence-based approach to treat mood disorders. It is on the principle that relationships and life events impact mood and that the reverse is also true (Miller & Rollnick, 2002; Shear, 2018).

<u>journaling method</u>-a design-thinking method where participants record their feelings and reactions over a period of time designated by the researcher. They can be given prompts, asked to provide visuals, or interpret their feelings and reactions. After submission, reactions are evaluated and analyzed (LUMA, 2012, p. 18-19).

motivational interviewing (MI)-a counseling method that helps people resolve ambivalent feelings and insecurities to find the internal motivation they need to change their behavior or thought process (Miller & Rollnick, 2002; Shear, 2018).

<u>palliative care practices</u>-a multi-disciplinary treatment aimed at improving the quality of life and overall wellbeing of individuals with chronic, life-altering illnesses (Kezirian et al., 2018).

<u>prescriptive memories</u>-a record or events written by a person having intimate knowledge of them based on personal observations and experiences.

<u>psychotherapy</u>-treatment of mental or emotional disorder or of related bodily ills by psychological means.

storyboarding method-a valuable tool in the design process that explains action or memory of events through visual images. In design thinking, images can be photographs or sketches that convey ideas or examples that represent a dialogue of an emotional situation: elements of action, transformation, and emotional impact. Preprinted templates or handwritten images are used. Participants then evaluate their created narratives and identify patterns that often reveal collective vision and value (LUMA, 2012, p. 68-69).

think-aloud protocol-a method used in design thinking used to gather data in usability testing in product design and development and also in psychology. This method involves participants thinking aloud as they are performing a set of specified tasks as they are asked to say whatever comes to mind (LUMA, 2012, p. 20-21).

#### **Chapter 2: Literature Review**

#### **Advanced Care Planning**

Advanced care planning (ACP) in nursing home settings has been considered in many studies with a focus on clinicians and their engagement in the care implementation. To identify gaps in ACP and improve confidence and proficiency in nursing homes at the start of Vancouver, Canada's Palliative Care in Residential initiative, Kezirian et al. (2018) developed and initiated formal education, real-time data feedback, and coaching support for 37 nursing homes and 4040 beds to discover clinical improvements needed during end of life using "the Plan-Do-Study-ACT (PDSA) model to improve ACP" (p. 328). The PDSA cycle tests "practice change initiatives," starting with developing a plan to test the change, implementing or trying the test, then studying and learning from the results, and finally acting on and making modifications to practice based on what was learned (p. 321).

For this project, "clinicians" referred to the nursing homes' family physicians, social workers, nurses, directors of care, and medical/clinical coordinators. ACP is viewed as a process that provides a valuable opportunity for clinicians to explain and discuss a resident's future health treatment and personal care goals with residents and families and avoid unnecessary hospitalizations (Brinkman-Stoppelenburg et al., 2014). They aimed to address the following questions to evaluate this initiative:

- 1. Following the PDSA initiative, did participating clinicians report a better understanding of frailty/dementia and increased confidence and frequency in ACP with residents and families?
- 2. Among the participating facilities, was there a change in the proportion of residents who went to hospital, who died at home, or who had an advance care preference for

- "home-based care"?
- 3. Was this initiative able to institute routine clinical data collection to support a culture of learning? And did the initiative foster relationships between family physicians and allied health clinicians? (Kezirian et al., 2018)

The organizing project team was comprised of five family physicians (all of whom had practice in residential care geriatrics or palliative care), one allied health professional with a leadership role in physician practice support, and a research associate affiliated with the University of British Columbia (UBC) Department of Family Practice (Kezirian et al., 2018, p. 331). The learning sessions provided educational presentations, case studies, and group discussions in the PDSA format, where in learning session 1 teams identified priority issues, then planned a project to "do" during the action period, and learning session 2, where role-play, presentations, and a "study" of their progress and identification of the next action plan occurred. The participants were 17 family physicians, eight directors of care, eight medical/clinical coordinators, 15 nurses, and four social workers who were enrolled in the initiative (p. 332-333). Used in the data collection were multiple surveys administered electronically using a Likert scale throughout learning session 1 and then a follow-up paper survey was given in person during learning session 2 with open-ended questions.

Out of six action plans discussed, created, and implemented by facility participants, three were directly related to engagement with residents' families: using a frailty scale and/or dementia staging to support goals of care conversations with families, delivering a workshop to nursing staff to provide coaching goals of care conversations, and increasing resident and family awareness of available palliative care services. In session 1, the self-reported confidence levels and ACP among the participating clinicians indicated that they felt more confident, more helpful

with communicating and engaging with residents' families, even at time of admission. Session 2 revealed more frequent conversations regarding goals of care with residents and families, and 16 participants reported "engaging more frequently and or more comfortably in goals" (Kezirian et al., 2018, p. 336-338).

While the research conducted by Kezirian et al. (2018) was beneficial in enhancing more family and resident focused conversations and care, anticipatory grief was not examined. Furthermore, studies that have approached AG for clinicians rarely mention family members and only in context of the clinicians' viewpoint. Even given such analysis, most feedback was obtained after long-term care or negative diagnoses were given. Based on these gaps in the literature, the question becomes could design-thinking methods with photography aid families and allow them to deal with AG through memory-making? When describing the discussions about prognoses given the resident's limited capacity for understanding, some clinicians feel "that although wellbeing in late life seems to be a dimensional process, there are groups of individuals who seem to show uneven patterns of wellbeing" (Zammit et al., 2014, p.13). As a result, families often find themselves inadequately prepared for a resident's decline or hold unrealistic expectations of the likelihood of improved quality of life (Munn et al., 2008).

Limitations of the literature are that in the 15 Canadian nursing homes studied, most provide long-term housing, support, and medical care to the elders who have lost their ability to function independently (Kezirian et al., 2018). No studies were directed at independent residents. And while certain elements of independence diminish with age with all aging individuals, the cases of severe physical frailty and/or dementia are very high in nursing home residents (Kojima, 2015). Researchers concluded that "the PSDA model was effective for expanding knowledge and affecting practice change with regards to initiating, communicating and influencing ACP with

nursing home families and residents with less than 6 months prognosis" (Kezirian et al., 2018, p. 341). Acknowledged is "the need for a critical mass of engaged facility providers over a longer period of time to "move the needle" (p. 341) with respect to these outcomes.

#### Anticipatory Grief: Contradictory Beliefs

The study of anticipatory grief (AG) was first documented in 1944 as a term describing the grief process that a person undergoes before a loss occurs (Reynold & Botha, 2006). During their review of "contradictory" opinions regarding AG within the last 60 years, such research acknowledges that it has not been determined how AG affects post-death bereavement.

Continued studies regarding long-term effects of death bereavement have reemerged unique to varied situations.

Originally discussed by Lindemann (1944) regarding the phenomenon among soldiers' wives during World War II, AG was deemed the cause of marriage woes when the soldiers returned. The wives seemed to have dealt with their mourning and "moved on emotionally" (Reynolds & Botha, 2006, p. 17). It was determined that an extended period of AG could lead to "premature detachment," so it was viewed as a negative occurrence.



**Figure 2.** Military father returning to son after 1-year deployment.

To add to the great deal of contradictory information regarding the authenticity of AG, researchers in the 1970s and 1980s claimed that grief is "exclusive to a loss by death and cannot be experienced in advance" (Reynolds & Botha, 2006, p. 16). Yet there also existed positive attributes of AG during the same time period that found it had a positive adaptive effect by easing the intensity of grief for the bereaved after the actual death occurred (Rando, 1986; Reynolds & Botha, 2006). Hill et al. (1988) related AG to the time when mourners had an awareness of the impending death (Reynolds & Botha, 2006, p. 19) and hypothesized that widows who expected their husbands' death would adjust better to bereavement than widows who did not.

A multidimensional approach grew from prior research to compare and contrast the features of anticipatory and conventional grief and found AG influenced the intensity of grief post-death bereavement (Reynolds & Botha, 2006). AG was further supported by commencing with a study within the Australian elderly population, reinforcing the notion that AG "tended to have less intense and acute levels of symptoms during post-death bereavement" (Sloan, 1999, p. 20). Reynolds and Botha (2006) concluded that the conceptualization of AG is lacking a clear definition and therein could lie limited types of interventions by mental health practitioners.

Additional studies about AG consistently emphasize that the definition is often disputed and yet constantly referred to as essential. It is necessary to include the processes of mourning, coping, interaction, planning, and psychological reorganization (Hemer, 2018; Rando, 2000, p. 29). Hemer's decade long study of people in Lihir, Papua New Guinea concluded that grieving does occur in enormous amounts much earlier than full incapacity or death. Grieving these losses "before physical death" may well change the nature or extent of grief that occurs after physical loss (Hemer, 2018, p. 131). Grief for family members involves several losses prior to serious

illness: loss of independence of various physical or emotional capabilities (Hemer, 2018). The relevance of AG is of increasing importance given the immediate deaths that we are experiencing during the COVID-19 pandemic. Death is closer than ever to our minds.

#### Current Approaches to Grief

The progression of AG study into 2020, during the COVID-19 pandemic, has exposed an urgent need to address new experiences of grief and modifications of approaches to support grief (Wallace et al., 2020). Provided in the study by Wallace et al. are suggestions for dealing with grief and new considerations for palliative providers during the pandemic. Defined is the pre-COVID-19 uncomplicated grief that encompasses multiple responses---emotional, cognitive, physical, and behavioral (Wallace et al., 2020; Worden, 2018). Wallace and colleagues suggest that palliative care providers need new key practices for advance care planning, quality communication, and provider self-care to help mitigate grief. Anticipatory grief is expected to increase, and these experiences that occur before death have a lasting impact on grief experiences of loved ones and providers alike (Wallace et al., 2020). Included in this study are suggestions for AG for the community, medical personnel, and bereaved families as they pertain to three impacts of COVID-19: pandemic fear, social distancing, and increase in death and overburdening of the hospital system. Recommendations for AG include "communication-based management, including recognizing, responding, and validating emotional responses of patients and families, which indicate a clear need for 'understanding the complexities of grief'" (Wallace et al., 2020, p. 75).

In general, grief studies have increased when addressing loved ones' condition after a death. There exist various types of therapy for grief after the loss of a loved one, such as interpersonal psychotherapy (IPT), cognitive behavior treatment (CBT), and motivational

interviewing (MI) (Miller & Rollnick, 2002; Shear, 2018). Shear developed complicated grief therapy (CGT) that lasted 16 weeks and was focused on "intensely painful and infused with deep longing" (Shear, 2018, p. 11). The treatment is typically delivered in 16 sessions over a 4-month period. The overall framework comprises information about grief and CGT, including the use of a grief monitoring diary, involvement of a significant other, and the facilitation of optimal interpersonal functioning. Also, participants work on personal goals and self-care, revisiting the story of the death and its implications and consequences and places and activities that are avoided, working with memories, pictures, and imaginal conversations with the deceased. Photography was used only as an enhancement to the written diaries, so no conclusions could be made about the effects of photography alone. Shear recommended that more research in this area is needed.

#### Memory-making for Grief

There exist mixed feelings about family support impact when facing a dying loved one; however, history informs us that there has always been a need for memory-making after a death: "locks of hair, personal items, or anything that allows the bereaved the opportunity to *touch* or see objects that can act as reminders and connections to those deceased" (Riegel et al., 2019, p. 443). The complexity of dealing with grief and the fear of death increases with the uncertainty during the COVID-19 pandemic, yet even before the pandemic, memory-making has been used to help bereaved loved ones. Riegel at el. addressed grief for end-of-life patients and found positive feedback from families: visual aids were provided such as printed copies of the patient's electrocardiogram as a memento, computer-generated word cloud images post-death that families can take with them, and photography during the illness. No focus was given to the time before serious disability, only after the patient was hospitalized, and all studies of photography

used were combined with diary writing. The researchers concluded that further research is needed to determine which memory-making objects contribute to family bereavement consolation. The timing of such visuals is sometimes not effective, as families are overcome with grief after the loss.

There should be other means of addressing family members' grief much sooner than after a serious diagnosis or death. Robert Neimayer (2016) emphasized how phototherapy such as "dreamscaping" offers psychotherapy an opportunity to "join the brain's hemispheres to make more integrated reconstruction of memories in bereavement possible" (p. 486). Psychotherapists have further explored "dreamscaping" and related it to memory reconsolidation and art therapy as related to bereavement (Gershman & Thompson, 2018). Praised for his dreamscaping approach to grief in suicidal cases, Neimayer helped edit Gershman and Thompson's new book in which they use resourcing, focusing on felt sense, re-scripting, and mental simulations to shift the focus from "what do you miss?" to "what gives you joy?" Perhaps if the premise of such focus was directed at the unchartered territory of anticipatory grief, then art could help the bereavement process far before seriousness or death.

Photography and its relevance to AG has been established on well-supported websites such as whatsyourgrief.com, a nonprofit organization, where there exists an extended support network for those dealing with multiple types of grief. Complicated emotions are often part of AG as family far in advance of death can be affected: loss of independence, loss of future, dreams, stability and security, and loss of cognition (Williams, 2013). Therapeutic resources on such sites emphasize how photography can help in bereavement, but only after loss. Visual "collage therapy" as well has been successfully implemented for patients with dementia (Stallings, 2010, p. 137), and during "reminiscence" has proven to be an "essential component of

the life review process." There needs to be more such therapy focused on families who are dealing with mental and physical stressors related to anticipatory grief.

#### **Design-Thinking Possibilities**

It is not surprising that during the 2020 pandemic there are many emerging websites that attempt to offer some consolation to family members experiencing the bereavement process. Design-thinking methodologies have been popular at addressing several aspects of health care to gain insight into patient and clinician experiences. In March 2020, at the TEDMED conference, I was fortunate to engage author Ellen Lupton and other attendees in my buy-a-feature homework assignment. We discussed at length her new book written with Bon Ku, the founder of the Innovative Health Design Lab at Thomas Jefferson University. The text, *Health Design Thinking* (2020), provides principles, methods, and 25 case studies of how design-thinking has been utilized. The book is addressed to clinicians, as a collection of possibilities for design thinking methods; these methods could translate to a photographic approach to AG.

Ku and Lupton (2020) detailed personalized asthma care; they used ethnographic observations in clinics and public events, and then conducted 15-minute interviews of two adolescents, 10 caregivers, two community advocates, three social workers, three doctors, and one nurse. They asked open-ended questions to elicit suggestions for asthma care process improvements and asked them to create images to go along with any words they generated. This brainstorm led to a stakeholder map creation that placed ideas from each group together by their type of suggestion: environment, protocol, system...etc. Then *visualize the vote* was implemented: each participant received 5 stickers to vote for his or her favorite ideas, and "the top-voted ideas got a chance to become real interventions through the prototyping process" (Ku & Lupton, 2020, p. 162). Such a method led to idea generation for storyboarding, as participants

connected images, and patterns emerged that could help identify patient issues such as body image, suicidal thoughts, abuse, and mourning post-death.

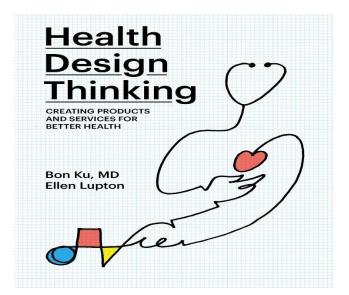


Figure 3. Ku and Lupton's textbook with popular methods for design thinking and health.

To further connect design-thinking and visual art to enhance meaningful memory-making, the Australian Research Council funded studies conducted by Professor John Gero of the University of Sydney. He focused on how "design-thinking and the creation of design used to be more linear, yet now relies on constructive memory, which involves analysis, synthesis, and evaluation" (Gero, 1999, p. 29). He believes that constructive memory not only produces new memories but helps people "reinterpret our previous experiences and memories" (Gero, 1999, p. 29-35). His research emphasized that the art of design-thinking can help people retrieve the original experience or memory more easily than allowing subsequent experiences from clouding perspective. Such regard for design-thinking and how it can help with memory association is reinforced by studies in explicit or declarative memory.

As revealed when studying how and to what extent students can retain and recall information, there exist three stages to memory processing: encoding, the process of forming new memories; basic storage; and retrieval, the process of gaining access to stored knowledge

(Berkeley Symposium, 2020). To engage participants in encoding, we must recognize memories as unfaithful "recordings," integrated into our now knowledge. Noted by educators, robust memories can be formed by quickly processing the new information as deeply as possible, maximizing connections with what is known, and situating new knowledge into an existing framework (Berkeley Symposium, 2020). With the steps proposed in this current study, such as journaling and storyboard creation of personalized art, people will be able to allow their constructive memories to emerge in the art, and therein "give meaning to what was experienced before" (Dewey, 1896, p.361).

#### Gaps in the Literature and Purpose

The phenomenal response of mental health care professionals during the COVID-19 pandemic has led to acknowledgement of the need to address grief counseling as quickly as possible after unexpected death. Evaluation of the literature establishes that while grief identification and counseling has increased, lengthy complicated grief has also increased (Parkes, 1996; Shear, 2011). Extensive studies in ACP have also grown when it is the focus of nursing home or assistive facilities (Kezirian et al., 2018; Wallace et al., 2020; Worden, 2018), yet people are dealing with anticipatory grief far before death. Even though advances in interpersonal psychotherapy, cognitive behavior treatment, and motivational interviewing have helped alleviate loved ones' ability to recognize and address grief, literature is focused on post death (Shear, 2018; Wallace et. al., 2020).

There are numerous websites, blogs, and organizations that encourage memory-making to help address individual grief, as the grieving process has been practiced for generations (Hemer, 2018; Neimayer, 2020; Sloan, 1999; Reigel et al., 2019; Reynolds & Botha, 2006; Williams, 2013). Photography in memory-making to address grief has shown great promise for post-death

family members and self-awareness (Gershman & Thompson, 2018; Stallings, 2010). Furthermore, design-thinking strategies have been used successfully to address many facets of the health care field such as architecture and patient and family members' experiences (Ku & Lupton, 2020). What is missing, however, is how photography and memory making may influence family members before loss or before the aging parent is solely dependent on others, or greatly physically or mentally incapacitated.

#### **Chapter 3: Methods**

Using design-thinking strategies (DTS), the researcher examined the awareness of and effect of anticipatory grief (AG) on family members of aging parents or parental figures. A secondary purpose was to discover how specific memory collection connected family members with their aging parent(s) and how memory-art photographic collage creations possibly helped address AG.

#### Sample

Stakeholders for the survey, journaling, storyboarding/photo collection, and interview methods included 6 family members with aging parents (those 70- 90 years old who are overall healthy but may be showing signs of some physical or mental decline). This purposive, nonrandom sampling allowed for participants who had generally healthy aging parents, which was necessary to avoid severe mental or physical disabilities that may influence the findings. Additionally, the aging parent(s) were allowed to participate in the storyboarding and photo collection with the recruited family members.

The reason for choosing this population of family members was to expand the knowledge of family relations and memories beyond family caregiver situations with severe physically or mentally impaired parent(s) or post-death situations and help address AG for an often-omitted

group. Recruitment and consent for participants was conducted through written email (see Appendix E for email recruitment). The student researcher reached out to her personal network in Canada and the United States and originally recruited 10 willing participants who through discussions of grief and loss over the last 6 months and via professional or personal exchange asked to be a part of the study. Comments such as "we need something positive right now" and "count me in," and "wow, I want to be a part of that" were given when talking about the intent of the study. Out of the 10 that were originally eager to participate, eight completed the first 2 methods and six completed all stages of the study.

#### **Instruments and Procedure**

#### **Part One**

Online survey: During the recruitment process, the consent form was attached to the initial email invitation to participate. If a family member agreed to participate, they were instructed to send the signed consent form (see Appendix E) prior to the start of the study. All signed consent forms were returned to the student researcher via email within 7 days of receipt and then the survey was sent via email.

Using a **grief survey** that was emailed to participants (see Appendix A), participants emailed their completed forms to the researcher within one (1) week of receipt. The questionnaire was used to identify how family members view their aging parents' diminishing capabilities and measured how anticipatory grief (AG) has affected them beyond family caregiver situations with severe physically or mentally impaired parent(s) or post-death situations and helped address AG for an often-omitted group. The questionnaire, based on the Grief / Depression Assessment Inventory-Survey Regarding Anticipatory Grief (AG) developed by John M. Schneider (2001), consisted of 10 questions that assessed anticipatory grief and took

approximately 20 minutes to complete.

Journal: Upon completion of the online questionnaire, participants were emailed a prompted memory journal in which they explored, discovered, and addressed the scope of their connections to facts or feelings about loved ones' memories and relations to them (see Appendix B). This journal revealed how much they know about their aging parent and what matters most to the family members while thinking about remembering them. Memories of basic information, personal perspectives of memories shared, special ambitions, likes, achievements dreams...etc. were discovered. Participants completed the memory journal on their personal computers and were given two (2) weeks. Once completed, participants emailed the journal back to the student researcher.

Affinity Clusters: When the memory journals were received, the student researcher collaborated with two work colleagues weekly for 3 weeks. They used affinity clustering to analyze the results and create common themes including family members' attitudes toward their aging parent(s) life and achievement, types of memories that are at the heart of their relationships, emphasized connections, times and moments that they remember with fondness, gaps in their knowledge, and identified their greatest concerns for their aging parent (Appendix C). The researcher returned to the clusters to gain perspective on the most accurate labels for such expressions and inform the advice for photo collection (Appendix D). For instance, in one subject's case she made several claims about her father's love of the outdoors, but then focused on jovial antics during childhood that showed to be more influential in their relationship. There was discussion of whether the clusters reflected the outdoors or the simplicity and rawness of her father's spirit and what that cluster should be labeled.

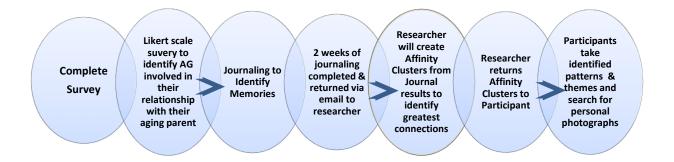
#### **Part Two**



Figure 4. Storyboard template

Storyboard: The student researcher emailed the findings from the affinity clustering to each family member and asked them to participate in the next phase of the study: **storyboard creation** (see Appendix F). Once participants reviewed the affinity clustering themes, they were instructed to find a minimum of 8 and maximum of 16 photographs based on the themes.

The photographs were arranged using the storyboard template provided by the student researcher as shown in Figure 4, or the participants could have used an album created in Google album or another template. They were instructed to save images as pdfs or JPG files with a maximum size of 700 KB if possible. They were told that they could create a storyboard by hand and scan the items and submit via email; photos were still required to meet the criteria listed to ensure artist quality of the final artwork. Participants were given 2 weeks to gather photos and arrange them in a storyboard or album, which were returned to the student researcher via email.



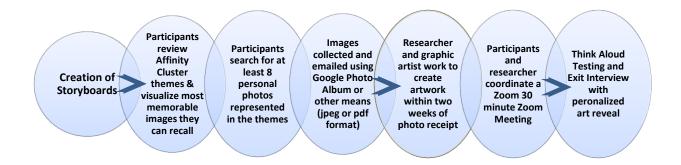
**Figure 5.** Illustration of the first phase of the research plan.

The student researcher then collaborated with the textile/photographer/graphic artist to create a collage artwork of the participants' photo selections. They worked together to evaluate photo choices and compared them to the themes influenced by the affinity clusters.

Approximately two to three exchanges between the student researcher and the artist were needed for each participant's creation, given the need to ensure the artwork reflected the themes accurately. After review of the themes, the artist asked for clarification via chat or email for each to ensure which photos she believed were best representative. She wanted to "be on the same page." She recreated art for three of the participants and sometimes offered two variations. The researcher revealed both variations to the participants. Approximately eight photographs for each participant were used from the submitted photos. The artist then created the collages of the chosen images using the *Photo Shop* software. The art was created within 2 weeks of receiving the storyboards with images and saved in a secure folder on the researcher's computer.

The Exit Interview: Lastly, **think aloud testing** (see Appendix D) and exit interview instructions were sent for the final method. This interview and art reveal commenced within 2 weeks of the personalized completed artwork. The date and time for the artwork reveal was coordinated via text and email for each participant. The Zoom link was sent via email within 24 hours of the scheduled reveal and question session; and a reminder was sent via chat 3 days

before. The researcher provided the participants with the exit questions the morning of the scheduled Zoom meeting to allow for raw reaction and reflection. When the exit interview occurred on Zoom, the student researcher asked individual questions of the participants (See Appendix D) simultaneously as they viewed their personalized artwork.



**Figure 6**. Illustration of the second phase of the research plan.

During the interview, participants were asked to verbalize reactions to the artwork/prototype via illustration selection, placement, colors...etc., the physicality of the production and their feelings and emotions upon viewing it for the first time. Participants were asked to examine the images and share their emotional reactions and feelings of connectedness to their parent as they viewed the prototype. Then the questions shifted to each method as it led up to the artwork creation and the participants' gains throughout the study and understanding of anticipatory grief. Driven by participant reactions, the researcher envisioned a multitude of possible end products with the collage. Envisioned is a response-directed print artwork or silkscreens---A wearing of aging loved ones' stories: story-telling silk wraps and scarves that can allow family members to address anticipatory grief.

#### **Chapter 4**

#### Results

The results largely supported my first idea that if given opportunity to explore feelings of grief before loss, design thinking can help people begin to understand anticipatory grief (AG) and how it affects them. The grief survey allowed participants to recognize anticipatory grief and its relevance to their relationships with their parents. Originally 10 people were asked to participate via personal relationships with the researcher. Out of the 10, nine completed the consent form and the survey. The two males that were expected to be in the study did not complete the journal and apologized for their lateness. The study could only warrant a 2-week additional allowance for journal completion, so they were thanked and released from commitment. The one female who eventually left the study completed the journal late and, was, in a manner, unhelpful to the researcher. After two follow-up telephone calls, the extensive journal seemed to cause this participant uncomfortableness, and she said, "I would understand if you don't want me in the study; I might not be the type of person you want due to my issues with loss in the past and my closeness to both of my parents now." I agreed with her and settled on the six participants who completed all steps successfully.

The results of survey completion and writing and reflecting in a journal to questions regarding their aging parents supported my second assumption that written response can help people focus on positive connectedness while allowing them to recall emotions and moments when given prompts about their memories about their aging parent. All six participants agreed that the first survey stage was revealing, and three of the six stated that it reinforced what they are already thought but did not know what to label as their reactions. The results shown in Figure 6 confirm this data as not one participant chose the option of "never" to evaluate how AG

affects them. While there are a few "all of the time" responses, most responses fall within the "regularly" or "occasionally" categories. This can be interpreted as most participants are aware of AG or possibly that they are ignoring or making excuses to not deal with the aging decline of their parent. This first step gained their attention and inspired them to complete the journal. To illustrate, all participants expressed a felt a sense of loss due to occasional decline of their parent's physical or mental state. Further, five of the subjects thought about their parent's aging and were saddened about the time that has passed.

	All the time	Regularly		Occasionally		Ne	ver
1. Loss	0	5	83%	1	17%	0	
2. Behavior/Feelings	1 17%	4	67%	1	17%	0	
3. Thinking	0	5	83%	1	17%	0	
4. Feeling	0	3	50%	3	50%	0	
5. Physical	0	4	67%	1	17%	0	
6. Pain/Pleasure	0	1	17%	5	83%	0	
7. Spiritual	2 33%	3	50%	1	17%	0	
8. Dreams	0	5	83%	1	17%	0	
9. Self	1 17%	3	50%	2	33%	0	
10. Support	0	2	33%	3	50%	0	

**Figure 7**. Survey results evaluating AG effects on the participants.

During the journaling, there were many surprise remembrances and some inability to express exactly what they felt at the time of certain memories, but it was great to see them all together. Many could not recall certain people but often described the scene with details of the surrounding, such as "the cod were everywhere on the shore, and Dad just couldn't help himself by making a fuss and having a blast making jokes" and "Dad always loved basketball and told us how he learned to play with the neighborhood boys on a small neighborhood court—all hours of the night with little light shown on the court." Another one spoke of how she holds her father in great esteem due to his embrace of religion and charity. Surprisingly, she focused on describing what he has done for people in detail but not how she felt when she witnessed these acts; the

church was more prevalent in some responses, as she saw it as most significant to him. She claimed, "Dad was the best saxophonist ever," and "music, music, music was what he has loved; that is why I learned the sax too." She listed all the musicians he enjoyed and immediately described a place in Denver where he would go to listen to jazz. Again, she mentioned specifically the moment and place—not what his expressions were or how she felt. She also referenced traits that inspired her participation and involvement in her own church.

And while five of the six participants commented positively on family being a large part of the parent's being, one showed lack of connectedness with their mother's decisions or motives, and there was almost removal from emotional sharing. She claimed, "she was never one to share much," and "that's just the way she is, that's mom-mom." This lack of depth in the journal from this participant could have been due to a revealed unorthodox upbringing where there was a lot of moving or introverted personalities. She wrote a lot about "stories about mom's childhood" and "she had a challenging childhood with her mom and that whole situation, but she had a fun childhood." So even though there was an emotional distance between them, she expressed admiration in many parts of the journal that acknowledged a challenging life. This participant also considered herself more emotionally connected to her father, who passed away in February 2022 unexpectedly. She had also been physically distanced from her parents since her early 20s and combined with these factors could have influenced her journal.

My third premise in this study was that design thinking methods such as affinity clustering and photo collection, i.e., the themes that emerged from the revealing journals and the physical search and touch of photographs, allowed for more than a distant memory to transpire, but rather transported some participants back to the time it occurred to experience how it *felt*. For one participant, the search for photos has been an ongoing habit for the past few years. Every

opportunity she has when visiting her parents is an attempt to remember now before the parents are gone. For this project, she expressed, "I was actually tearing up remembering how he had to always stay productive, always had to be doing something; and now he cannot do those things he loved to do like fish." Her memories became more of a mindful experience that allowed her to admit and accept his aging decline. She reiterated that the search for photographs was most enjoyable of the methods. There were laughs with her sister, discussions with her two young boys, and comfort. Along with these feelings was an overwhelming shared feeling of guilt, where five of the six felt at least some guilt in this process while viewing hardship or other losses to illness or age. But most offered that they believe their lack of time spent with their aging parents cannot be helped and is natural.

In the journal, five of the six participants viewed their parent's commitment to family as so admirable that they now aim to create as many all-family events as possible before they are unable to participate. Only one participant, who has been an emergency room nurse for more than 20 years and deals with aging people and decline from a medical perspective, voiced that she did not feel guilt. Her responses were somewhat reserved; she said, "I am not the touchy, feely type anyway, but this was cool." Yet surprisingly she shared that this "jot" down memory lane inspired her to seriously consider what she had pondered for some time. The importance of the summer camp to her father and what it meant to their childhood led to her search for a home closer to her family for her parents. She worked with her sister, another participant in the study, and together they purchased and closed on a one-level house this October 31, 2022, just two miles away. It was not a difficult task to convince her parents to move, as the original family home has 13 steps, and their father is 86 now. While no serious accident has happened, she feels more at ease knowing they will be in closer proximity. She shared with the researcher that this

study gave her the push she needed to make it easier for them and her and made her think more about the impending loss.

Overall, the consensus pattern of results suggest that the positive connections emphasized in this study were felt uniquely by all participants and all gained some understanding of what AG is and how they might be able to address it. This notion was supported by the results of the final stage in this study—the artwork creation and reveal—that was planned via Zoom and completed within 7 days for each submission of photos. Two participants were late turning in the journal and photos, but factors such as a hurricane in their region and commitments at work played an understandable part. The researcher remained flexible, yet once scheduled, all participants attended the Zoom sessions on time. When the Zoom session was planned, the researcher sent a reminder with the link 3 days before via email.

The first question was created to illicit simple phrases and reaction to the question "While viewing the artwork, can you please describe your emotional reactions, any *feelings* or words that come to mind?" The results were positive for all participants, and they had much more to say as they viewed their personalized art on the screen (Figure 8). The researcher found that conversation increased after one gave the phrase "a life well-lived" when describing what she saw while looking at her artwork. She continued for almost 3 minutes describing what that meant, how "he has done everything he has wanted and still does," and "I don't think he has any regrets except that his one illness in his earlier years prevented him from accomplishing more in his profession, and I am not sure he thinks of that as a failure of any sort." Having the ability to speak aloud seemed to naturally encourage more reflections.



**Figure 8.** Cumulation of subjects' first words and expression while viewing the art for the first time.

Then when asked if seeing their personal photographs turned into artwork makes them feel closer to their aging parent, most said yes, and then began explaining aloud what certain locations, moments in the parent's life meant, and what different people in the photos meant to their parent or themselves. There was laughter and fluctuation in their voices and nods of heads, and even hands over their mouths when viewing certain photos. The emergency room career nurse made revealing comments about why she thought that her sister "might be more emotional about the artwork because she hasn't been here to deal with the gradual aging decline." She continued, "there is a great deal of responsibility and groundwork" that falls on her; and "that is just the way it goes, and I am okay with that; that's what I do." As she was prompted to comment on the photos in front of her on the screen, reassuringly she said, "Yep, that's him; that was our wedding, he loved dancing, always doing something," and "that picture in the upper left is us at the camp, always at the camp (pause)—his happy place" (Figure 9).



Figure 9. Participant's artwork that emphasizes large photo as center focus.

She then moved on to more reflection and stated, "a good life, one that I know will not be for much longer, but I see a good life." The researcher noted that this participant is very active in fundraising and events at her Catholic church and often posts on social media events to help others locally or worldwide such as a drive for Ukrainian children during the current war. She also has an autistic grandson who requires a great deal of guidance at time, something she has lovingly embraced since retiring from full-time nursing.

More physically distanced from her parents than her sister who completed the study also, 1 participant chose her father as a subject. She said that she was not surprised they both chose their father over the mother because she is more "closed off." In the past 21 years she kept in touch as best she could, but it wasn't the same as her sibling, who was local in Newfoundland and close to her parents. While viewing her art, she was shifting in her chair and smiling when she noted that "Ha! That photo, right there—that is, well (pause)—dad. We would go to camp

and have fun every chance we had, and that dog Sandy. He loved his dogs." She went teary-eyed, let out a chuckle and smiled and rocked a bit, "Yes, that is dad's favorite person, his brother in the upper left hand there; see him there? He meant the world to Pop." She closed with, "seeing dad's life like this is really something. We always danced together, any moment he could, loved to dance" (Figure 10). This participant naturally kept returning to moments they shared together, as she continued to examine, react, and describe the moments she had chosen to represent her connection to her father. The word "sad" was mentioned only once, and she explained he was never a sad person and would think it was silly to be sad because he "has had a good run."



Figure 10. Participant's artwork that emphasizes focus on prideful accomplishments.

Very few prompts were necessary once the talking-reflections started for each question.

Placement of the bible behind other photos meant a great deal to one participant, as she believes the image emphasizes how faith holds all aspects of her father's life together. She will be

enlarging her artwork and framing it to give to her father (Figure 11). She noted, "That is so awesome. It reminded me of how important caring for others is, and what holds it all together is faith. And ironically, he was never religious a religious man earlier in life, not until he met mom. Then it was his whole life, and he gave that to us---inspired us." Others noted similar reactions to larger photos used in their artwork, noting that the importance of certain elements in their parent's life were accurately reflected and made them feel proud (Figure 10).



Figure 11. Participant's artwork that shows religion encompasses all else for living parent.

While participants discussed whether the art creation of their photographs allowed for new or enhanced feelings of connectedness between their parent, their clarity emerged as the discussion continued. The researcher interjected only with the promoted questions to allow contemplation and raw reaction to occur. Lessons emerged as they began to make connections between each moment as it pertained to their parent---and as they spoke to the researcher---it

became clear they had more to say as the process went on. One commented, "this really taught me to take time to 'listen' to my dad," and "I think I need to 'track' behind him instead of ahead



Figure 12. Participant's artwork reflects similarities that most connect to the parent.

of him, if that makes sense?" She commented on how much she focused on sports when
choosing the photos and how she naturally was inclined to have the same interests as him:

"There you have it; that is why I have always felt so much like him; we think a lot alike." This
participant and 4 others became noticeably moved when describing moments shown in the
photos and how those moments helped shape their upbring. One stated, "It's different to bring up
memories and chat about them time to time but seeing the photos at those different stages in my
dad's life triggers a different feeling, (pause), a reaction to the memory." Collectively all said
they appreciated this opportunity to express themselves as they viewed their chosen photographs
as art (Figure 13 and 14).



**Figure 13.** Participant's artwork centered on her parents' marriage wherein all photos focused on role in family.



Figure 14. Participant's artwork shows mother's childhood and upbringing significant. Family connections to her Native American roots and large family. Also noted was her mother's accomplishment of earning a doctorate degree in nursing at age 65. Her dogs as well still remain important to her, so you included many in her photo submissions.

Lastly, they were asked whether photographic art creation and design thinking can help other people with aging parents recognize what anticipatory grief is, how it affects them, and how it can help address it. The participants shared their views about this type of study helping others with the following comments:

- 1) AG is more apparent now and affects emotional well-being
- 2) The prototyped artwork brought up a lot of positive times that allowed for a focus on positive attributes and pushed aside aging decline issues
- 3) Helped her understand why she is so close to her father
- 4) Helped her think about upcoming decline in a more natural/positive way
- 5) Felt like a mini-lesson in preparation for what she will feel when death comes
- 6) Taught that you need to take time to get to know your parents now as they age because it will create too much regret in the future
- 7) Felt like a living celebration
- 8) Made her realize that she sees herself in her mother

The final talk aloud reflection showed a consensus that design thinking methods and addressing AG may help people think about their aging parents' decline in a positive way. The "call to memories" made an impact throughout all stages of the study, and the end results inspired them to spend more time with their aging parents.

# Chapter 5

# Discussion

Loss of a loved one such as a parent can affect a child for life, and yet when the parent reaches the ages between 70-90, the focus of grief studies is often centered around those with mental or physical decline that warrants them incapable of independence. Palliative care is often

mentioned with grief experience or long-term illness (Kezirian et al., 2018; Wallace et al., 2020; Worden, 2018). But most people like the participants of this study, who try to balance personal lives with attention and time given to parents, who are naturally physically and mentally declining are dealing with a much different situation and need education on AG. Since the beginning of the COVID-19 pandemic, just as professionals "are unclear" about how to identify how people now can deal with grief, as discussed in work by Wallace. et al (2020), people with aging loved ones often don't know what they can do to address their feelings. Most people of this study acknowledged their awareness of possible extensive long-term effects grief can have for some people. Also, noted in studies by Parkes (1996) and Shear (2011), while studies regarding grief identification and counseling have increased, there has also been an increase in complicated grief. Whether due to the COVID-19 pandemic or other variables such as physical distance, there was a shared awareness that the participants of this study were able to identify AG and what is involved. They now understand AG as "grief as a *process*, not a state" (Parkes, 1996; Shear, 2011).

There is at least a chance that when participants view their photographic artwork in the future that the steps experienced here will trigger those positive emotions as they *see* and *touch* photographs of their aging parent; for they found comfort and deep feelings of appreciation embedded with "a bit" of sadness. The latter will always remain with any loss, but why not give people a sense of hope through a prototype as their parent continues to age? What is interesting about these findings is that they support the work by Robert Neimayer (2016) and Gershman and Thompson (2018) who emphasized a focus on "what gives you joy" in their bereavement studies. The focus on the positive thoughts creates a positive process. They specifically emphasized that the process can help people connect with grief through a visual process. This study highlights as

noted in the works by Simon (2013), that the focus on the timing to address grief is hard to predict.

Reflecting on journals written in her 20s, this student researcher now reads about her feelings, visions, and reactions while, as a flight attendant for Pan American Airways, she watched 407 young miliary men in the thick of the Gulf War in 1990, depart in the darkness of the Middle Eastern runway. Reading her words of "heartbreak and internal turmoil about these babies going off scared into the unknown" brings back the memory of the event and recollection of facts and details but not the feelings felt at that time. The "poor, young, taped-up-glasses" of the soldier from Nashville, Tennessee, is in a photo somewhere; yet the feelings felt at the time of journaling are distant. We simply write and reflect for in the moment or immediately after expression and often do not return to those journals. But there is great use in what others can see in those journals that may help address anticipatory grief. In the case of six women journaling in this study, the objective was more reflective than immediate. We often keep past emotional events private in journal writing; but if others were to look for thematic clusters, and complete affinity clustering to identify themes we are incapable of seeing ourselves, certain complex emotions and raw sadness of the experience could emerge, allowing us to be better prepared to deal with impending loss. Continuing works by Hannah Snyder et al. (2015) show clear clinical focus on studies regarding the benefits of spirituality and well-being, including in cases of bereavement and loss.

Grief affects the well-being of and the ability of sons, daughters, and anyone close to an aging loved one between the ages of 70-90, who witness aging decline. Personalized addressment of predeath worry and pre-dependency concerns is usually accessible to those with parents with serious illness or incapacitation due to illness such as Alzheimer's or Parkinson's,

where the decline is expected. Very closely related to work by Hemer (2018), with naturally aging parents between the ages of 70-90, the participants of this study concluded that grieving their parents "before physical death" may well change the nature or extent of grief that occurs after physical loss.

The participants also noted that they had never considered how the anticipation of decline affects them both mentally, spiritually, and physically presently, but they do worry about the future. They all agreed that each experience or relationship brings a great deal of complexity to the table. By completing first, the altered grief survey, originally intended for post death responses, all participants felt this first step helped them become aware of what they were feeling. Two shared that they felt validated knowing that there is a name, AG, for their emotions while dealing with their parents' decline.

The research of memory expands greatly into how a person interprets the past; and studies often delve into negative recall as determining factors or as a primary influence on self-identification and group identity later in life being shaped by past experiences (West, 2014). The design thinking method of affinity clustering gave the study the necessary *removed* feedback that revealed the major connections in the journals. Chosen at random for their nurturing engagement with students at a community college, two female student services colleagues assisted the researcher. If those looking for connections in such personal, heartfelt journal responses know the participants and their relationship with their parents, there could be inadvertent bias. There were multiple returns to the clustering after discussion and relabeling after the first participant's journal was deciphered, the flow of ideas and the *seeing* of the themes became more apparent. Attributes such as charitable spirit, humor and wit, education, and work ethics were commonly highlighted.

There are clear limitations of this study given the small group of six, all female participants. Having this group known to the researcher makes the study very limited in what they were willing to openly share. Perhaps they left out certain details they did not feel comfortable sharing, or perhaps the researcher felt at times uncomfortable learning certain information. A more general study with a higher number of participants who do not know the researcher would be best; though two of the participants were distant cousins in Canada and offered robust feedback. Most participants are religiously involved to some extent with their Catholic or Christian churches, so therein they were opened to share emotions. Perhaps an open study to various types of religions or those with no religious affiliation would add to a broader consensus. This study showed them how to define and recognize anticipatory grief (AG) that can affect their outlook and reactions to the decline of their loved one now; yet how each may go about addressing what is to come is not necessarily formulaic due to certain variables. Most noted are the following influences: the geographic closeness to the aging parent, the recent loss of the other parent or another close to the participant, and personality traits. Shown to influence how the participant reacted to the methods in this study was also affected by personal and professional time constraints, COVID-19 illness, and natural disaster.

More limitations of this study could involve the artist selection and limited explanation of the affinity clusters. The photographer/graphic artist used for this study has one vision, so perhaps a software might be created with different types of design to inspire participants differently. For instance, if someone is more into pop art, or certain types of design, then they could choose that from an array of design types. Such different design could alter the responses. Also, after the affinity clusters were created, it would most likely illicit more insightful responses if the researcher scheduled even a 15-minute explanation of the clusters. While the clusters are

clear, discussion and verbal expression of their reactions to the clusters might offer more insight.

And lastly, more in-depth studies of historical photographs and how people react to photographs could have added a bit more insight to the researcher's vision.

In 2022, we are accustomed to viewing photographs of all sorts that populate our smart phones, social media sites, and in advertisements. When viewing the past, however, "photographs can be used to change and modify our memories" (Hyman, 2013). The consensus of happiness experienced by all six participants in this study showed that addressing AG can assist to some extent a person's mental and physical well-being, and that design thinking and photographic art creation can help. The questions remain whether a person who has aging parents can feel relief and become better prepared to deal with continuing decline in a healthier way. This study highlights, however, that people can benefit from understanding what AG is and how they can address it, and how design thinking can help them feel and think more positively about their parents' lives and their relationship with them today.

# **Appendices**

# **Appendix A**- Likert Scale Grief Survey

This survey is emailed to participants immediately after the consent form is received:



Welcome to the start of the research! Please follow the directions below and email your completed form to <a href="mailto:dstanbach@radford.edu">dstanbach@radford.edu</a>.

This survey was adapted from the Grief Assessment Inventory-Survey Regarding Anticipatory Grief (AG) © 2001 John M. Schneider. All rights reserved] and wording from Holm, M., Alvariza, A., Fürst, CJ. *et al.* Psychometric evaluation of the anticipatory grief scale adapted to suit AG from the original survey to address post-death grief; adapted to address AG in family members of healthy, aging parents.

There are a series of paragraphs below that are paired. The first step is to *recognize* that you experience anticipatory grief (AG) for your healthy, aging loved one because of certain *physical* or mental decline as they age.

- 1. For each paragraph, check the occurrence that best describes your response. See the range below in the survey. Not all the statements will apply completely. You may wish to underline statements within a question that do apply.
- 2. After marking the range for each question below, you feel best applies to your current state, use the chart to mark your responses.
- 3. Follow the directions given with the chart, and you will distinguish how aware you have been of anticipatory grief. By the end of the inventory, you will have an idea of how often AG influences your feelings associated with your aging loved ones.

Mark your response and keep all answers handy for the final tally.

# #1. How have you noticed or commented on changes or occasional decline in your parent' physical or mental state?

The way I am feeling makes sense in light of their age. These losses or changes I have commented on to at least my spouse or partner, one of my siblings or close friends in regular discussion. Others have validated my concerns. My loved one may forget an event, mix up a memory, get tired, or is unable to complete a physical task that they used to handle. I may have discussed these declines with siblings or other family members. It saddens me when I think about their decline at length.

#### For me this item is most like:

	All the time	Regularly	Occasionally	Never	
Put a					
Under your selection					

# #2. Your feelings about their physical changes with age.

I wish my parents at times looked better. I sometimes feel like I ignore my concerns-push them aside. Sometimes I feel better about my parents or make excuses for their lapses, but eventually I feel sad (maybe even just a bit) about their aging. I am aware of life's fragility due to my parents' aging process. I sometimes do not discuss my parents' decline and keep it to myself and stay busy with other family, work, hobbies, or sports to avoid thinking about it. At times I feel like I am overacting.

### For me this item is most like:

	All the time	Regularly	Occasionally	Never
Put a				
Under your selection				

# #3. After thinking about your aging parents, how has your thinking been affected?

It's hard to concentrate when something even small has happened with my parent(s) (a fall, mental delay, etc.) but I can if I have to. There are times when I am saddened that time has passed after daydreaming about my parents' aging. At times, I can think about other things than this—only to find myself right back in it. I can lose myself and feel a sense of guilt, perhaps ponder what I will do in the future as they continue to age. I try to embrace our time now that we have left together.

I find myself at times pondering what is next as they age. I am often aware of what I have lost or what has or will change.

#### For me this item is most like:

	All the time	Regularly	Occasionally	Never	
Put a					

# #4. How have your feelings been affected while thinking about the limited time you have left with your aging parents?

My heart feels heaven at times. I can get frustrated about the impending loss. I can be very sad. I dismiss thinking about the inevitable. There are times when I can laugh, appreciate our time together. I can feel joy, and these are times that mean more to me. There are times when my feelings can overwhelm me. Sometimes I am feeling bad, thinking about more time I should have spent with them. There are times when I feel terrific and embrace our time, feeling fulfilled and accepting. Then there are times when I feel like I am not doing enough.

### For this item is most like:

	All the time	Regularly	Occasionally	Never	
Put a					
Under your selection					

# #5. How do you feel *physically* when thinking about or dealing with issues that arise due to your aging parents? Say a fall, lack of stamina, or a noticeable mental error?

I can start out a day feeling okay and get a bit wiped out during the day. Sometimes any sustained effort to dismiss an impending or current issue can sometimes exhaust me. I may feel lethargic, totally drained, lacking in energy. It sometimes affects my sleep. I have trouble staying asleep if something has happened. My heart can hurt, but I feel better after I exercise. I do better when I'm active.

#### For this item is most like:

	All the time	Regularly	Occasionally	Never	
Put a					
Under your selection					

# #6. How do you feel pain and pleasure when thinking about or dealing with the fact of your parents' aging process and their limited time?

The pain comes and goes. There are times when the impending loss takes away from my enjoyment of things, but other times I'm okay. There are times when something that is ordinarily pleasurable isn't as enjoyable because I think of my parent(s) and their limited time. When around them, I feel more relief from the pain than real pleasure. Except when I am reminded of my impending loss, I can enjoy life. I have a sense of humor. I can laugh. I enjoy being in nature. I watch sunsets and/or sunrises. Sometimes a time of joy produces tears and sadness because I think of my parents and their decline or how many years we will have them around.

## For me this item is most like:

	All the time	Regularly	Occasionally	Never	
Put a					
Under your selection					

# #7. How have these thoughts of impending loss affected you spiritually?

I pray for strength to get me through this. If I lose them it will seem unfair. I recognize that I am naive to think this couldn't happen. I am sometimes confused by what this means. I will have lost something essential. A part of my life's story will lose its thread of meaning. My religious faith (or another higher power) is getting me through this *or* I'm changing (or know I must change) some of my most cherished beliefs. I feel (and hope to maintain) a connectedness to something beyond me —e.g., a Higher Power, God (or love). Getting through this will heal me—something better lies ahead. Being in nature restores part of my soul that will be lost when my parents are no longer here. Sometimes I lose sight of my faith— but I am sustained by knowing others believe in me. I don't yet know what meaning this loss will have.

#### For me this item is most like:

	All the time	Regularly	Occasionally	Never
Put a				
Under your selection				

# #8. What are your dreams like?

I dream often to some extent, but I don't usually remember them. I wish I would dream of past experiences with my loved one but do not. When my dreams involve the past or future and my loved one, they are usually vivid and clear, and they are often comforting. There are lessons imagined from my aging loved one. I wish there were more remembrances of past experiences with my loved one in my dreams.

#### For me this item is most like:

	All the time	Regularly	Occasionally	Never
Put a				

# #9. How does the idea of losing your parent(s) affect how you feel about yourself?

My parent (s) natural decline has put me in touch with my "best self." I think about some of my values and beliefs. There are things about these possible losses that I need to process. There are some things I need to rectify before they are gone, and that will help me feel better about my role as their child. The more my parent(s) age and decline, I sometimes feel that my commitment is greater than others acknowledge. I am doing the best I can.

### For me this item is most like:

	All the time	Regularly	Occasionally	Never	
Put a					
Under your selection					

# #10. What kinds of support do you have?

I feel comforted when I'm with sympathetic people. I get uncomfortable when the conversation centers on my parents and their aging decline. I respond when someone is warm, persistent, and reassuring. I enjoy listening to others. Sometimes I feel like I talk too much. Sometimes I am vulnerable in ways I wouldn't be otherwise.

I am reassured by the presence of friends or siblings who will listen to my story. I feel connected to people with similar situations of impending loss.

#### For me this item is most like:

	All the time	Regularly	Occasionally	Never
Put a				
Under your selection				

# How To Calculate Your Profile:

Repeat below your responses to each of the items above. Total your stars in each section and find the total below: All the time, Regularly, Occasionally, and Never.

# How To Interpret Your Scores:

	All the time	Regularly	Occasionally	Never
1. Loss				
2. Behavior/Feelings				
3. Thinking				
4. Feeling				
5. Physical				
6. Pain/Pleasure				
7. Spiritual				
8. Dreams				
9. Self				
10. Support		_		
TOTALS				

All the time: If you scored highest in this category, you seem to be already well-aware of Anticipatory Grief (AG). In most instances, you are clearly grieving normally and would most likely gain new perspectives as you explore how your healthy, aging parents affect you. Addressing Anticipatory Grief (AG) can assist you.

**Regularly:** If you scored highest in this category, you are most likely aware of Anticipatory Grief (AG) at certain times. You most likely use work and other commitments to distract yourself from the issues regarding your aging parent(s). In most instances, you are grieving normally and would benefit from exploring how your healthy, aging parents affect you. Addressing Anticipatory Grief (AG) would benefit you.

Occasionally: If you scored highest in this category, you are more likely pushing aside the issues related to your parent(s) decline. There are instances when you acknowledge your healthy, aging parent(s)' issues but are not quite sure how to identify or label the effects their natural decline has on you. Depending on your relationship with your parent(s), you may distance yourself from close connectedness on some level. Addressing Anticipatory Grief (AG) would benefit you.

**Never:** If you scored highest in this category, you most likely do not know how to address the natural aging decline of your parent(s). It would help you on many levels to explore your connectedness and address Anticipatory Grief (AG).

# **Appendix B**- Collecting Memories-Journaling: Email and Directions



Dear Participant,

Attached please find the Memory Journal questions for your completion. You may use your personal computer to answer the questions in the Memory Journal. Please return the journal to me via email by August 20, 2022.

#### **Directions:**

As you work through the questions below, be truthful - be authentic - don't leave anything out that will help you get to know the one you love so well. Please remember that any information shared is for the sole purpose of this study. The more complete your answers, the more authentic the results will be. If some questions don't apply or you don't feel comfortable sharing, simply leave them blank. If possible, set aside photos that reflect that time [of the person, scenery, particular times in life...etc.]

As you remember and share, may your spirit begin to connect with your loved ones as they age.

Please put your responses <u>below</u> the question or on the same line. You can respond in list form or full-sentence response. If you do not know the information asked, please leave blank. Your participation is greatly appreciated.

Identify your relationship with the aging adult: only child, one of many siblings...etc. Is he or she your parent, aunt or uncle, or companion/close friend? How old and in what condition of health is he or she?

# **Topic 1: Relationships & Shared Stories**

Does the participant have a nickname(s)? What details can you recall about how your parents or parental figures met or courted? Or if they departed early from your parent's life (death or divorce), what stories has she or he shared with you?

Please share any stories that you have always remembered about your loved one (s) (even if they are just rumors about them).

What can you recall about your grandparents' relationship(s) with your parent (s). Mention good memories.

What kind of relationship do your children or nieces & nephews (if applicable) or grandchildren have with your loved one?

Any other important inter-generational relationships?

How would you describe his/her outlook on life? Please describe as completely as possible.

Would you describe the participant as quiet or outgoing or something else?

# Topic 2: Stories of childhood & upbringing they have told you about

What education level did the participant reach?

What did the participant major in? Was there Did he/she ever serve in the military?

Which branch?

Where?

Any stories you can recall that bring a smile to your face or pride?

# Stories about teen and young adult years & items of significance-outlook on life:

What did (does) he/she do for a living? For what company? For how long? Had (has) he/she retired? Did (does) he/she enjoy the work? Why and to what extent? Are there any stories about his/her work life that you remember? Share one or two. Did he or she have any pets? If so, please describe them and what you remember about their relationship.

Does he/she enjoy music? What kind? Any favorite songs that you can recall? Name three things he/she has enjoyed doing. Did he/she have any obstacles to overcome in his/her life?

# **Topic 3: Spirituality**

What do you think he/she would say were the biggest achievements of his/her life (other than having and raising family)?

What do you think he/she was most grateful for in life?

What was the most important thing in life to him/her (other than family)?

Do you think he/she had any regrets about his/her life? If so, what might they have been?

Is he/she a religious person? If so, to what extent? Does he/she have a church or synagogue or mosque?

What special memory of him/her do you have - something you have done together or something he/she said or some quirk he/she has?

What would you say might have been the greatest day or days of his/her life (other than children being born)?

Is there some phrase or words he/she always used - some expression uniquely his/hers? What did it mean?

Is there something about him/her that most people wouldn't know? Perhaps a hidden talent or habit or way of doing something...

Is there anything about the city or place where he or she grew up that has left an impact on you? What brought him/her to this city or place?

# **Topic 4: Leaving His or her Mark**

Was (is) he/she involved with any clubs or other organizations? Did he/she hold office?

What are his/her favorite pastimes or hobbies? What talents or skills did (does) he/she have? What trait or characteristic or value do you think he or she would most like to pass on to the next generations?

How do you think he/she has most influenced the lives of those he/she knew?

If he/she think that stranger would describe him/her?

What do you feel is his or her greatest accomplishment in life?

How do you think he/she has most influenced the lives of those he/she knew?

If he/she think that stranger would describe him/her?

Are there things you think might be important for us to know about him/her that we haven't asked?

What three words (at least three - feel free to use more) do you think best describe him/her? What makes you love him/her?

After you complete the journal:

- 1. Upon completion, please email the file to <a href="mailto:dstanbach@radford.edu">dstanbach@radford.edu</a>. Use the Subject Line: Collecting Memories

  Journal. Please send only a file or a "copy and paste" document in the email body. Do not send a photo of the questionnaire to ensure readability.
- 2. Your affinity cluster will be returned within 7 days with themes for the next step-the Storyboard. Please look for the Storyboard email with directions. You will have two weeks to round up those photos and images.

Thank you so much for your participation in this study!

Sincerely,

Dianne Stanbach

# **Appendix C**- Affinity Clustering explanation and examples

**Affinity Cluster:** Upon collection of journals, the researcher analyzed and distinguished themes indicative of the participant's relationship with the aging parent:

Understand what themes are most important to the participant Identify connections between the aging parents & the family member

Identify connections in data

Create hierarchies

Identify themes

Identify what factors to focus on that will support the most successful design possible from a participant's perspective.

An affinity diagram is a method used to organize many ideas into groups with common themes or relationships. Affinity diagrams are tools for analyzing large amounts of data and discovering relationships which allow a design direction to be established based on the associations. This method may uncover significant hidden relationships.

Post-It notes are a flexible method to organize ideas into various levels of groups and sub-groups. It is both a creative and analytical method & most effective when applied to a team with varied perspectives and open mindedness.

Is useful to make sense of complex apparently unrelated ambiguous or chaotic data. It makes analysis highly visible to others.

**Figure 8**. Example of Virtual Affinity Clustering: A graphic technique for sorting items according to similarities, Lumen.



Affinity Cluster Results, Luma Learning

# <u>Appendix D</u>- Email sent with Return of Affinity Cluster to Guide Photo Collection and example



# Dear participant (name):

Below you will find the results of your journaling and specific guidelines that will influence your photo collection. Please view each section and find the best matches in photos, images, or sketches and follow the directions below for the storyboard collection. Most or all of these selections will be the foundation of your personalized artwork, so you are given 2 weeks to match the criteria identified in the affinity cluster. At least 8 images are encouraged.

# The results of Your Journaling

# Barbara's zip

### Her personality & Humor

Based on the results of your journaling effort, it is clear that Barbara's ability to enlighten conversation and be 'the life of the party' is how you most identify her character most. You are drawn to her humor and admire it.

### Barbara's love for animals

#### Her heart

Based on the details you offered, you admire her caring for animals and the empathy she naturally has for all living creatures. She treats dogs and cats like they are part of the family.

# Barbara's spirituality

#### Her faith

Based on her mentioned focus on prayer and belief in God and doing good as best she can, it is obvious the Catholic religion is very important to her. When dealing with loss and during remembrance she looks to her faith.

# Barbara's role in the family

#### Matriarch

Based on your emphasis of Barbara's organization and planning the household it is clear that cooking, baking, and other household chores mean more to her than just work. Memories you recall often involve food at the center of her sharing, teaching, and nurturing. She keeps the house working like a well-oiled machine!

# **Barbara's Hobbies**

### Creativity

Based on numerous recollections of Barbara's creativity in speech writing, sewing, and arts and crafts, it is apparent you believe such skills helped define her.

# HOW WE REACHED THESE CONCLUSIONS

This information was gathered from your two (2) weeks of journaling.

Researchers evaluated all content to decipher using an Affinity Cluster method,

which grouped like themes and revealed patterns of connectedness.

These suggested themes will now lead to your storyboard creation.

# Photo or image collection instructions for the participants:

- 1. You have reviewed the journal feedback form.
- 2. Time to start digging! Find photographs of the listed elements (the themes revealed in your journal).
- 3. Place a minimum of eight (8) and no more than sixteen (16) photographs within the template provided or in another organized form, preferably an album created in Google photos. If you must create the story board by hand, then please scan your completed board and submit the image (jpeg or pdf is preferred).
- 4. You have two (2) weeks to put together the storyboard and email them to the student researcher

See examples of templates and a photo collage below.

If you cannot find a photograph example, then choose an image that reflects something about your parent (but please try to obtain real life photos).



Figure 4. Luma Template; Storyboards.

You must provide a minimum of eight (8) photos or images and no more than sixteen (16). Please upload them electronically for collection via the Google Photo app, Facebook photo album creation, or via email in any folder to be shared with the researcher. Please attempt to keep the picture size to a max of 700KM and in jpg or PDF format. If you need assistance with this stage, please contact the researcher and a Zoom meeting with instructions can be provided.



I look forward to your sharing of photos and to your reaction to your original artwork.

Sincerely,

Dianne Stanbach Student researcher

# **Appendix E**- Email Letters: Invite to participate and Consent Form

# **Invite Email**



# Dear Participant,

My name is Dianne Stanbach, and I am a graduate student at Radford University. As you are aware, I am currently working on my master's thesis where my research will focus on identifying and addressing anticipatory grief (AG) in family members with healthy aging parents or parental figures. For this study, we seek to expand identification and understanding of AG. I believe that you may be able to help me with this topic.

The study will consist of a 20-minute survey, online journaling, which should take up to 3 hours at most, photo collection, which is allotted 2 weeks but can be completed within 2 hours, and a 30-minute exit interview. You will receive personalized artwork to keep at the end of this 4-week project, or perhaps sooner depending on the expediency of your responses. We estimate that this study will take about 4 hours of your time.

I am asking you to participate in this project because I believe your perspective would help discover the connection between art creation and AG. Please respond by email to let me know whether you will participate. If you are interested in participating, you must complete the attached consent form and return it to me within seven (7) days of receipt. Feel free to contact me at <a href="mailto:dstanbach@radford.edu">dstanbach@radford.edu</a> or at 757-955-4351 if you have any questions. I appreciate your time and hope that you will work with me on this project.

Thank you, Dianne Stanbach

# **Consent Form**



# Dear Participant,

Please see below the required consent and return it as directed.

Title of Research: Addressing Anticipatory Grief with Design Thinking and Photographic Art Creation

**Researcher(s): Dianne Stanbach and Dr. Joan Dickinson** *P.O. Box 6967 Radford, VA 24142* 

(540) 831-5386 (540) 831-5719 FAX

# www.radford.edu

We ask you to be in a research study designed to address anticipatory grief (i.e., grief that occurs prior to death or loss) in relationships of aging loved ones. If you have at least one living loved one between the ages of 70-90, who is primarily healthy, you qualify. If you decide to be in the study, you will be asked to complete a 20-minute online survey, journaling for 1-week focused on your relationship with your loved one, collect photographs, sketches, or images for a storyboard for 1-2 weeks, and within 2-weeks your artwork will be created. You will then participate in a 20–30-minute exit interview via Zoom, as you evaluate the personalized art created for you by the student researcher. You will be presented with our artwork, and it is yours to keep.

This study has no more risk than you may find in daily life. Because of the sensitive nature of the topic (dealing with aging loved ones and the emotions it brings to the surface), participants could potentially become upset while brainstorming on this subject. If at any point during the study, you feel like you cannot continue discussing this topic, the discussion can cease until you are ready to resume, or you can withdraw from the study without penalty.

There is no other compensation from being in this study besides your artwork. If you decide to be in this study, what you tell us will be kept private. If we present or publish the results of this study, your name will not be linked in any way to what we present. If at any time you want to stop being in this study, you may stop being in the study without penalty by contacting: Dianne Stanbach, <a href="mailto:dstanbach@radford.edu">dstanbach@radford.edu</a> or Dr. Joan Dickinson <a href="mailto:jdickinson@radford.edu">jdickinson@radford.edu</a>.

If you have questions now about this study, please ask before you sign this form.

If you have any questions later, you may contact Dr. Joan Dickinson 540-818-1669.

If this study raised some issues that you would like to speak with a professional, it is suggested you access the free website "*The Tragedy Assistance Program for Survivors*," which encompasses all resources and information regarding support for those dealing with anticipatory grief or simply those with aging parents: https://www.taps.org/webinar/2020/anticipatory-grief

The Radford University committee approved this study for the Review of Human Subjects Research. If you have questions or concerns about your rights as a research subject or have complaints about this study, you should contact Dr. Jeanne Mekolichcick, Associate Provost for Research, Faculty Success, and Strategic Initiatives @ jmekolic@radforf.edu 540-831-6504.

It is your choice whether to be in this study. What you choose will not affect any current or future relationship with Radford University.

If all your questions have be please sign below.	en answered and you would like to	take part in this study, then
predict sign cerew.		
Signature	Printed Name(s)	Date

I/We have explained the study to the person signing above, have allowed an opportunity for questions, and have answered all his/her questions. I/We believe that the subject understands this information.

# **Appendix F- Think-Aloud Testing and Exit Reflection Questions**



Dear Participant,

I have now received your photos and images via email. Your artwork will now be created!

Please email <u>dstanbach@radford.edu</u> to give the researcher your availability the week of September 10<sup>th</sup>, 2022. The researcher will coordinate a time that works for you via chat or text and confirm via email with the Zoom link.

This final stage of the research project involves the <u>Think Aloud Session</u>, an exit interview, where your personalized artwork is revealed to you. It should not take more than 30 minutes. You can share your reactions with family, friends at this unveiling, or with only the researcher. I will document your discussion, comments and thoughts, and include anything else you want to share about the process.

# Please use the following questions as a guide for your reactions.

# Your Artwork: Reactions & Thoughts of Anticipatory Grief

While viewing the artwork, can you please describe your emotional reactions?

Does it make you feel closer to your loved one or establish a new or enhanced connection? Please be specific.

Which photos in this collage mean the most to you? Does their placement add anything to your reactions to them? In what ways?

How does the color and enhancements (size, light or dark, metallic...etc.) add to or detract from your reaction?

Do you think the steps in this study have helped you feel closer to your loved one? Which step(s) do you think accomplished this best: the grief survey, journaling, journaling feedback, storyboard creation, or this Talk-Aloud testing method? Please explain.

As you move forward, can you envision this study being helpful to you or others as aging loved

ones' decline is certain? Why or why not, and in what ways?

After this experience, do you recognize Anticipatory Grief (AG) as an influential force on your emotional wellbeing?

Would you recommend this study to others with aging parents? Why or why not? Any last comments or thoughts about the project or the results?

P.O. Box 6967, Radford, VA 24142 I540-831-5386 I fax 540-831-6719 Iwww.radford.edu

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