

THESIS

THE ART OF LOVE: USING ARTS ENGAGEMENT AS A PROMOTER OF RELATIONAL
MAINTENANCE IN COUPLES WITH DEMENTIA

Submitted by

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In partial fulfillment of the requirements

For the Degree of Master of Arts

Colorado State University

Fort Collins, Colorado

Summer 2019

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ABSTRACT

THE ART OF LOVE: USING ARTS ENGAGEMENT AS A PROMOTER OF RELATIONAL MAINTENANCE IN COUPLES WITH DEMENTIA

Previous communication scholarship has thoroughly examined the use of relational maintenance behaviors as outlined by Canary and Stafford (2003) on various types of relationships. These relational maintenance behaviors include openness, positivity, assurances, shared tasks, and networks (Canary & Stafford, 2003). However, little scholarship applying relational maintenance to contexts involving a life altering illness exists, especially from the care partner's perspective. With the rising threat of Alzheimer's Disease and related diseases (ADRD), it is necessary to better understand how these behaviors might play into interactions between loved ones. Specifically, this research explores the use of relational maintenance behaviors between partners where one person has ADRD and the other is their primary care partner as they are involved in a participatory arts engagement workshop. Data collection involved video observation during the workshop sessions and follow-up phone calls with care partners about their experience after each session. Using thematic analysis, this study implicates that participants use relational maintenance regardless of their mental capacity, and that the use of these behaviors creates tensions primarily for care partners to balance. The findings of this research encourage further exploration of the use of relational maintenance by people with a life-altering illness and their loved ones in order to understand the complicated communicative process associated with the immeasurable effects of a life altering illness.

ACKNOWLEDGEMENTS

There are many important people that I would like to thank for their help and effort in this research. I would like to extend my sincere appreciation to the therapists who led each workshop session and helped make this a meaningful experience. This includes Beth Gherardi, who was the Education and Outreach Coordinator for the Fort Collins Museum of Art at the time and the art therapist who led the mask workshops in 2017, and Alison Cope, the occupational therapist who led in 2018. Additionally, Lisa Hatchadoorian, the Executive Director Fort Collins Museum of Art was instrumental in this program. Sarah Harlow from Home Instead provided the snacks at each session which allowed for continued conversation and connection. A special thanks to others involved in recruitment and planning including Cyndy Luzinski with Dementia Friendly Communities, Angel Hoffman from Banner Health, and Dawn Paepke from Kaiser Permanente.

The research reported in this publication was supported by Colorado State University's Office of the Vice President for Research Catalyst for Innovative Partnerships Program. The content is solely the responsibility of the authors and does not necessarily represent the official views of the Office of the Vice President for Research.

I have so many people to thank for standing by me and supporting me throughout this whole graduate program, and the process of writing this thesis. Without them, this process would have been even more confusing and overwhelming. However, with them, it has been meaningful, challenging, and has expanded my horizons in more ways than I can count.

Dr. Faw, you deserve the ultimate "Thank you!" When one day I decided to change everything about the thesis I had been working on, you took a chance on me and offered me a

beautiful opportunity to do interpersonal research. I do not know how I would have gotten through this process without you. You have supported, challenged, advocated for, and guided me. Thank you for your insightful comments and for continually asking me to think deeper. You are kind, patient, and incredibly intelligent. What a privilege it has been to learn from you.

Dr. Long, you are truly one of the kindest and most patient people I have ever had the privilege of knowing. I have learned so much from you while taking classes with you, working on this thesis, and being a TA for your class. Thank you for always advocating for your students, guiding us, and then supporting our decisions. You are a force to be reckoned with and I consider myself very lucky to have been able to learn from you.

Dr. Malinin, despite having an incredible workload this year, you willingly stepped onto this committee and have offered an immense amount of insight into this project. Thank you for your support, challenges, and knowledge. This research was heavily guided by you and it was a privilege to be able to step into this project and learn so much.

Thank you, dad, for your continued support. You have always taught me to see the beauty in the world, which has taught me to dream. You are the ultimate support system because you challenge me to think bigger, deeper, and to reflect on who I am and who I want to be. Over the years, you have expanded your own horizons and have walked with each of your children as we do the same. Thank you for loving me so well and teaching me how to share that love with others. The world is a better place, and I am a better person because of you.

To mom, you are my constant support. I do not know how I would get through each day without you. You are the Lorelai to my Rory in more ways than one, and I am so thankful to have my mom as the ultimate best friend. Thank you for the pep talks, for commiserating with me, for telling me I am more capable than I think, and for doing the small things like making

sure I have a steady supply of food and chocolate. You have taught me to be bold, strong, intelligent, and compassionate. The world is a better place, and I am a better person because of you.

Nathan, thank you for being my partner and best friend. You have supported me and encouraged me everyday for the last five and a half years and I cannot imagine my life without you. When I am with you, I feel more myself than I have ever felt before and your calm spirit is the perfect balance to my *ahem* less-than calm spirit. You are one of the most beautiful people I have ever met, and I cannot wait to watch you realize and fulfill your dreams just as you constantly and selflessly support mine. The world is a better place, and I am a better person because of you.

Charles and Parker, my boys. You two have been, and remain to be, the most important role models in my life. You have taught me so many lessons over the course of my life and I cannot thank you enough. Thank you for playing Pretty Princess with me, for driving me to and from various activities, for always rooting for my successes, and for protecting me. It is a privilege to be your younger sister. Parker, you have this magical ability to make everyone feel important, loved and welcome. I strive to be able to connect with others like that. Charles, you are fiercely loyal to the people you love and would give the shirt off your back to anyone who needs it. I strive to emulate that. The world is a better place, and I am a better person because of you.

I would like to thank the members of my cohort for making me think deeper and work harder. Thank you to Jenna, Juliet, Eleanore, Erin, and Savanna for brunches, the Oscars/Grammys, group texts, dinners, and all the support in the world. You all are important, and I feel blessed to have gotten to know you. Jenna, you are bold. Juliet, you are strong.

Eleanore, you are kind. Erin, you are determined. Savanna, you are hilarious. James, you are brilliant. Brooke, you are generous. Selena, you are thoughtful. You eight will change the world.

I cannot wait to watch.

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CHAPTER ONE: INTRODUCTION

Dementia and other memory related illness affect millions of people (“Facts and Figures,” 2018; Ferri et al., 2005; Plassman et al., 2007). An estimated 5.7 million Americans live with Alzheimer’s disease, with numbers increasing daily (“Facts and Figures,” 2018). In fact, by 2050, researchers project that Alzheimer’s disease or dementia will affect nearly 106 million people, meaning 1 in 85 people will have the disease (Brookmeyer, Johnson, Ziegler-Graham, & Arrighi, 2007). Researchers are scrambling to determine what causes the disease, and while treatments are designed to slow its progression, there currently is no cure (Ferri et al., 2005).

With this illness affecting so many people, it is important to investigate various ways to manage or minimize its effects to enhance quality of life. One notable way scholars have found as an effective approach to managing the disease is through arts engagement programming. Given its creative and tactical nature, people with Alzheimer’s disease or dementia can use arts engagement to stimulate memory, create social networks, enhance mood, and maintain relationships, along with several other positive effects (Basting, 2006; Beard, 2012; Camic & Chatterjee, 2013; Flatt et al., 2015). While there are several therapeutic strategies used for people with Alzheimer’s disease or dementia such as sports therapy, speech therapy, physical therapy, and activities for daily life (ADL) therapy, arts engagement offers a unique experience (National Collaborating Centre for Mental Health, 2007). Engaging in the creation of art allows a person to engage both physical, emotional, and cognitive processes by asking them to reflect on their emotions, reminisce on their experiences, use their body to create art, and interact with others to better complete the task at hand (Gerdner, 2000). While several types of therapy may help a

person with Alzheimer's disease or dementia, arts engagement asks participants to draw on multiple skills that other therapies may not necessarily address (Stuckey & Nobel, 2010).

This paper places relational maintenance, arts engagement, and the effects of dementia on family and spouses in conversation with one another to more fully realize the relationship-building potential of arts engagement. Canary and Stafford (2003) define relational maintenance as "...actions and activities used to sustain desired relational definitions" (p. 5). In other words, people behave in specific ways in their relationship to make sure that it continues. If a connection can be made between arts engagement programming and relational maintenance behaviors, it stands to reason that arts engagement programming's positive effects on both health and communication may be more expansive than currently highlighted in literature.

Previous research states that people with dementia lose their ability to communicate and connect with people (Stone, 2013). Through identifying how often and which forms of relational maintenance the partners use, and through conversations with the care partners, this research looks specifically at the care partner's experience regarding whether they identify participatory community arts engagement as a promoter of connection with their partner. While ample research supports the mental and physical health benefits of participatory community arts engagement, little research looks at the experience of caregivers. More specifically, not enough research looks at the caregiver's perception of participatory arts engagement as a promoter of connection between them and their spouse with dementia. Through this research, I begin to uncover the extent to which partners where one person has a memory related disease use relational maintenance behaviors, and the extent to which arts engagement can play a role in maintaining relationships between partners.

The next chapter looks at previous research on dementia and other memory related diseases, participatory arts engagement, and relational maintenance to highlight the gaps in current research form an argument in support of this research. This chapter also presents the research questions used to collect data. Chapter three looks at the methods used to collect and analyze data to answer the research questions. The fourth chapter outlines the findings and results whereas chapter five includes discussion of the findings, their implications, limitations, and directions for future research.

CHAPTER TWO: LITERATURE REVIEW

Alzheimer's Disease and Dementia

With the rising prevalence of Alzheimer's disease or related dementia (ARD), researchers have sought to investigate what causes the illness and its effects on the people diagnosed with ARD, as well as care partners, family members, support networks, and friends. Scholars define Alzheimer's disease as a type of dementia resulting in a decline in cognitive function which occurs over time until a person becomes incapable of completing daily tasks of living, as well as remembering family and friends (Mace & Rabins, 2001; "What Is Alzheimer's?," n.d.). ARD is a progressive brain disorder caused by amyloid plaques and tau tangles that form in the brain due to abnormal protein deposits ("Alzheimer's Disease Fact Sheet," n.d.). The amyloid plaques and tau tangles cause once-healthy neurons to stop functioning properly, leading to their eventual death.

Early symptoms of ARD include difficulty remembering newly learned information, but ARD is degenerative, meaning that as it progresses, a person may face mood and behavior changes, confusion about events, time, places, general disorientation, and difficulty swallowing, speaking, and walking ("What Is Alzheimer's?," n.d.). Alzheimer's disease is the sixth leading cause of death in the United States today and people with ARD live an average of 8 years after diagnosis, although that span can be much shorter or longer depending on the person ("Alzheimer's Disease Fact Sheet," n.d.; "What Is Alzheimer's?," n.d.). Since the scope of ARD research is so broad, this study focuses on the barriers to communication that memory and cognitive issues create for the person with the disease, their care partners, spouses, and families.

When diagnosed with ADRD, one of the main barriers a person may face is communication (Stone, 2013). Past research has looked at the communicative patterns of people experiencing cognitive impairment in several different contexts and found that these issues have largely negative effects on the person, their family, and their caregivers (Kindell et al., 2014; Stone & Jones, 2009). One study highlighted how a specific type of dementia, called semantic dementia, manifested for one family. In semantic dementia, recent day-to-day memories are relatively well-preserved, meaning that people are able to live a relatively normal life as long as they engage with people and activities that are familiar (Kindell et al., 2014). However, the eventual loss of semantic knowledge leads to difficulties in finding words along with significant difficulties in understanding the speech of others (Hodges & Patterson, 2007). Although previous research emphasizes that this process is gradual, a main tenant of dementia is the loss of ability to communicate with loved ones. This can have strong negative effects on a person's loved ones that alter the family dynamic and function of their relationships.

Effect on families. Previous research has thoroughly examined the negative effects that a dementia diagnosis can have on families. Kindell and colleagues (2014) completed an extensive qualitative case study with one family in which the patriarch had semantic dementia. In this study, they found that the family adjusted in four areas of their life to make up for the various losses that they experienced: they learned to live with routines; to police and protect the father both inside and outside of the house; to still try to connect with him; and to be adaptive and flexible (Kindell et al., 2014). Within each of these strategies, the family members noted the difficult aspects of the situation, and how they had learned to adjust. For example, the son in the family highlighted how his dad could no longer ask about how he was doing, so instead they talked about household tasks and practical conversations, which provided some form of

connection for the two (Kindell et al., 2014). Due to the loss of communication on the part of the person diagnosed with ADRD, the burden falls on family members to adjust their behavior in order to minimize the negative effects of this loss of communication.

These changes can greatly affect the nature of these relationship, which can be a painful process for all members involved. For example, children of a parent with diagnosed early onset dementia may experience negative relational consequences because of the illness. In one study, children ages 13 to 23 reported a change in their parent's behavior and that they feared for their parent's safety (Allen, Oyrbode, & Allen, 2009). Some reported feeling as though they had lost their "real father," and that they did not know how to manage their parent's difficult behavior (Allen, Oyrbode, & Allen, 2009). Because of the unpredictable nature of ADRD, family members often reported uncertainty about ADRD resulted in stress. These families reported feeling as though they did not adequately understand the situation or the disease (Stone & Jones, 2009). They worried about having insufficient information about the prognosis, noting the lack of clear patterns or symptoms with ADRD, as well as concerns over their caregiving responsibilities (Stone & Jones, 2009). While family members experience a large shift in their family dynamic as a result of an ADRD diagnosis, other research has looked specifically at the experience of spouses and partners.

Effect on partners and spouses. For spouses, the diagnosis of ADRD can greatly change the marital relationship, especially when caring for their loved one. Spouses tend to care for their partner until it becomes unmanageable (Buhr, Kuchibhatla, & Clipp, 2006). Past research has found that the caregiver burden is significant, resulting in stress, anger, sadness, guilt, or other negative emotional states (Butcher, Holkup, & Buckwalter, 2001; Cohen & Eisdorfer, 1988; Seltzer, Vasterling, Yoder, & Thompson, 1997). In one study, husbands and

wives who typically served as their partner's caregiver reported diminished intimacy in many forms (e.g. sexual, emotional, social, physical) as a result of the ADRD (Hayes, Boylstein, & Zimmerman, 2009). Additionally, women were more likely than men to report that they struggled with their own identity within the marriage as their husband's disease progressed (Hayes et al., 2009). Another study found that family members experience enduring stress and frustration when caring for a loved one with ADRD (Butcher et al., 2001). The same study also found that family members had to deal with the loss of who their loved one used to be, while learning how to integrate ADRD into their lives to still find meaning, joy, and support (Butcher et al., 2001). Many participants explained the process of caring for a loved one with ADRD as being heartbreaking, as they watched their loved one slowly lose their capabilities, highlighting the painful grief process that comes along with an ADRD diagnosis (Butcher et al., 2001).

Past research studies have discovered that a life-altering diagnosis such as Alzheimer's disease or dementia can lead to social isolation on both the part of the diagnosed person and their care partner/family (Burgener, Buckwalter, Perkhounkova, & Liu, 2015). In fact, one study found that caregivers and care receivers had only half the number of friends as a person of the same age without caregiver responsibilities, as well as decreased support from or contact with pastoral or clergy members who were previously actively involved in their life (Burgener, 1999).

In a later study on this isolation, Burgener and colleagues found that this lack of external support can cause both people with dementia and their care partners to experience stigma (social isolation and rejection) as a result of the diagnosis (Burgener et al., 2015). Research indicated that feeling social rejection was negatively associated with anxiety, health, and activity participation for both the care partner and person with ADRD (Burgener et al., 2015). Additionally, social isolation was negatively associated with depression, anxiety, personal

control, health, self-esteem, social support understanding, and activity participation for participants. Past research has also shown that caregivers experience high amounts of isolation and other negative burdens resulting from the time they dedicate to caring for their loved one (Dyck, 2009; Jae-Seon Jeong, Young Kim, & Myoung-Gi Chon, 2018).

While research to date focuses largely on the perceived negative effects of an ADRD diagnosis on family communication and experiences, it does not present a comprehensive look at the disease. Although much more limited, some research investigates the ways that people can and do manage the negative aspects of the disease. Such research identifies the challenges and burdens associated with the disease, but also presents findings that might provide encouragement, acknowledging that a dementia diagnosis may not be as dire or unmanageable as initially perceived.

Tactics to manage communicative barriers. While family members and spouses experience many losses when their loved on is diagnosed with ADRD, Young and colleagues (2016) found that communication can still be reciprocal between families and their loved one with ADRD. They found frequent communication partners (FPCs) such as spouses and caregivers used certain strategies when they were having a conversation with their partner. FPCs yielded the floor to their partner with dementia to encourage conversation. Additionally, the researchers found that participants with diagnosed memory issues did the same, using both strategies such as continuers (saying “yes” or “hmm” when a person is talking to show you are listening) and yielding the floor (letting the other person provide input) also to encourage their FPC to continue the conversation. The researchers claim that these retained abilities on the part of the participant with dementia demonstrate conversational sensitivity and proficiency because of their ability to adjust their conversational behaviors (Young et al., 2016). Ultimately, they

argue that a person's ability to communicate does not completely disappear with ADRD, an important consideration when seeking to address the relational well-being of people with ADRD and their caregivers.

Regardless of the intensity and negative effects of these communicative changes, previous research has clearly highlighted the various ways that ADRD diagnoses can hurt or burden family members dealing with these changes in their loved one. However, previous research has also looked at the various ways that family members have tried to counteract this perceived loss of communication. Care partners and loved ones use many techniques to connect with a person with dementia to manage the losses experienced because of ADRD. Researchers have identified touch as an important source of connection (Gleeson & Timmins, 2004). Through a meta-analysis of previous research, Gleeson and Timmins (2004) highlight that physical touch can benefit both the caregiver and the person with ADRD on a physical and psychological level, reducing anxiety and increasing affection. Additionally, spousal care partners have been found to connect with their partner by asking questions (Small & Perry, 2005). Small and Perry (2005) examined the different types of questions that caregivers asked their spouses with ADRD, finding that "yes" and "no" questions yielded better communication when compared to open-ended or choice questions. However, it is important to note that a person's ability to answer any questions was heavily dependent on which kind of memory the question required them to use. The two major kinds of memory that Small and Perry highlighted in their research were episodic memory (memory of times, places, events, etc.), and semantic memory (long-term memory accrued throughout lives). People with ADRD responded much better when a question stimulated semantic memory rather than episodic memory (Small & Perry, 2005). Since communication is a central concern for families or couples managing a loved one with ADRD, it

is essential that researchers explore how these intentional efforts to improve communication on both the part of the family member and the person diagnosed with ADRD can promote feelings of caring and connection.

Even with strategies such as yielding the floor, physical touch, asking probing questions, and extensive patience, no perfect way to manage the effects of ADRD on both the person diagnosed and their loved ones exists. However, ample research suggests that the positive effects of arts engagement programming on persons with dementia as well as their loved ones show promise in addressing the relational and communicative challenges inherent in ADRD.

Participatory Community Arts Engagement Programming

Although arts engagement has several definitions, this research focuses specifically on the role of participatory community arts engagement programming for people with ADRD and their caregivers. Participatory-based arts typically consist of interactive and hands-on participation for community members, as opposed to non-participatory arts, which consist of passive activities such as observing art or having discussion about specific pieces of art (Flatt et al., 2015). In participatory-based arts programs, the people involved create art and can use it for a variety of purposes (Flatt et al., 2015). For those dealing with life-altering health illnesses, art can serve as a way to express difficult emotions and process difficult diagnoses (Camic & Chatterjee, 2013). These forms of arts engagement can take place in hospitals and clinics, but research increasingly supports the positive effects that activities in art museums and galleries may be better suited for effective participatory community arts (Camic & Chatterjee, 2013). Typically used to address public health issues, participatory community arts engagement can serve several important purposes for both people with life-altering illnesses, and their caregiver.

Benefits to communication. One important benefit of arts engagement is the ability to help people communicate feelings that may be too difficult to express with words (Camic & Chatterjee, 2013). One study focusing on three women recently diagnosed with cancer found that engaging in art as a form of therapy can assist people in coming to terms with their diagnosis while learning how to integrate their cancer into their life experience, ultimately assigning it meaning (Borgmann, 2002). Using a variety of mediums such as ink drawing, pastel sketching, and collaging, Borgmann (2002) was able to look at the ways the three women processed their feelings and came to terms with the fact that cancer was now a part of their lives. Another study, asked participants to draw their heart in three steps, ultimately highlighting what they knew about their disease and how they perceived their condition (Guillemin, 2004). Although art may not serve the same purpose or have the same effect on everyone, ample studies highlight the potential positive influences that art can exert on the power of expression for those who are struggling with serious health issues (Cohen, 2006; Flatt et al., 2015; Guillemin, 2004; Kim, 2013).

While arts engagement may help the person with a life-altering illness, research shows it can also have positive effects for family caregivers. One study looked at photojournalism course in which family caregivers of people with cancer took photographs to represent what being a caregiver meant to them (Wharton et al., 2018). Taking photographs of their experience helped caregivers communicate their experience, which can be hard to put in words. Additionally, another study found that care partners reported experiencing increased communication both with their cancer patients and healthcare providers resulting from creative arts intervention (Walsh, Martin, & Schmidt, 2004). For care partners of loved ones with ADRD, another study found that arts engagement helped cohesion between the two, allowing for better communication and

enjoyment (Flatt et al., 2015). Regardless of the type of life-altering illness, ample research supports that arts engagement programming can have positive communicative effects for both the person with the illness, and their family caregiver.

Benefits to mood. Besides helping a person process their feelings or address their identity, research shows that participatory arts engagement has a positive influence on participant's moods. Kim (2013) looked at fifty older adults (ages 69 to 87) to determine the effect of arts engagement on their affect, anxiety, and self-perception. This qualitative study found that engaging in painting and clay art helped reduce anxiety and negative emotions while also promoting a better self-perception (Kim, 2013). Another study found that involvement in a variety of arts engagement can increase morale while decreasing depression and loneliness (Cohen, 2006).

Research has also examined the perspective of the care partner and how arts engagement can influence their mood. One study, by Walsh, Martin, and Schmidt (2004) looked at the efficacy of creative arts intervention on the care partner. Results found that the forty-five care partners had significantly reduced stress, lowered anxiety, and increased positive emotions following the arts participation (Walsh et al., 2004). One outreach program, called Meet Me by the Museum of Modern Art, specifically aimed to provide a space for both people with ADRD and their caregiver. An executive report published after the event highlighted increased moods on the part of both the person with ADRD and their caregiver (Mittelman & Epstein, 2008). Increased mood for both the person with a life-altering illness and those who care for them demonstrate how the effect of arts engagement reaches beyond just one person or one health benefit.

Benefits to social isolation. While ADRD can be associated with stigma and isolation, research shows that arts engagement programming can work to minimize these negative effects. Cohen (2006) reported that arts engagement in a variety of mediums (music, visual art, etc.) can help encourage people with Alzheimer's disease to persist in various group and social activities. In that study, it was found that, in a follow up a year after the initial study, participants in arts engagement reported being involved in an increase of two activities per person (Cohen, 2006). This is important because social connection has been correlated with increased overall health (Cohen, 2006). One study found that for caregivers, meeting people in similar situations to them was very important for them (Camic, Williams, & Meeten, 2013). Consequently, research has also found that arts engagement programming can help foster social inclusion and engagement, providing a space for caregivers to meet other caregivers going through similar experiences (Camic, Tischler, & Pearman, 2014; Camic et al., 2013). Social inclusion such as that highlighted in these research studies can benefit both the person with dementia, while also providing several benefits to care partners who deal with their own challenges as a result of the diagnosis. This serves as a point of connection between the two, which is important when dealing with limited communication as a result of the disease.

Participatory arts engagement and dementia. Within the context of dementia and Alzheimer's specifically, several studies have examined the effects of arts engagement on both those with ADRD and their care partner. One researcher states that "...where rational language and factual memory have failed people with dementia, the arts offer an avenue for communication and connection with caregivers, loved ones, and the greater world" (Basting, 2006, p. 17). While a person may no longer be able to communicate their thoughts in the ways they used to, evidence presented in this section of the literature review suggests that art

engagement programming can work to fill at least a piece of that gap. In her systematic review of research, Schneider (2018) argues that creativity is not dependent upon memory. Through her research looking at art from three lenses: visual, music, and dance, Schneider examines seven different dimensions of each lens to better understand how each works as a medium for self-care for people dealing with dementia. Through questions such as who is participating, what are the outcomes, and what is the role of the person with dementia, Schneider (2018) claims that art can remain accessible despite memory loss due to its multi-sensory nature and the possibility of experiencing art in the moment, regardless of prior knowledge or talents.

Additional research reiterates a similar perspective, arguing that art offers a nonverbal way for individuals to be seen and heard as it provides alternative ways to communicate (Johnson & Sullivan-Marx, 2006). While their research used two case studies to look at the overall experience of art therapy for the elderly, Johnson and Sullivan-Marx specifically found connections to people with dementia. Through their observations of the two case studies collected through an art therapy session in a community program, the researchers argue that the artwork created by those with dementia is a “visual reminder that they can still accomplish and learn new things despite limited mobility or cognition” (2006, p.312). The fact that the researchers pulled out information specifically related to their participants with dementia when the overall study focused on the elderly overall shows that the effects for those with dementia might be significant and clearly distinguishable.

Previous research has explored some of the negative complications life-altering illnesses such as Alzheimer’s disease can create for both the person and their family, while also highlighting the ways that participatory arts engagement programming can work to minimize some of those issues. However, when looking at art engagement’s role in improving mood,

social isolation, communication, and other factors, it is important to also look at how those improvements can aid couples and families in relational maintenance.

Relational Maintenance

As ample research documents the largely negative effects that diseases such as Alzheimer's or dementia have on family and spousal communication, it is important to investigate the ways that people manage these complications and how they continue their relationships. To more fully justify this research study, it is important to understand the concept of relational maintenance. Canary and Stafford (2003) define relational maintenance as "...actions and activities used to sustain desired relational definitions" (p. 5). In other words, people use specific behaviors to ensure that their relationship continues as they want it defined (Canary & Stafford, 2003). For example, in a relationship, a person might make sure that the kitchen is clean before their significant other comes home because they know that it will please their partner. By showing that they understand their partner's wants and needs, a person is using a relational maintenance behavior. As a result, the relationship is likely to continue so long as each person agrees that the relationship functions to their liking.

In fact, Duck (1988) argues that people spend more time working to maintain their relationship than they do developing or dissolving it. If that is the case, then many people spend most of their relationships employing different behaviors to communicate to their partner that they wish to continue the relationship. This component of relationships is very important to understand because it is where most people spend most of their relationships, and it can better explain how and why people behave and communicate in certain ways during that time.

Canary and Stafford (2003a) argue that all relationships require some sort of maintenance to be sustained. This means that relational maintenance communication and behavior serve as an

essential component to the success and continuation of a relationship. However, a person may use a specific maintenance strategy during one time in their relationship but might stop using or change that maintenance strategy at a different time in the relationship because the nature of the relationship itself has changed (Canary & Stafford, 2003a). For example, a new couple might wait to tell each other that they love one another until it feels most appropriate. Over time, this behavior might become much less intentional as they fall into the habit of telling one another that they love each other. While saying “I love you” intentionally and as a habit are both relationship maintenance strategies and the meaning behind the words likely has not changed, the nature of the relationship has changed as the couple has become more comfortable, meaning that they might not use each strategy in the same way and now require a new or different relational maintenance behavior to communicate that they love one another.

Additionally, Wilmot (1975) argues that stable relationships are not static, but rather changes in the relationships are worked through and adapted to fit the needs of both participants. Relational maintenance is particularly salient for this study as this research looks at a time in a couple’s life where they are experiencing intense change as a result of dementia. After several years as a couple, many couples with a dementia diagnosis must readjust to a “new normal” as they learn more about the disease. During this time, relational maintenance acknowledges these changes and seeks to understand how couples work to come to terms with the loss of the old form of their relationship as they try to understand each other in their “new normal”. Not only does relational maintenance work to help researchers better understand how couples react to losing their old forms of relational maintenance, this framework also acknowledges that the adjustment period associated with illnesses such as dementia is continuous and consistently requires relational maintenance to ensure understanding (Canary & Stafford, 2003b). Overall,

relational maintenance is important to research on couples such as those dealing with an ADRD diagnosis because of its highly adaptive nature. As this couple transitions in every aspect of their life, relational maintenance is a framework for explaining how each partner works or does not work to sustain the relationship.

Purposes of relational maintenance. In their seminal work, Dindia and Canary (1993) argue that relational maintenance exists for one of four purposes: to keep a relationship in existence, to keep a relationship in a specified state or condition, to keep a relationship in satisfactory condition, and to keep a relationship in repair (Dindia & Canary, 1993). To them, *keeping a relationship in existence* simply means that the relationship continues, regardless of how often a pair communicate, or what behaviors they use. This means that the relationship is simply in existence with little regard for how the two interact. The relationship could be unhealthy, but each person still might use certain relational maintenance behaviors to keep the relationship in existence. *Keeping the relationship in a specified state* involves sustaining whatever relationship partners consider to be important characteristics or qualities of the relationship (Dindia & Canary, 1993). For example, a partner in a relationship might behave in a specific way to make their partner happy, even if they do not naturally resort to those behaviors. By behaving in a particular way, that person is maintaining the relationship in a specified state because they are not asking for anything to change. Instead, they want to relationship to stay as it is.

A third reason that relational maintenance exists is *to keep a relationship in satisfactory condition*. This differs from the first two reasons by highlighting the reality that relationships can be stable but unsatisfying. Ultimately, people seek to have both satisfying and stable relationships (Braithwaite & Schrod, 2014). If a person does not feel like they are in a stable

and/or satisfying relationship, they are more likely to dissolve the relationship (Braithwaite & Schrod, 2014). In keeping their relationship in a satisfactory condition, each partner might have to make certain changes or behaviors to communicate to their partner that they hear and understand them. They do those actions to make sure that both members of the partnership are pleased and view the relationship as satisfactory. Finally, some relationships require maintenance *to keep them in a state of repair*. Dindia and Canary (1993) equate this to a mechanical metaphor, emphasizing that repair can keep a relationship in a working and good state or it can fix a relationship that has fallen apart. They view repair and maintenance differently by explaining that repair refers to the changing of a relationship whereas maintenance is keeping a relationship in its current state. In a relationship, a person may work on changing some of their unhealthy habits. By doing so, they are trying to keep their relationship in a state of repair by actively changing the nature of the relationship. Through repairing their relationship, they are also maintaining its existence.

These four reasons are important because they better explain how and why people use specific behaviors in their relationships. More specifically, they are important to this research because the four reasons can better explain the ways that couples may interact when one of them has diagnosed ADRD, and the other is the care partner. Due to the changing state of a relationship when a person has ADRD, the purposes behind relational maintenance can better explain why some caregiver participants were more engaged in the arts engagement project than others. Additionally, it can explain how caregivers interact with their loved one. For example, if a person views their relationship as satisfactory, they might use different behaviors with their partner than a person who simply wishes to sustain the relationship. While currently broad, I expect the four purposes of relational maintenance to become clearer after analyzing the data.

Five Relational Maintenance Strategies. One way that researchers have used relational maintenance to better understand how people communicate in long-term relationships is through investigating the five primary communicative strategies of relational maintenance: positivity, openness, assurances, networks, and tasks (Canary et al., 1993; Canary & Stafford, 2003b). Positivity includes prosocial behaviors such as being encouraging, polite, friendly, and kind to another person (Canary & Stafford, 2003b). Engaging in positivity behaviors can be either verbal or nonverbal. For example, Canary and Stafford (2003b) note that positivity can be as simple as doing a favor for a loved one or holding their hand and giving them hugs. It can also be positive words of assurance such as offering compliments or being upbeat as often as possible (Canary & Stafford, 2003b).

Additionally, openness refers to the discussions that people have about their relationship (Weigel & Ballard-Reisch, 2001). Nearly always verbal, this requires a concerted effort to set aside time to address the relationship and can include offering advice, self-disclosure, or simply listening. Sometimes, couples will engage in meta-relational behaviors where they discuss past issues of their relationship in order to fix current issues or they identify where they have progressed to see change in their relationship (Canary & Stafford, 2003b). Assurances can take many forms, but are related to expressions of love and typically imply that the relationship has a future (Canary & Stafford, 2003b). In action, assurances can be one spouse supporting the dreams and passions of their partner, as well as overt expressions of love for one another (Canary et al., 1993).

Networks include surrounding the relationship with friends and family who offer support and a shared community (Canary & Stafford, 2003b). A partner may try to engage in networks by making friends with their partner's friend group in order to share that experience, or it could

mean forming a relationship with their partner's family. Networks can also include participating in specific activities together (Weigel & Ballard-Reisch, 2001). Finally, tasks as a strategy includes the equitable sharing of responsibility, household obligations, etc. Tasks can be unspoken agreements in the relationship, such as a couple sharing cleaning duties, or may include a person doing a task that they may not do normally for their partner.

These five strategies have the potential to be either strategic and routine (Canary & Stafford, 2003b). Evidence suggests that people use both strategic behaviors that are intentional and motivated to connect with another person as well as routine behaviors that are mundane and common behaviors. Routine behaviors occur at a lower level of consciousness and they are less mindful as compared to strategic behaviors (Greene, 1984). Understanding the difference between the two is important because it helps differentiate between what is natural in a relationship, and what is intentional for connection.

While many studies of relational maintenance focus on pro-social behaviors, more recent research has looked at various negative relational maintenance strategies (Goodboy, Dainton, Borzea, & Goldman, 2017). In their study, Goodboy and colleagues (2017) outline five negative relational maintenance strategies that couples may use. They were jealousy induction (showing interest in someone other than partner), avoidance of important conversations/person, spying on one another, infidelity, destructive conflict including fighting and speaking harshly, and allowing control (Dainton & Gross, 2008). These strategies are important to consider because they can occur in conjunction with positive relational maintenance strategies and can shed more light on the relationship and how it functions.

In relationships such as this research where one member of the partnership has a life-altering illness such as dementia and the other is their care partner, the role of routine and

strategic behaviors is important to understanding how the relationship functions as it goes through changes such as limited communication. For example, if a person with dementia says something positive to their partner, whether that was a strategic or routine behavior can shed light on the nature of the relationship and how each member interprets their connection. Additionally, routine and strategic behaviors may also highlight equity or inequity in a relationship. If one person uses more strategic behaviors than their partner, that might have implications for how their relationship functions.

Contexts of past research. Past research has supported these four reasons by looking at a wide variety of contexts to see how people use relational maintenance in their relationships. For example, one research study found that people's use of specific maintenance strategies differed across friendships, family, and romantic relationships depending on the type and its context (Canary, Stafford, Hause, & Wallace, 1993). Relational maintenance has been applied in friendships (Forsythe & Ledbetter, 2015), professional relationships (Goldman & Goodboy, 2017), online relationships (Ledbetter, 2010), dating relationships (McEwan & Horn, 2016), marital relationships (Canary & Stafford, 1992; Ragsdale, 1996), and even relationships where people have not met or one person does not exist (Eyal & Dailey, 2012).

With such a wide range of focus areas for research, few contexts do not apply to relational maintenance. While the health communication discipline is extensive, and several studies have looked at topics such as life-altering illnesses, dementia, patient-caregiver experience, and doctor-patient relationships, very few, if any studies investigate the role of relational maintenance in the interactions. This study seeks to investigate not only how relational maintenance applies to health communication, but also how it can be a form of health communication. If an argument can be made for arts engagement as a form of relational

maintenance, this study serves to branch not only interpersonal communication between spouses, but also the therapeutic benefits of participatory arts engagement.

Arts engagement as a promoter of relational maintenance. This research works to align arts engagement as a viable activity that couples can use to maintain their relationship. Consequently, it is important to understand other activities couples do together. However, an essential component of each activity is that each partner gets something out of it. The effects of dementia are significant on both the person with the disease and their loved ones and previous research shows that shared activities such as having meals together, being outside/going on walks, and watching television together serve as a point of connection for participants.

Having meals together may be common activity for many families, but for those dealing with an ADRD diagnosis, it can be particularly important. One study found that both preparing and having a meal together can serve as an important connection for families (Wong, Keller, Schindel Martin, & Sutherland, 2015). In their study, Wong and colleagues (2015) found that continued meals help sustain the identity of a person with dementia, but also can put a strain on family members as they must adjust to their loved one's condition. However, through a narrative analysis of one family dealing with dementia, Wong and colleagues (2015) also argue that meal times can provide a designated space where family members build resilience to the situation. While mealtime is important to dementia families, food-oriented activities in general can serve as important connection points for families. In her book, Emilia Bazan-Salazar (2005) identifies several activities that family caregivers can use to both connect with their loved one with dementia, as well as stimulate their memory. She suggests cake decorating, creating edible art, and other activities to caregivers (Bazan-Salazar, 2005).

Another important activity for both caregivers and their partners with dementia is reminiscing (Astell, Ellis, Bernardi, et al., 2010; DiLauro, Pereira, Carr, Chiu, & Wesson, 2017). These activities can vary greatly as some are more interactive than others. For example, in one study, Astell and colleagues (2010) found that using a touch-screen software program can meet both the needs of caregivers and people with dementia, allowing them to communicate and begin reminiscing on past events. While very different, DiLauro and colleagues (2017) highlighted that caregivers use basic leisure activities to stimulate reminiscing with their partners. For example, one partner discussed taking her husband to a park near an airport. Since her husband was a pilot, the activity, as simple as sitting on a park bench, allowed both to reminisce on past events, as much as each was able. Regardless of its form, the process of trying to stimulate the brain and allow for reminiscing is important and pleasing for both caregivers and their partners with dementia, allowing for a small form of connection between the two.

Additionally, activities as simple as watching television can be used as relational maintenance strategies (Ledbetter, 2017). In fact, one study found that watching television was a top-ten favorite shared activity for both a person with dementia and their spouse (Searson, Hendry, Ramachandran, Burns, & Purandare, 2008). As an enjoyable activity for both people involved, Ledbetter (2017) found that romanticism in television was positively associated with the use of relational maintenance behaviors, and that those behaviors would predict relational quality. However, while Ledbetter (2017) did not find evidence to demonstrate that watching television with a partner, which could be a relational maintenance activity, increased relationship quality or satisfaction, Searson and colleagues (2008) found that watching television together worked as a form of shared affection and companionship. Research studies such as these highlight the benefit of shared activities for both the person with dementia and their loved ones.

Although very different from arts engagement, previous research has shown that engaging in an activity such as having meals, watching television, or looking through photographs can work as a relational maintenance tool for individuals and couples. With research supporting these other activities, it stands to reason that arts engagement can also be a viable promoter of connection for couples.

Relational maintenance in life-altering illnesses. While the various activities couples can use as a form of connection is important, another key element to this study is the role that a life-altering illness such as Alzheimer's disease has on spousal communication and experiences. Previous research on relationships affected by tragic or life-changing events have found that partners of a person diagnosed with ADRD deals with several challenges spanning from mental health issues to loneliness (Butcher et al., 2001; Cohen & Eisdorfer, 1988). Henson and colleagues (2004) found that loneliness, whether chronic and situational, is negatively associated with maintenance strategies, meaning that loneliness causes a decrease in relational maintenance behaviors that help a couple sustain their relationship. Additionally, chronically lonely people used the fewest number of relational maintenance behaviors (Henson et al., 2004). Since previous research shows that care partners deal with a wide variety of issues such as loneliness, and loneliness is negatively associated with relational maintenance behaviors, a study such as this one might help explain why people do or do not use arts engagement as relational maintenance activity.

Another study looking from the relational maintenance perspective at the effects of communication debilitating illnesses (CDI) such as Alzheimer's disease on family communication found that despite the challenges involved, family members were still able to continue to sustain their relationships with significant others who have a CDI (Bute, Donovan-

Kicken, & Martins, 2007). Studies such as these show a wide range of opinions on what effect life-altering illnesses have on relational maintenance strategies for families and couples. Due to the wide-scope not only of relational maintenance, but also of research on dementia and Alzheimer's disease, it is necessary that research combine the two and narrow scope to better understand the family experience.

This research study seeks to investigate not only whether couples use relational maintenance when navigating the struggles associated with dementia, but also seeks to highlight how and why spouses use or do not use certain strategies. Ample research supports the negative effects of dementia on relationships, but limited research explains the circumstances and offers ways to minimize those effects. While this study will not fix every problem related to communication issues in dementia-ridden relationships, it contributes to the conversation by offering arts engagement as a relational maintenance tool. Not only does this research acknowledges the challenges that couples face, but it also seeks to offer at least a small strategy that some couples may find helpful in restoring some lost communication.

Connection to equity theory. Outside of spousal communication, relational maintenance provides a model to explain what happens in a relationship in conjunction with other theories (Dindia & Canary, 1993). One theory commonly associated with relational maintenance and salient for this study is equity theory (Adams, 1963). Canary and Stafford (2003a) argue that people are more motivated to maintain relationships that they view as equitable versus those that are inequitable. Equity theory is particularly relevant in this instance, as it highlights how people in relationships balance between inputs and outcomes (Canary & Stafford, 1992). Relationships are considered balanced if the ratio between what a person puts into a relationship versus what they get out of it is equal, or at least viewed positively by both members of a relationship.

Without equity, research has shown that it is more difficult for relationships to sustain (Canary & Stafford, 1992).

Particularly for this study, previous research has shown that care partner relationships are naturally inequitable. When caring for their loved one, care partners experience grief, care partner burden, isolation, and both physical and mental stress (Dyck, 2009; Walsh et al., 2004). Previous research has shown that the majority of spouses take care of their significant other with dementia until it becomes too unmanageable (Buhr et al., 2006). Consequently, several spouses willingly continue in their inequitable relationships fraught with challenges caused by dementia. Since this goes against research on equity in relationships, this study takes a different perspective by examining the experience of a person who is willingly in an inequitable relationship. Due to the extreme life-challenges and changes that spousal care partners manage, more research exploring the care partner experience, particularly as it relates to equity and relational maintenance is needed.

Previous research has looked at various instances of how people use these strategies to sustain their relationship, but little research has examined the unique relationship between partners when one person has ADRD and the other is their care partner. Relational maintenance research in the health communication discipline is important because it can better identify where communication works, where it can improve, and how each person experiences their situation. More specifically, this research study seeks to investigate the therapeutic potential of arts engagement as a promoter of relational maintenance. Through this literature review, I have highlighted the challenges associated with dementia on both the person and their loved ones. I have also identified the use of participatory arts engagement in life-altering illnesses and have identified arts engagement as a promoter of relational maintenance. With the previous research

and the strategies of relational maintenance in mind, this research investigates the following research questions:

RQ1: What relational maintenance behaviors do people with ADRD and their care partners use while participating in arts engagement?

RQ2: How does the use of these relational maintenance behaviors help or hinder the arts engagement experience for couples?

CHAPTER THREE: METHODS

To explore the role of arts engagement as a promoter of relational maintenance, this study employed a qualitative approach. First, I discuss the general workshop. Following, I explore the participants in the workshop, the data collection process, and finally, the data analysis process and procedures.

The Workshops

This research study included observations from two, four-week long workshops in which couples created masks designed to promote connection and cognitive stimulation. The first series of workshops took place during April of 2017, and the second occurred from September to October of 2018. All sessions took place at a local art museum in Colorado. Each workshop was led by a therapist who would offer ideas, materials, and support to participants. In 2017, the workshops were led by an arts therapist, and, in 2018, an occupational therapist led the program. Participants included adult pairs where one person had diagnosed ADRD and the other was their informal care partner or friend who did not have the disease.

In the first week of class, the therapist gave participants a blank clay mask. Then they looked through magazines to gather inspiration, sketched ideas, and compiled other forms of brainstorming. Class two involved creating the first layer of detail on the masks. Some participants chose to use tissue paper as color on their mask, while others used paint or drew on the masks directly. In the third and fourth sessions, participants continued working on their masks using a variety of techniques such as applying beads or tissue paper, painting, or hot gluing paper, feathers, and other miscellaneous supplies to the mask. The final masks varied

greatly in design. Some participants chose to mount their masks on a poster board or basket to create a larger piece of work. All of the masks were brightly colored.

Each workshop lasted approximately 1.5 hours and included a snack break. At the beginning of each session, the researcher would ask participants to rate their mood on a scale of one to ten (with ten being the highest mood). After answering that question, participants began work on their masks. The workshop took place in a small room within the museum dedicated toward art education. In the room, the walls were adorned with colorful crafts and other projects that visitors had completed over the years. Participants sat at tables to work but were free to move around the room as desired. Employees of the museum had offices near the room and would stop by to say hello to participants. The environment was calm and friendly, allowing participants to work at their own pace. Involvement in the mask-making project varied between participants. For example, some dyads worked on the mask together, whereas in some couples, the person with ADRD worked on the mask independently. Most commonly, the care partners would assist their partner with creating the mask while asking their partner for ideas and comments. The workshops were highly interactive in nature.

Researcher Positionality

Art has been a prominent fixture throughout my life. My familiarity with the arts began at a young age since my father is a watercolor artist and my mother runs their art business. In my own professional and academic life, I was consistently involved in the arts, particularly music, up until the time I entered graduate school. I had the privilege to study music intensively throughout all of grade school and have a minor in music from my undergraduate institution. Additionally, I have worked with arts organizations in various capacities as an intern or fellow.

As a white, middle class woman with a family background in the arts, I fit into the typical description of a person who works for or supports the arts (Dubois, 2010).

Having grown up in an artistic environment where people continually encouraged me to participate in art of any form, I approached this research very aware of my beliefs in the positive benefits of arts engagement. However, I have not been involved in specific art activities directly for the past few years, which has created some distance between myself and arts engagement. This position allowed me to approach research participants from an interested but disconnected perspective. From one angle, I hold my opinions about experiences related to arts engagement. However, since I have been detached from arts engagement myself, I was able to clearly see when the arts engagement was effective for a person versus where it was not an ideal fit. Consequently, I balanced the space between proponent of arts engagement and professional researcher, which was beneficial in data collection and analysis. I managed any bias in the research process by creating an observational protocol for coding the data based on previous research before beginning my analyses.

Participants

In total, six dyads participated in this study, with four dyads in the 2017 workshop and two dyads in the 2018 workshop (see Table 1). However, in the 2017 workshop, two dyads were unable to complete all four weeks of the workshop. All other dyads were able to attend all workshop sessions. Participants consisted of a person diagnosed with Alzheimer's disease or dementia and their care partner. Care partners were typically spouses, although they could be a best friend, adult child, or other family member. Five of the dyads were male-female partners, and one was a female-female dyad.

Participants were predominantly white, older adults. Only one dyad consisted of non-white individuals. Participants' ages ranged from 69-79 years. Each dyad had a seemingly long-standing relationship with one another. Some partners lived together, while others lived separately because their partner lived in a long-term care facility. Although they did not talk about their children in detail, many of the couples had adult children. All participants were retired and represented diverse professional experiences. For example, one dyad consisted of two former educators, one who worked as a professor at a university and the other had worked as an art instructor in a high school. Other former professions included a nurse, medical researcher, ironworker, and pilot. The participants diagnosed with Alzheimer's disease had varying levels of function complete with varying communication abilities, and some participants used a wheel chair.

The small sample size of each workshop allowed for an interactive and connected work environment. In each data collection cycle, one instructor led the group, though the workshop leader changed between cohorts. Groups of two or four dyads allowed for the instructor to have personal interaction with everyone, and for the researcher to listen and gather important data from each dyad equally. The small numbers of participants were beneficial for this research because I was only involved in one year of the data collection. I have a relationship with the researcher from the 2017 workshop and the data I was given is very detailed, which and allowed me to look closely at each dyad as though I were there in person. A larger set of participants might not have allowed for such a personal look at the experiences of the dyads, particularly the care partner. Additionally, the small participant number was partially due to physical space limitations. The space where the workshop took place was small and could only accommodate small groups of participants at each time.

Recruitment. Participants were all involved in a larger, interdisciplinary research study exploring how social engagement affects the well-being of adults with Alzheimer's disease/dementia and their caregivers. This research team collects data in conjunction with other events such as a symphony, dance, and theater performances. All participants were recruited through the larger study. All study methods were reviewed and approved by the Institutional Review Board at Colorado State University.

Table 1. Study participant background and demographic information.						
Names	Ages	Race/Ethnicity	Relationship	Former professions	Basic description	Year
Jan and Lewis (ADRD)	Unknown	White	Married	Art teacher and professor	Jan was very vocal and talkative with the group. She helped Lewis with the mask. Lewis was very quiet but funny when he did speak. They talked about their lives together and the adventures they had as a married couple.	2018
Carol and Bruce (ADRD)	Unknown	White	Married	Unknown, and former statistical process controller, a training manager, and a truck driver	Carol was very quiet and did not help Bruce with the mask. Her husband, Bruce, was very kind and liked to talk with the group. Bruce was very creative and had plenty of ideas for the mask. He rarely accepted help.	2018
Emily and Deb (ADRD)	Unknown, 79	White	Best Friends	Unknown, and a former nurse	Emily was very talkative with her partner and with the rest of the group. Emily and Deb are best friends of 40 years. Deb was quiet and spoke mostly to Emily.	2017
Louise and Aaron (ADRD)	Unknown, 69	Latina and Black	Married	Unknown, and a former medical/dental research illustrator	Aaron had many of his own ideas, and Louise would brainstorm with him. Aaron and Louise did not talk extensively to each other but would talk with other participants.	2017
Jessica and John (ADRD)	Unknown, 70	White	Married	Unknown, and former pilot, Navy	Jessica and John were only able to attend one week of the workshop. During that time, John	2017

					was very social with other participants. Jessica was quiet, but very engaged with her partner. John made jokes and engaged most with Charles.	
Sharon and Charles (ADRD)	Unknown, 69	White	Married	Unknown, and former ironworker, excavator	Sharon and Charles were only able to attend one week of the workshop. During that time, Sharon was incredibly engaged with Charles and helped him with everything. Charles was a little agitated during the class and did not seem to be enjoying his time.	2017

Participant Background

In order to understand the experience of arts engagement, it is important to look closely at the participants involved. Below is an in-depth look the background and general demographics for each dyad. All names are pseudonyms to protect anonymity.

Emily and Deb. 2017. Emily and Deb are best friends of 40 years. They have lived together for 39 of those years and have moved to several states with one another. Both are white women in their 70s, although Emily's exact age is unknown. Deb suffers from dementia, and Emily is her care partner. Overall, Deb moves very well and does not need much assistance as she walks, though she does have slight tremors. Deb has been married twice and has six children between her two marriages. She previously worked as a nurse. Together, the two enjoy the outdoors. Emily has a very friendly personality whereas Deb is quieter presence.

Aaron and Louise. 2017. Aaron and Louise are a married couple. Aaron suffers from dementia and is 69 years old. He identifies as Black, and Louise identifies as Latina. Aaron previously worked as an illustrator. They have an unknown number of children together. During one workshop, Aaron's adult daughter attending the session with him as Louise was unavailable.

Aaron is very high functioning and does not require much physical assistance. In interactions with him, it is hard to tell that he has any mental or cognitive decline as a result of his disease.

Jessica and John. 2017. Jessica and John are both white and in their 70s. They are married. John loves fishing and being outdoors. Although it is not known what Jessica did for a career, John is a former pilot. Together, they travelled extensively. Outwardly to the rest of the participants, John showed little to no signs of his dementia. He was very personable and physically agile. He required very little assistance and seemed to like being self-sufficient.

Sharon and Charles. 2017. Sharon and Charles are both white and in their late 60s. They are a married couple, and Charles has been diagnosed with ADRD. In his career, Charles worked as an ironworker and excavator, but Sharon's former career is unknown. Out of all of the participants, Charles showed the most signs of his ADRD. He was physically independent, walking without assistance or a cane. However, cognitively, he seemed to get confused easily and did not interact with many people in the class except for Sharon and John.

Jan and Lewis. 2018. Jan and Lewis are a married couple. Lewis is a white, older man who is wheelchair bound as a result of his dementia. He also suffers from Parkinson's disease. Although she still sees him regularly and cares for him in many ways, Jan has relocated Lewis into an assistive living facility as she could no longer care for him due to his increasing mobility issues. As a result, Jan now lives alone in the home that their family home but spends a significant amount of time with Lewis. They like to take walks together, do puzzles, talk with other residents in his facility, and attend as many events or activities as possible given his physical and mental capabilities. Although the exact length of their relationship is unknown, it became clear that they had been together for several years. Lewis is a retired professor and Jan is

a retired teacher. Together, they have adult children. While it was not immediately clear how many children they had, they talked about a son who had children frequently.

Carol and Bruce. 2018. Carol and Bruce are also white, middle to older adults married to one another. Bruce suffers from an unspecified form of dementia and Parkinson's disease. He lives with his wife, Carol, who is his primary care provider. Bruce appears very self-reliant. He walks with a cane but moves quickly and with a purpose. Although they did not go into detail, Bruce and Carol have at least one adult child who lives in another state. While Carol's previous occupation is unclear, she did talk about how Bruce had worked in several different careers over the years, including as a statistical process controller, a training manager, and a truck driver. He holds a Master's degree. When asked if they do activities together, Carol stated that they did not do much together anymore but that he liked to read. She stated that their household is fairly quiet, especially since his diagnosis.

Data Collection

After gaining appropriate IRB approval, data was collected in two steps. The first part included video-recorded observations during each week of the four-week arts engagement workshops in partnership with a local art museum. The second part included follow-up phone interviews with care partners within a week of each workshop session. Collecting data in these two steps allowed for the examination of participants' experiences from multiple angles.

Video Observations. In each workshop session, one or two video cameras were set up on opposing sides of the workshop space to record participants' verbal and nonverbal communication. Throughout the 2018 workshop sessions, a member of the research team took approximately 14 pages of field notes which were included in the analysis. While the researchers interacted with participants before and after the workshop, they sought to be inobtrusive and

distant during the time the participants were making masks. Approximately 12 hours of video recordings were obtained across both years of workshop sessions.

Follow-up Phone Calls. During the week after each workshop, researchers called the care partners for a follow-up conversation. The conversations focused primarily on care partners' perceptions of the workshop. Follow-up phone call interviews followed a semi-structured interview protocol (Lindlof & Taylor, 2011). The protocol was derived from the larger research project's previous work and documents, though three questions specifically aimed at understanding relational maintenance were added for the purposes of this research (see Appendix A). Because interview questions were about participants' personal experiences, participants became respondents instead of informants during the interview process, sharing their experiences in the workshop and with their partner who had ADRD (Lindlof & Taylor, 2011).

All phone calls were audio recorded. Phone calls averaged 15 minutes in length, ranging from ten minutes to forty-five minutes. Interview length varied as some participants were more open to conversation than others. All conversations took place with care partners only; the individual with ADRD did not participate in follow-up phone interviews.

Data Analysis

Thematic Analysis. Analysis of the video data stemmed from a grounded approach to thematic analysis (Braun & Clarke, 2006). Thematic analysis was an appropriate data analysis technique, because it allows for open analysis without a specific tool or unit needed for analysis (Owen, 1984). Consequently, important concepts from the data were woven together with Canary and Stafford's (2003) relational maintenance typology to find themes and recurring ideas. While doing the analysis, it is important to make sure that the themes created are accurate depictions of the data. In her 2010 publication, Sarah Tracy outlines eight criteria for high quality quantitative research. They are to having a worthy topic, rich rigor, sincerity, credibility,

resonance, significant contributions, ethics, and meaningful coherence (Tracy, 2010). Through data analysis, special attention was paid to these eight contributions to create the strongest analysis possible. For example, to address sincerity, I had several conversations with my advisor to ensure that the conclusions drawn were well-founded. Additionally, I established my own researcher positionality and biases before analyzing the data to increase my own awareness of my blind spots. To address credibility, I included both participant reflections through the follow-up phone calls as well as multiple and rich examples of participant's interactions, per Tracy's (2010) suggestions.

Procedures for video data and follow-up phone calls. To do thematic analysis appropriately, three criteria are important to consider: the recurrence of ideas, the repetition of terms, and the forcefulness of concepts (Owen, 1984). Specifically, for this project, data analysis included a constant comparative analysis of the video footage and follow-up calls to identify themes in the data. This was done through six steps (Braun & Clarke, 2006). First, the researcher needs to familiarize themselves with the data (Braun & Clarke, 2006). This was done by watching the videos (2017 and 2018) in their entirety, reading through all researcher field notes, and by listening to all the follow-up calls with care partners. The follow-up calls were not transcribed but rather listened to several times while taking further notes on the conversation in addition to the notes that were taken during the initial phone call.

Following familiarizing myself with the data, a general observational protocol (see Appendix B) was created for use when analyzing the videos, audio recordings, and researcher notes. This observational protocol was based off literature on relational maintenance and focused specifically on positive relational maintenance strategies, two negative relational maintenance strategies, and other forms of relational maintenance identified as important in the literature

(such as touch and reminiscing). The relational maintenance behaviors included in the protocol were networks, assurances, shared tasks, positivity, openness, touch, reminiscing, destructive conflict, avoidance, and an ‘other’ category for important interactions that did not fit in any pre-existing category (Astell, Ellis, Alm, Dye, & Gowans, 2010; Canary & Stafford, 2003b; Dainton & Gross, 2008; Gleeson & Timmins, 2004). This observational protocol helped differentiate between behaviors. For example, *openness* focused on conversation about a pair’s relationship in the present day whereas *reminiscing* focused on conversation regarding their relationship prior to the ADRD diagnosis. Based on the observational protocol, participants were involved in *network* relational maintenance if they had conversation with other members of the workshop, and/or if they talked to or about family and friends who were not at the event. Participants *shared tasks* when they worked on any aspect of the mask together, and *positivity* occurred when participants joked with or encouraged one another. *Touch* occurred when participants made intentional contact with each other. For example, a person might ask their partner questions and if their partner did not respond, this was qualified as an avoidance technique. *Avoidance* occurred if a person would not or did not actively engage with their partner. *Assurances* were comments made about the future of the dyad’s relationship. Finally, *anti-social behaviors* included sarcastic or short comments to one another.

Using the observational protocol, initial codes were created (Braun & Clarke, 2006). To do this, the data was scoured a second time, by breaking the video and follow-up call recordings into 10-minute segments, focusing on one dyad at a time per constant comparative analysis’ recommendation that data be evaluated in manageable pieces (Corbin, 2015). The first round of coding was open, meaning basic themes or concepts were noted when they were recurrent, repetitive, and forceful, specifically as they related to arts engagement and relational

maintenance (Glaser & Strauss, 1967). Data was organized in a spreadsheet where the specific relational maintenance strategies were categorized as they occurred in the data.

Using Braun and Clarke's (2006) third step of thematic analysis, searching for themes, an axial code of the data was created (Glaser & Strauss, 1967). To do this, data was engaged in 10-minute increments for how those concepts found the first round of coding could be grouped together to create meaning. The rounds of coding continued until the data saturation. Afterward, the themes were reviewed as part of the fourth step of thematic analysis (Braun & Clarke, 2006). In this instance, a thematic map of the analysis was crafted from the data in the spreadsheet. During this process, unimportant observations were filtered out and conclusions about the implications of the data were drawn. From there, the themes were named (step 5) and the analysis was written (step 6) (Braun & Clarke, 2006). Throughout the process, reflexive coding, through conversation with an advisor and inside member about the findings helped develop thoughts, and challenge any assumptions to ensure proper coding and thematic analysis (Lindlof & Taylor, 2011).

Following the same general steps explored above, the follow-up calls and researcher notes were analyzed using thematic analysis. This included listening to the audio-recorded calls again, rereading notes from those calls, and looking over researcher notes. From there, the data was coded for important themes and concepts, particularly as they related to the findings from analyzing the videos from the workshops.

CHAPTER FOUR: RESULTS

The following chapter provides an overview of how the data gathered throughout this study answered the outlined research questions. To clarify the differences in participant behaviors and personality, this chapter begins with a general overview of how each participant dyad interacted during the workshop. Then, each research question is addressed using a combination of data from both the observations and the follow-up phone calls.

Participant Workshop Profiles

2017 workshop cohort.

Emily and Deb. Emily and Deb were life-long best friends, and Emily served as a caregiver for Deb. Emily was the most vocal and personable participant in the 2017 workshop cohort. She would make sure to talk to each person in the room, asking others about themselves while also offering information about herself, Deb, and their lives as best friends. Deb was quiet but friendly. She would talk to the people around her and would always respond when addressed by others. She sat for nearly all of the workshops, whereas Emily walked around the room and stood for large portions of it. The mask Emily and Deb created paid to homage to Deb's life, and Emily was involved in many of the photos they included. Emily helped Deb with most parts of the mask but would always ask her what she wanted to do and if she liked what they had created. Most ideas seemed to come from Emily, but Deb verbally approved of all of them. Deb grew frustrated during one of the sessions, but it was not apparent to the larger group. Instead she seemed to shut down and did not want to work anymore. The next week she did not want to attend the workshop, so Emily attended in her place and worked on the mask alone.

Louise and Aaron. Aaron and Louise, a married couple with Louise served as Aaron's caregiver, were both quiet and personable. Whereas other couples made the mask together, Aaron largely created the mask alone. He came up with the ideas on his own and did most aspects independently, though Louise was always ready and willing to help when needed. She offered a few ideas to him throughout the process. During one session, Louise was unable to attend, so Aaron's adult daughter brought him instead. She worked on her own project next to him. When Aaron and Louise did interact, it was not audible to the rest of the group. Aaron talked with Emily and Deb frequently and was very kind. Louise was much quieter, although she talked with Emily the most of anyone. Aaron would ask about other participants if they were not there and seemed interested in getting to know other people.

Jessica and John. Jessica and John were also married, with Jessica serving as John's caregiver. They were only able to attend the first week of the program. During this workshop, John was very social with everyone in the group. Showing few signs of his ADRD diagnosis both physically and cognitively, he talked with everyone but paid the most attention to Sharon and Charles, the other couple at his table. When it came to the mask, he worked thoroughly and talked with Jessica frequently during the process. Jessica was much quieter and did not interact with anyone outside of those sitting at her table. The two worked on the mask together, although John took the lead on many of the activities. John liked to make jokes that would make Jessica laugh.

Sharon and Charles. Sharon and Charles, another married couple with Sharon caring for Charles, were also only able to attend one week of the workshop sessions. During that first workshop, Sharon had trouble engaging Charles in the mask-making. While she seemed to want to share the creative responsibility, he either could not or would not engage. He grew frustrated

during various parts of the workshop session, particularly when completing cognitive tests for the research process. Charles would not talk to members of the research team until Sharon came over and assisted. He mostly sat and watched and would only speak on occasion. Charles and John got along and made jokes to one another, although John was the instigator of those interactions. Sharon was friendly with everyone but seemed to grow frustrated with the process because Charles was upset and would not help her. She never spoke harshly to him, but she would repeat questions up to a dozen times to elicit a response from him.

2018 workshop cohort.

Jan and Lewis. Jan and Lewis were an older married couple, with Jan serving as a primary caregiver for Lewis. Lewis' disease had progressed to the point where he had limited communication with others, typically only saying a few words when prompted. Regardless of his limited communication, Lewis still had a strong sense of humor. He would frequently make funny comments when his wife would ask him questions, and then they would both giggle at the joke. Jan was the most vocal and involved participant in the class during the 2018 cohort. She was consistently joyful and talkative with everyone in the room. She paid special attention to Lewis, helping him with every aspect of the mask making process. Jan would continually ask Lewis what he wanted to do next and if he was pleased with what they were making together. Lewis consistently affirmed her questions and had a calm demeanor. Jan created conversation with Lewis almost entirely by asking him questions about their past together, in a seeming attempt to trigger his memory.

Carol and Bruce. Carol and Bruce were also a married couple, with Carol serving as Bruce's caregiver. While quiet through most of the workshop, when he did speak, Bruce was personable and liked to make jokes. Sometimes the jokes would be at his own expense, and he

would then laugh at himself. When asked a question, Bruce would usually answer with a joke while looking down, and then look up at the person who asked him, smiling. Bruce would listen to what Jan and Lewis were talking about and would sometimes talk with them about their mask. Carol was much more reserved. She tended to take time in the workshop to read a magazine quietly by herself. At times, she would look up from her reading to ask Bruce if he needed help. Rarely, if ever, did Bruce accept assistance. Bruce clearly had a creative mind. In the first class, he immediately started sketching his ideas. He made several drafts of his ideas and took his time to make intentional choices. Carol and Bruce did not collaborate together on the mask. It was almost entirely Bruce's project, and he was very particular about what he wanted. He clearly had a vision in mind. Bruce stood for many aspects of the mask-making process, sometimes walking around the room to look at his creation from several angles.

RQ1: Relational Maintenance Behaviors

Research Question one sought to outline what relational maintenance behaviors partners used in participatory arts engagement. Results found that participants used *touch, reminiscing, positivity, networks, shared tasks, openness, assurances, avoidance, and other anti-social behaviors* in their interactions. These behaviors will now be explicated in detail.

Touch. *Touch*, defined as making intentional physical contact with another person and excluding unintentional contact (Canary & Stafford, 2003b), was an important relational maintenance behavior used throughout the arts workshops. Participants used touch for three main purposes: *to affirm, to assist, and to elicit a response*.

To affirm. Affirmation was the most common form of touch used by all six care partners and usually consisted of a care partner encouraging their partner with ADRD in some way. Affirmative touch was often paired with another relational maintenance behavior, like positivity.

For example, care partners would tap their partner on the back, shoulder, or hands while telling them “good job” on the mask, combining two relational maintenance behaviors in a simple act.

Touch as affirmation was prevalent during the few times in the workshop sessions where individuals with ADRD became upset or agitated. For example, without prompting, Sharon smiled at Charles (who was not enthusiastic about the activity) and patted him on the leg as they received instructions on how to make the mask at the onset of the workshop. Soon after, she wrapped her arms around Charles to talk to him after he had hesitated to answer questions asked by one of the researchers. When he did not immediately answer her questions, Sharon moved her body so that she was right in front of Charles and looked him in the eyes while keeping her hands on his shoulders. In this instance, she used touch to encourage him to talk with her about his feelings and to affirm that she was physically near him to support him.

In another instance, Emily brought a poem to the workshop session that Deb had recently written so that they could attach it to their mask. After reading it, the therapist asked if she could use Deb’s poem for marketing material for their outreach programs. The participants then interacted, with Emily using touch to affirm Deb and her creative expression:

Therapist (T): So is it okay that I made a copy of that, of your beautiful poem? I was also thinking it is such a beautiful poem, uh, and I am going to make a nice colorful brochure of all the finished masks. It might be nice to have that on the little inside...

Emily: (*patting Deb on the back*) Oh wow. Oh, you’ll be published yet again!

Deb: (*nodding*) Yeah.

T: Yeah, beautiful, just beautiful.

Emily was excited for Deb, and she used a pat on the back to affirm that she was excited and that being published was positive. Deb responded positively to both the idea of her poem's inclusion in the brochure as well as Emily's touch in the interaction. When partnered with positivity, touch often worked to affirm the person with ADRD and encourage their engagement with others or the activity.

Touch as affirmation also occurred among the broader network of participants and not just between dyads. At the beginning of some workshop sessions, Bruce and Lewis (both individuals with ADRD) would shake hands or Bruce would tap Lewis on the back and say hello. This behavior represents an intentional effort to acknowledge and affirm the other person's presence at the workshop. In one instance, John and Charles (also both individuals with ADRD) were walking and talking when they both laughed and John patted Charles on the shoulder in response. In a similar incident during the third workshop session, Emily arrived to find Aaron already working on his mask. After saying hello to the therapist, she tapped Aaron on the back and asked what he was working on. This effort sparked a conversation between the two, and she continually told him she liked what he was creating. Shaking hands or patting each other on the back affirmed that participants were interested and connected with one another in the workshop.

To assist. Although less common, four dyads used touch to assist one another. Most often, care partners used touch as assistance in response to a need of their partner with ADRD. For example, if his tremors were particularly bad, Jan would hold Lewis' wrist as he painted to steady his hand. Carol similarly held Bruce's wrist as he used a marker to draw a face on his mask. This touch served to help the person with ADRD complete their task while managing their tremors. In another instance, Jan patted Lewis on the back to help him sit up straight while he was taking a drink of water. Similarly, Emily would position herself beside Deb and hold her

arms as she stood to make sure that Deb was stable before moving. During the first workshop, when Sharon and Charles were ripping tissue paper to apply to the mask, Charles either could not or would not work on the project. Consequently, Sharon physically guided his hands and ripped the paper with him to demonstrate what she was asking him to do. From there, he was able to rip a few pieces of tissue paper.

While the other care partners with loved ones who still had strong mobility did not assist their partners with touch, there were several instances where they were prepared to use touch to assist if needed. For example, when he was painting his mask during the first workshop, Louise was standing behind Aaron with her hands hovering nearby in case he needed her at any minute. Additionally, as John walked, Jessica kept her arms open behind him or would walk with her arm reaching back toward him so that he could grab onto her at any moment if he lost stability. Due to the relationship between care partner and their loved one with ADRD, *touch as assistance* played a unique role in the setting because not only did the behaviors act as a form of connection for partners, but in many cases, the art workshop could have been ineffective for half of the participants (the ones with ADRD) if their partner was not there to assist them.

To elicit a response. As previous research has stated, an ADRD diagnosis is usually correlated with a decreased ability to communicate (Stone, 2013). At times, care partners touched their partner to encourage a response from them. Three out of the six care partners used touch to elicit a response. For example, during the first workshop, Sharon was trying very hard to get Charles to look through photographs or to attach tissue paper to their mask. When he would not do that, she would tap him to remind him that she was asking him to do a task. Other times, she would ask him a question and then tap his hand when he did not respond. Usually, he would respond to that touch with a brief answer. Jan also used this technique with Lewis as he had

trouble answering questions. She would ask him a question, look at him, and if he did not respond in about 10-15 seconds, she would tap his wrist while re-asking the question. This would typically elicit a response. Touch to elicit a response was used by care partners to encourage people with ADRD to interact with them, which led to further connection between the pair.

Reminiscing. Another common relational maintenance behavior that occurred during the workshops was *reminiscing*. Reminiscing involved participants reflecting on their shared past or having conversations about past experiences either with a partner or other workshop participants. Reminiscing manifested in two ways: *to encourage conversation*, and *to trigger a memory*.

To encourage conversation. At some point across both years of the workshop sessions, all twelve participants used reminiscing as a conversation starter. This behavior was most common amongst care partners and occurred both between dyads as they worked together as well as among the whole group of workshop participants. For example, Jan and Lewis talked about their lives together many times during the 2018 workshops. In one interaction, they talked about where they had traveled:

Jan: Does that remind you of anything? Where were we when we saw that?

Lewis: Uh, Africa

Jan: Remember that special place that we went then?

Lewis: (nodded his head)

Jan: What does that remind you of? See anything so far? I've got a few pictures but I want you to choose some. Try and pick out some animals. Maybe some trips that we have been on. Some fishing, football.

Therapist: I am curious about our trip to Africa. Where did you go in Africa?

Lewis: What was that four years ago?

Jan: Yeah, she said where though I think, where?

Lewis: Well we flew into South Africa.

Jan: No, we flew into Kenya first. Remember we flew in and did the safari first in Kenya because remember that was the year Obama got elected that year? We had signs in our car and people cheered as we were going through their town. Then where else did we go after that? Tanzania? And then what you said. What was the place you just said, the place you really liked?

Lewis: South Africa.

Jan: What did you like about South Africa? Do you remember?

Lewis: It was everything that I did not expect.

Jan: That's a good answer. It was a really big, beautiful city right?

The two then smiled at each other and they continued looking through magazines. Although the conversation was short lived, the act of reflecting on past experiences together, sparked by the therapist, allowed for an important conversation amongst three of the five people in the room that later informed how the dyad would design their mask. Soon after, Carol, who had been listening to the exchange, showed Jan and Lewis a photograph that she thought they might like, and the group began talking about traveling. In this instance, the conversation between Jan, Lewis, and the OT sparked a larger conversation with the whole group.

Reminiscing also allowed for extensive conversations between participants during the 2017 workshop sessions. At one point in the mask making process, Emily and Deb were looking at the photographs they had decided to attach to their mask while talking about their lives together. When asked by the therapist about one photo, Emily said:

Emily: That was when we moved to [location] in 1981 and we had the house built. The we build the deck around it.

Therapist: So, you built the deck yourselves?

Emily: Yeah, we have developed decks on nearly every house we have had pretty much.

Deb: That's what we do.

Emily: We made a nice floor and a walk out dining room from our kitchen onto the porch too and uh the ceiling. We have done it all.

Aaron: (to Emily) Is this your mom?

Emily: Oh no, she's my best friend Deb, we have known each other for 40 years.

Aaron: Oh that's right, you told me that.

Emily: That's alright! Hey if I faulted you for asking a question again... well we have known each other for probably 40 years and we have pretty much lived together for 39.

By talking about their lives together, Emily created conversation with Aaron and Louise, the only other dyad present at the time. Overall, Emily was the most vocal and talkative member across both cohorts. Her primary way of creating conversation was to share stories from her life, Deb's life, or to ask others about their lives. This crafted a welcoming and collaborative environment, where participants talked with one another or the therapist as they worked instead of sitting silently.

To trigger a memory. Reminiscing to trigger a memory worked as a way for all six dyads to gather inspiration for their mask. Early in the first workshop session, Jan asked Lewis several times what specific photographs reminded him of, and he would respond with a word or two. In one instance, Jan asked Lewis what a specific photo looked like to him and he responded:

Jan: (pointing at photograph in magazine) What does that remind you of?

Lewis: [City Name].

Jan: Yes! Good for you. Boy, that's a word you haven't said in a long time. We used to go fishing in [State]. Wow, that certainly brought up a memory.

Jan continued to tell the therapist that Lewis used to love to fish, ride horses, and be outdoors.

Seeing this photograph clearly sparked a memory for him and Jan regarding fishing back when

they lived in another state. This served as a point of connection between the two as they reminisced on their past.

Sharon also used reminiscing to trigger a memory in her partner, Charles, as they worked. Similar to Lewis, Charles enjoyed fishing and Sharon made sure to choose photographs related to that and to the mountains, where they used to live. She told Jessica and John, “I brought some photos and green tissue paper because he loved to fish and be outdoors since we lived up in the mountains for a long time. He also liked to hunt.” Although he did not talk about it, Charles seemed to like the concept Sharon had designed for their mask. Emily and Deb also used reminiscing as a main strategy for their mask, as they used a photo collage of memories from their lives (primarily Deb’s life) as the main focal point on the mask. As they selected photographs and attached them to the mask, Emily would ask Deb if she remembered certain aspects of her life as depicted in the photographs. Each of these examples illustrate the ways that reminiscing allowed people who had a memory disease to briefly remember and discuss aspects of their life with their care partner, allowing for a moment of connection between the two.

Positivity. Another relational maintenance behavior used by all six dyads was positivity. Positivity included the use of generally prosocial behaviors such as being upbeat, friendly, polite, encouraging, and kind (Canary & Stafford, 2003b). Throughout the workshops, positivity took two distinct forms: *jokes and affirmations*.

Jokes. Participants enjoyed making jokes to one another as they worked. In fact, one person from five of the six dyads made at least one joke during the process. For example, at one point, Bruce and Carol had the following exchange:

Bruce: [pointing at a picture in a magazine] You ever think about crocheting these things?

Carol: Well you can crochet...

Bruce: [interrupting Carol] No I cannot!

Although a simple exchange, Bruce's joke about being unable to crochet made both chuckle and smile. Jessica and John also shared several moments where they laughed and smiled at one another. While those exchanges were quiet and largely inaudible to the rest of the group, they each made various comments to one another that created a fun, private moment.

When looking through magazines early in the process, Jan made a comment about liking a photo. Lewis then looked at the photo, smiled, and said it reminded him of something she liked to do. When Jan inquired about his comment, he responded, "Spend money." They both laughed in response to this exchange. In another instance, Emily and Deb were talking when Emily laughed out loud and the therapist asked what had happened. Emily responded, "Oh, she [Deb] is just teasing me!" while both laughed. These short interactions were important to how the participants interacted as individuals made a concerted effort to make the other smile.

Affirmation. Most dyads were very affirmative of one another through positive remarks. One way that they showed positivity was through words of affirmation specifically about the mask. Across all workshops, every participant (whether they had ADRD or were the care partner) remarked about how they liked their mask and were having a nice time. Participants also make a concerted effort to connect with participants who were not their partner during the workshop. As participants arrived at each session, they would say hello to one another and to the therapist. Emily was particularly good at positivity. At one point, Aaron remarked:

Aaron: I just am not that creative.

Emily: I disagree, and I don't even know you! He could have fooled us, couldn't he, Deb?

Deb: Yes, he did!

In another example, although they did not respond often because Sharon was trying to get Charles to focus, John was curious as to what they were working on and continually told them he liked what they were doing. At several points throughout the workshop, Bruce asked Lewis to see what he was working on and then complimented whatever Lewis and Jan had created. Across all workshops, no one made disparaging comments about other participants or their masks. These words of affirmation created a welcoming environment where participants asked about and encouraged one another as they all worked on their masks.

Shared Tasks. Shared tasks included the equitable sharing of responsibility during certain activities (Canary & Stafford, 2003b). For this research, shared tasks meant that dyads worked together on the mask on tasks such as brainstorming, painting, attaching items, etc. Although care partners tended to do more work than their partner with ADRD, there were several instances where pairs shared tasks. Shared tasks took two forms throughout both workshop cohorts: *to brainstorm* and *to assist*.

To brainstorm. Throughout the mask-making process, four of the six care partners specifically asked their partner to help with brainstorming an idea for the mask. For example, Jan and Lewis worked together to discover inspiration for their mask through photographs in magazines.

Jan: This is a pretty photo. We could do something with that.

Lewis: It is pretty

Jan: It is a toucan. We could do a bird theme for our mask. Something about travel with bright colors and feathers.

Lewis: Okay.

In this dialogue, they come to a joint decision on how they want to create their mask together. This process came before they started working on the mask and informed how they would then look for photographs and what colors they would use. In another instance during the process of painting the mask, Jessica talked with John about the color of their mask.

Jessica: Do you want to do the whole thing blue or do you want to do multicolored?

John: I like this blue. It looks nice.

Jessica: Okay, then just keep painting the whole thing.

Although a simple interaction, the two made a joint decision on what color they would use, which then informed their next step in the process and that was to paint the whole mask. While some of the participants could have come up with ideas for the mask on their own, sharing the task of brainstorming allowed for all people to participate and engage with the process and to have a voice in what they created.

To assist. For all six dyads, shared tasks came out of a need for the care partner to help their loved one with ADRD with physical tasks. While *touch to assist* focused on the pair making physical contact, such as holding wrists to manage tremors or assisting partners in standing, *shared tasks to assist* meant doing tasks the person with ADRD could not do but did not include physical contact between partners. For example, at one point near the end of the mask making process, Carol held Bruce's mask up as he walked around the room and examined his work. He could not have looked at the mask so intently without her assistance. In another example of shared tasks to assist, John kept experiencing issues with the mask moving while he tried to paint it, so at times, Jessica held it in place so he could continue painting. Jan also took an active role in the mask-making process with Lewis as he had limited physical capabilities. To allow him the chance to help with the mask physically and not just conceptually, she would pour

the paint for him since he could not lift the container himself. Louise helped Aaron carry materials to their table so that he did not need to make several trips back and forth. She also helped Aaron apply different items to the mask with glue. As all of the participants with ADRD suffered from cognitive limitations and several also suffered physical limitations as well, every care partner needed to assist their partner with a task at some point throughout the workshops. Through sharing tasks to *brainstorm* and *assist*, the care partners helped increase productivity between dyads, which allowed for more work on the arts engagement.

Networks. Networks as a relational maintenance behavior is typically understood as surrounding the relationships with family and friends who support the relationship by spending time with one another and doing similar activities (Canary & Stafford, 2003). For the purposes of this research, networks included dyad's discussions about their relationship that they shared with their partner or others. Although the class did not get to meet extended family or friends (except for Aaron who was once accompanied by his daughter to one workshop), participants frequently discussed their loved ones and initiated conversation with each other. Networks as relational maintenance presented in two ways during the workshops: *network created by workshop participants* and *network created outside of workshop*.

Network created by workshop participants. As in many collaborative situations, all twelve participants tried to create community by talking to and asking questions about each other. This form of networks as relational maintenance helped participants build connections with each other. A common manifestation of network creation in the workshops included care partners offering each other information that might help them take care of their partner with ADRD. For example, Jan shared with Carol how she used a ride share program so that she did not have to transport Lewis. Additionally, Emily invited Louise and Aaron to come to another

program she and Deb attended, explaining that the group activities fun and enjoyable. When Louise expressed interest, Emily gave her directions to the location. Interactions such as this highlighted how the care partners could glean potentially important information from one another.

Participants also used questions and conversation throughout the workshop for more general network creation. This included asking about each other's interests. John and Charles talked frequently during the first workshop about their shared interest in cars. Additionally, the whole group had a conversation about phone numbers and area codes at one point during the 2018 workshop. Although unrelated to creating the masks, this conversation revealed personal information about each participant and where they lived or had lived previously. Through getting to know more about one another, participants created a network amongst themselves of people experiencing similar challenges with Alzheimer's disease and dementia. Similarly, at one point in the 2017 workshop, Aaron asked about John, Sharon, Charles, and Jessica, who were all missing from the workshop. He clearly saw them as a part of the process and was curious as to why they were not present. Overall, these small interactions created a relaxed and welcoming workshop environment and helped participants see the situation as a group process instead of solely individual.

Networks created outside of workshop. While external network members may not have attended the creative workshops, four of the six dyads talked about important people in their network outside of the workshop. In many cases, they talked about their children and how they wanted to tell them about the experience. For example, at the end of the 2018 workshop the workshop participants talked about their anticipation for sharing their creations with others:

Jan: We need to get a photograph of you [Lewis] with your mask so that I can send it to your kids. They would love to see this.

Lewis: Okay.

Carol: Bruce, do you want me to take a photo to send to (daughter's name)?

Bruce: Yeah, she would like that.

In this instance, both participant dyads wanted to share what they had done with their children because they valued their relationship with their children even if they were not physically present. Emily made a similar remark when she told Deb “I am excited to send this to your kids and see what they think!” The inclusion of these external networks is important in this instance because it shows that the work created in the sessions connected to the dyad’s larger lives such as family and various experiences that occurred beyond the walls of the museum.

Openness. Openness is traditionally defined discussions that people have about their relationship (Canary & Stafford, 2003). For the purposes of this research, the scope of openness was broadened to include general self-disclosure. Openness was distinct from reminiscing (e.g., disclosure about their life in the past) in that openness was present-focused disclosure around their relationship and experiences. Openness was a less prevalent relational maintenance strategy across the workshops as only three dyads used this relational maintenance behavior. Ultimately, openness as disclosure was the only form of openness found in across the workshops.

To disclose personal information. Throughout the workshop sessions, many participants slowly disclosed personal information about themselves to either their partner or, more often, to the larger group. Their disclosure was typically related to what the person was working on in their mask at the time, but also manifested in conversation that occurred naturally throughout the workshop as people asked questions about each other. Four of the dyads disclosed personal information to the group. Disclosure included talking about where the dyads lived, the activities

they enjoyed, how they were feeling in the moment, and what they had done that day in the workshop. Across both cohorts, Emily was the most open participant. At one point, she talked about how she and Deb lived by a local reservoir in a house that they had built together. As she talked, she would ask Deb for confirmation on every topic that she discussed, and Deb did not object with Emily sharing. In the 2018 cohort, Jan was also very open to discussing her and Lewis' life together. She talked with Lewis, the therapist, and the larger group about how they were retired, how they enjoyed being outdoors, and how Lewis liked to joke. In follow-up phone calls, she also talked about how Lewis lived in a residential assistance facility and she continued to live in the house they had previously shared together.

While most of the participants with ADRD did not self-disclose without prompting from their loved one, there were small instances of self-disclosure. One notable instance came from Bruce after the therapist stated that she liked his sketch:

Therapist: Bruce, I love the shading you have done here.

Bruce: You want to know my secret? It is a technique called "the shakes" (laughs). My Parkinson's...

Therapist: Oh, well it looks good!

In this instance, he was making a joke (a form of positivity) about his tremors while also making himself vulnerable through self-disclosing the cause of his tremors (Parkinson's disease).

Assurances. Assurances were the least common prosocial relational maintenance behavior among participants. Assurances include expressions of love and commitment that explicitly or implicitly indicate that the relationship has a future (Canary & Stafford, 2003b). While encouraging behavior between participants was quite common, only three dyads had explicit conversation about the future of their relationship. However, when assurances were

shared, they were most commonly manifested as conversations about *how the mask could be used outside of the workshop*.

To emphasize how the mask can be used outside of the workshop. To emphasize the usefulness of the workshop, a few participants talked about how they would display the mask in their home. These instances functioned as assurances, because they showed that the mask they had created together would not go unused or unappreciated. Jan and Lewis were the most vocal about how they would use the mask once it was complete. Since they had based the mask off their life together, they both mentioned that they would display it in their house (where only Jan lives). Additionally, while painting the mask a light blue color, John mentioned to Jessica that the mask would look good against one of the walls in their home. She smiled and agreed. In another instance, Bruce had run out of ideas for the mask, showing visible agitation. In response, Carol said:

Carol: You don't have to do that right this minute, Bruce. I have hot glue at home.

Bruce: Okay.

Therapist: Or we have a whole other hour here, you can take your time.

Carol: Don't push.

Later in the same workshop, Jan made a similar remark, mentioning "...We are thinking we might add some beads once we get home since we forgot them." These remarks show that the masks did not need to be completed within the workshop and that the pair could continue the process in the comfort of their own residence, which further shows that the relationship exists outside of the workshop and will continue to exist.

Avoidance. Although negative relational maintenance behaviors were not as common as prosocial maintenance behaviors during the workshops, two dyads used *avoidance*. Avoidance

involved intentionally failing to address a conversation or task that was deemed undesirable or burdensome. Typically, avoidance appeared in two forms: *by being disengaged in conversation* and *by rejecting help*.

By being disengaged in conversation. At certain points in the workshop, some participants became disinterested in conversing with others and/or their partners. At one point, Bruce showed Carol a photo that he liked. Instead of responding affirmatively, she simply looked back down at the magazine that she was reading, and he went back to working on the mask. In this instance, she chose not to engage in conversation with her partner. A similar incident occurred between Sharon and Charles, the latter of whom would not or could not engage in the mask making process with his partner. As mentioned earlier, he first did not want to answer questions by the researcher and later did not seem interested in helping Sharon as she found photographs and attached tissue paper to the mask. While this could have simply been indicative of a larger problem he was having on this day, he was unable to engage in conversation or action with his partner, making the mask mostly her activity. Out of the participants, three couples (Jan and Lewis, Emily and Deb, Jessica and John) worked on the mask together by brainstorming together and sharing physical tasks, one was done largely by the care partner (Sharon and Charles) who came up with both the conceptual idea and did the physical work, and two were completed predominantly by the person with ADRD (Louise and Aaron, Carol and Bruce) as they came up with their own design and did the majority of the work independently.

By rejecting help. Throughout the mask-making process, all of the care partners, regardless of whether they saw the mask as a solo activity or partner activity, asked their loved one with ADRD if they needed help. While there were times when the participants would accept help, two participants (specifically, Aaron and Bruce) preferred to work on the mask alone. Both

of them had partners with them during the whole process, but they chose to work largely independently. While it is important to note that part of the reasoning for this was likely that they had higher levels of function than other participants, each rejected help from their partners (Louise and Carol) several times during the process. They were not unkind in the way they rejected help, but simply made it clear that they did not need or desire assistance and had their own ideas as to how the mask should be made and ultimately look.

Anti-social behaviors. At times, participants would use specific anti-social behaviors that ultimately created distance between the partners. While not common, this usually occurred with the partners who did not collaborate on the mask and typically took one form: *Making sarcastic or antagonistic comments to their partner.*

Making sarcastic or antagonistic comments to partner. Bruce and Carol were the only dyad who made sarcastic or antagonistic remarks to one another, though this happened several times over the course of the four weeks. One example took place when Carol asked Bruce for help. When he responded that he did not need help, she said “Okay. I’ll shut up and leave you alone,” with a sarcastic tone. Bruce did not acknowledge this remark and kept working, creating an environment where the two did not interact extensively and Carol’s job was to sit across the table from Bruce and let him work on the mask independently.

Use of relational maintenance behaviors by participants. Throughout the arts engagement process, certain relational maintenance behaviors were used more frequently by either the care partner or the participant with ADRD depending on the behavior and the situation/context. To better understand the use of each behavior as it relates to the arts engagement experience, Table Two below differentiates between which group was more likely to use the various relational maintenance behaviors. Overall, care partners were more likely to

use relational maintenance behaviors than their partners with ADRD, but there were also ample opportunities in which the participant with ADRD used relational maintenance behaviors both with and without prompting.

Table 2. Study participant use of relational maintenance behaviors.		
Behavior	Group more likely to use behavior	Explanation
Touch	Care Partner	Touch was used more frequently by the care partner as they asked the participant with ADRD to respond to their question or used touch to assist their partner in a task or encourage them to continue working on that task. Participants with ADRD were less likely to use touch but when they did, it was largely to affirm another person with ADRD.
Reminiscing	Care Partner	Reminiscing was introduced more frequently by care partners, but participant with ADRD engaged in the act of reminiscing when prompted. While the behavior was typically shared equally, it was commonly stimulated by the care partner in order to create conversation or stimulate their partner's memory as they worked.
Positivity	Shared Equally	While care partners did most of the positivity to affirm everyone in the workshop, participants with ADRD used jokes more frequently than the care partners. These jokes were commonly at their own expense. Therefore, of the two purposes behind each behavior, care partners used positivity to affirm, and participants with ADRD used positivity to joke.
Shared Tasks	Care Partner	Like reminiscing, care partners were more likely than the participants with ADRD to begin the relational maintenance behavior of shared tasks. However, once asked to share the task, several people with ADRD readily engaged in the relational maintenance for an extended period, particularly in relation to sharing tasks to brainstorm. Sharing tasks to assist was exclusively associated with the care partner as they helped the person with ADRD complete a task that they would otherwise be unable to do alone.
Networks	Care Partner	Networks created with other workshop participants were used by people with ADRD when they would talk and ask each other questions but appeared more frequently between care partners as they shared experiences and advice with one another. Additionally, networks created by family and friends outside of the workshop were usually brought into conversation by care partners as they remarked on how friends and children would enjoy seeing the creations.
Openness	Care Partner	Throughout the interactions, care partners were much more likely to disclose information about themselves, their partner, or their relationships than people with ADRD. When people with ADRD did disclose, it was nearly always as a result of care partner asking them a question about themselves.

Assurances	Care Partner	Although infrequent in interactions, assurances were used almost exclusively by care partners as they commented on how the mask could be used outside of the workshop while making the mask with their partner. Only one person with ADRD commented on how he saw the mask being displayed in the home he shared with his care partner.
Avoidance	Shared Equally	Avoidance appeared for two reasons in this research: by being disengaged and by rejecting help. Care partners were more likely to be disengaged in the mask making process and subsequent conversation whereas participants with ADRD were exclusively the people who would reject help either from their care partner or the therapist.
Anti-social behaviors	Care Partner	There were few, if any instances in which a person with ADRD used sarcastic or antagonistic comments with their partner. Instead, this behavior appeared in how some care partners reacted to the participant with ADRD rejecting their help or becoming agitated in the mask-making process.

RQ2: Effect of Relational Maintenance Behaviors

Research question two sought to investigate how the use of relational maintenance behaviors helped or hindered the arts engagement experience for the partners. Results found that the use of relational maintenance behaviors created tensions for both the person with ADRD and their care partner during the workshops. These tensions included finding a balance between *stimulating versus impairing cognitive function, social connection versus vulnerability, helping versus dominating versus not helping, and activity convergences versus activity divergence*.

Stimulating cognitive function versus impairing cognitive function. One tension that couples faced during the workshop sessions was finding a balance between engaging in an activity that would stimulate participants' cognitive function while not asking too much of them and, thus, inhibiting their ability to engage in the workshops. For people with ADRD, stimulating a person's cognitive function included focusing their attention, triggering small memories, and utilizing a creative outlet. On the other hand, inhibiting cognitive functioning occurred when a person with ADRD experienced confusion or agitation at the process. Cognitive inhibition also took place as participants with ADRD sought to deal with residual fatigue after the event as a

result of expending their energy during the workshops. For their care partner, stimulating their loved one's cognitive functioning meant they got to see pieces of their loved one that the disease had largely taken away through moments of memory, whereas impairing cognitive function created a situation for the care partner where they then needed to calm their partner and help manage their emotions. Examples of how this played out for both the person with ADRD and the care partner are explicated below.

Many care partners noted both during the workshop sessions and during the follow-up phone calls that they thought the activity was good for their partner and that it provided a creative outlet for both participants. In a follow-up phone call, Carol noted that, "You can see the gears turning in his mind..." as Bruce works. However, this could be burdensome at times. For example, Louise noted that Aaron enjoyed his time creating the mask, and that it was healthy for him. However, the next day, Aaron would often be exhausted and would sleep in later than normal. As Louise explained, "He gets really tired and he's worn out for the next day, day and a half... He used to be very detailed, and he wants to be the same way, and he has to really think about it." In this instance, the dyad had to balance both the positive and negative aspects of the workshop sessions. While Aaron wanted to create the mask, it required an immense amount of physical and cognitive energy from him.

As Louise and Aaron did not share the majority of the tasks associated with creating the mask, the ownership fell upon Aaron to complete the project independently with only some planning assistance from Louise. Therefore, their lack of the shared task relational maintenance behaviors may have contributed to an imbalance in this tension, as Aaron struggled with fatigue afterward each class. Had the couple shared more of the tasks, such as Louise helping with painting or gluing items to the mask, Aaron might have felt less fatigued the next day. Louise

also noted in her follow-up phone call that while Aaron enjoyed himself, she did not see any evidence of his improved cognitive functioning the day after the event. Similarly, in a follow-up phone call with Carol, a care partner who also did not engage in task sharing, she noted that “[Bruce] will be tired so he will go back after the workshop and read. He likes to read.” After an extended period of focusing his attention on a creative task, Bruce liked to do a different, more relaxing activity. In both situations, the lack of shared tasks in the assembly of the mask likely contributed to the fatigue experienced by the person with ADRD, even if they did enjoy working alone, creating a tension.

Jan and Lewis also identified aspects of the stimulating-versus-impairing tension. While Jan spoke highly of the workshop, she also acknowledged that they could be challenging at times. For example, she noted that Lewis had made certain comments during the process that led her to believe he temporarily remembered aspects of their lives together. While this made her very happy, she also acknowledged, “I know he may not remember certain things tomorrow...” For Jan, these glimmers of memory in Lewis were fleeting, and she ultimately did not know how much he was benefitting from the workshop besides getting out of the house. To try and ignite his memory, Jan used reminiscing, touch, and positivity with Lewis. At times, these attempts at asking him questions such as “What does this remind you of?”, tapping his hand, and encouraging him were successful, but other times they were ineffective. Ultimately, she noted that the “...benefits outweigh [the costs] because I look forward to it, and he seems to enjoy the class.” The use of certain relational maintenance behaviors could have provided her with momentary stimulated cognitive function from Lewis, but they were ultimately ephemeral. Additionally, for both Bruce and Lewis, the act of creating the masks helped to focus their attention, specifically as it related to their tremors. Throughout the process, both participants and

their partners remarked that creating the masks slightly reduced their tremors. While temporary, the fact that they were focusing their full attention to the task at hand slightly reduced a physical ailment of theirs.

Unfortunately, not all participants experienced these positive moments. Despite her attempts at both positivity (through jokes and smiling) as well as shared tasks (through asking him to rip tissue paper with her), Sharon talked about the workshop's difficulties in her follow-up phone interview about the experience for both her and Charles. During the workshop, Sharon struggled to get Charles to focus and assist her, and he grew increasingly agitated. During the phone conversation, she noted that the entire research process done in conjunction with the workshop was too overwhelming for Charles, and, as a result, he could not participate in the mask making. Sharon also talked about how Charles did not enjoy himself at all, nor did they have any meaningful interactions. They did not return for another workshop. In this instance, despite the use of several types of relational maintenance behaviors, the experience was largely negative for the pair because the process was too much, overwhelming him cognitively. Emily made a similar comment about the research in a follow-up call, noting "the research was a little too much for [Deb]."

From the interactions between the participants during the workshop sessions and from the perspective of the care partner in follow-up calls, the acts of using positivity, touch, shared tasks, and reminiscing by either partner could provide temporary positive experiences. However, there were also times where those behaviors could push participants with ADRD into feeling overwhelmed, ultimately impairing their cognitive functioning and limiting the effectiveness of the mask-making workshops.

Social connection versus vulnerability. In other moments, participants sought a balance between *engaging in social connection* while also *protecting themselves or their partner from embarrassment or alienation* as a result of too much vulnerability. According to the observational data as well as follow-up phone call data, social connection could lead to enhanced mood and feelings of similarity and solidarity between both individuals with ADRD and their care partners. However, at times participants demonstrated fatigued, embarrassment, or uncertainty about the situation. In this case, their interactions were self-identified as negative.

On the more positive end of this tension, many participants reported enhanced mood between the beginning of the session and the end, largely as a result of the connections made with other workshop attendees. The workshops provided organized space for people to interact with one another, encouraging the relational maintenance behavior of shared networks. During the workshop sessions, participants interacted with each other frequently, using openness to disclose personal information, reminiscing to trigger a memory, and creating positivity through jokes. From Aaron asking where other participants such as Charles and John were on days they missed, to Bruce and Lewis asking each other how they were doing and complimenting each other's work, none of the participants blatantly rejected interactions with others. Additionally, participants like John seemed to enjoy their time with the group. He made jokes with the whole group (a form of positivity), and everyone said goodbye to him as he left. He also laughed several times throughout the workshop session he attended.

For many care partners, this was an important aspect of the process for their loved one with ADRD. As Emily noted in a follow-up phone conversation about Deb's behavior after the workshop sessions, "[Deb] does seem to be a little sharper. She's a little more talkative right now. I think there was an improvement [in her mood]." The workshop time was also helpful for

the care partners as they could spend time with other care partners and potentially share important information with one another. Jan noted in a follow-up call:

I think it would be nice if there were a few more people. I would just be curious to see if there were more people how the interaction would be. I used to be a teacher for 30 years and always wanted a smaller class, but if you have a small class and don't have a mix of people... having more people keeps the class lively.

Louise and Emily also spent a large amount of time talking to each other and offering advice, creating a network. Clearly, finding connection with people in a similar position was a positive experience for most participants, showing one side of the tension.

However, on the other side of this tension, participants at times felt overly vulnerable as a result of the social interaction (or lack thereof). Jan noted that she felt as though she and Lewis were “in their own bubble” as they worked (a shared task), and the therapist paid more attention to other participants who were not working on the mask with their partner. She noted, “I feel like my whole attention is to make him have a successful time, so the overall sharing of ideas is important.” In addition, she mentioned that she did not feel the interactions with other participants were meaningful, and she consistently feared that Lewis would have an accident and be embarrassed during their time. In this instance, she expressed that she enjoyed the workshop and interacting with others, but the interactions were often superficial. At times, she felt as though she and Lewis were excluded from the broader, and she continually worried about her partner and how he would feel if something embarrassing were to happen during this social interaction. While the other participants served as a form of network during the process, that existence of that network had both positive and negative components.

In a conversation, Carol noted that while Bruce generally enjoyed his time, he was going through a tough time the third week of the workshop, and she saw no difference in him after interacting and creating a network with others through relational maintenance behaviors such as positivity. Additionally, Deb got upset after one workshop because she felt embarrassed (the exact cause of the embarrassment was not clear), noting to Emily that, “She hadn’t been that embarrassed since she wet her pants when she was six.” While ten of the twelve participants noted that they enjoyed themselves overall in the workshops, these social connections are also inherently tenuous because they made participants vulnerable to alienation, embarrassment, or exclusion.

Helping versus dominating versus not helping. Another interesting tension that most care partner participants faced was balancing between helping their partner with ADRD, dominating the work, or not helping them. If they did not assist their partner with the mask, the mask risked being incomplete. However, they could also alienate their partner if they took over too much or did not help them.

Most care partners tried to achieve a balance by sharing the task and helping their partner only when necessary, leaving them to work independently the rest of the time. For example, Carol explained that she did not assist Bruce often because, “He was a little more capable than other people in the workshop.” She would occasionally help him by offering suggestions, but most of the time she let Bruce work independently. Louise took a similar approach to balancing this tension, allowing Aaron to work independently while also letting him talk through his ideas with her. At times, though these care partners appeared use avoidance or anti-social behaviors with their partners, each was working to achieve balance between offering help while also respecting their partners’ autonomy.

In other cases, care partners took a much more engaged role and helped their partner through the whole process with positivity, shared tasks, and touch. Jan and Emily reported emphasizing involvement (rather than independence) because their partners were unable to do the task alone. Jan also noted that, “I don’t think I could just sit back and let him [work]. It is just not my personality. And I want us to both be successful, so I try to work with him on the project.” In this instance, she expressed her conscious need to share the tasks with Lewis because of her personality and his physical limitations. However, Jan noted that even if she was doing too much or if he was not enjoying himself at the workshop session, Lewis “did not have the type of personality where he would say anything or mention it in class.”

While Lewis may not have let Jan know if she was doing too much, Emily attended one workshop alone because Deb refused to attend as a result of being embarrassed the previous week. During the session the week before, Emily was unable to attend, and another friend brought Deb. As she worked on her mask, Deb felt as though the therapist interfered with her process, reducing the need for shared tasks with her care partner that day. Of the event, Emily noted, “Deb felt humiliated; I think it was [the therapist] was doing the work for her. She felt like a child. She said [the therapist] just did it, and she didn’t ask for help.” This instance more broadly highlights the tenuous relationship between helping a person with ADRD and letting them remain independent.

Sharon also struggled to find balance helping Charles. In her case, Charles was largely unresponsive to the activity at hand regardless of Sharon’s positive remarks and pleas for help in the shared task. If she had let Charles work on the mask alone, they would have both sat quietly and unproductively for the duration of the workshop session. However, since she could not get

him to engage (a form of negative relational maintenance), she ended up doing most if not all the work by herself.

In these instances, the care partners tried to balance between assisting their partners when necessary and stepping aside when their partners wanted to work independently. Some felt left with a difficult choice: If they did not help at all, the mask might not be completed. This perception occurred in Sharon and Charles' situation. On the other hand, if individuals helped too much, they risked upsetting their partner and making them feel patronized, as in the case of Emily and Deb.

Activity convergence versus activity divergence. For some participants, the workshop sessions provided a good source of connection with the person diagnosed with ADRD, whereas other participants viewed the workshop as an activity only for the person diagnosed with ADRD. This effected participants' use of relational maintenance with their partner during the workshop. When care partners experienced a connection through the workshop, they were more likely to engage in assurances, shared tasks, networks, and positivity with their partner. However, when participants viewed the workshops as a predominately independent activity, they were less likely to interact with their partner and others, using avoidance and, in the case of one dyad, anti-social behaviors that minimized the positive effects of the network by creating a disjointed dynamic in the workshop.

Jan was the most vocal about how the workshop sessions offered a connection for her and Lewis. She explained, "I spend a lot of time with him, but I wouldn't say it is quality. This I feel like it's a little more quality and we get to work together." For Jan, this workshop presented a unique opportunity for quality interaction with her husband. Jan noted, "I've lost so much of what we had together, so anything [any connection] feels good and makes me happy." To her,

the workshop provided her an essential opportunity to connect with her husband, since they no longer lived together and as his illness continued to worsen. Other participants tried to use the mask-making experience to build connections with their partner by engaging in reminiscing. For example, Sharon tried to talk with Charles about activities he used to enjoy, and Emily took the same approach with Deb. These attempts to reminisce about the other person's likes and preferences offered a small form of connection and assigned meaning to the mask that they were creating.

However, other participants did not view the art workshops as a shared task. For example, Louise and Carol mostly left the mask-making process to their partners (Aaron and Bruce, respectively) and offered help only when necessary. Carol stated that the workshop, "[...] was more for him than it was for me," and that, "...I let him do his thing but feel like there are other things I could be doing that would be a better use of my time." While this may have helped manage the balance between when to help her partner versus letting him work independently, it became clear through both observations and follow-up calls that Louise and Carol's dyads (partnered with Aaron and Bruce) experienced few genuine moments of connection during the workshops as a result of their decision to take a more passive role in the process. Since they did not view this as a shared task, the two dyad's interactions were much more fragmented because at times, they would be engaged in what they were creating, and they would have conversation about the process, whereas other times they disengaged in the process and let their partners work completely independently. It was in these couples that the only occurrences of anti-social behavior or avoidance were apparent.

CHAPTER FIVE: DISCUSSION

Alzheimer's disease and other related dementias (ARD) are an increasing public health concern in the United States, with illness diagnoses projected to increase to 106 million people by 2050. While ample communication research illustrates the effects of ARD on those diagnosed with the disease as well as their close relationship partners, few studies have sought to understand how the use of relational maintenance behaviors as outlined previously by Canary and Stafford (2003) influence the experiences of people with ARD and their care partner. Additionally, very little research has explored how interventions designed to facilitate increased social engagement and creativity might provide unique opportunities for relational maintenance behaviors among people with ARD and their care partners. Recognizing these existing gaps in the literature and the growing need to examine how ARD influences relational communication among close relationship partners, this research identified different forms of relational maintenance behaviors that care partners used throughout a four-week participatory arts engagement intervention. Additionally, this research explored the effects of those relational maintenance behaviors on the participant's overall experience in the art engagement program from the perspective of the care partner.

In total, six dyads participated in the art workshops, and their video-recorded interactions as well as follow-up phone interviews were analyzed to illuminate nine relational maintenance behaviors (touch, reminiscing, positivity, shared tasks, networks, openness, assurances, avoidance, and anti-social behaviors) as well as four key tensions around relational maintenance behaviors (stimulating versus blocking cognitive function, social connection versus vulnerability, helping versus dominating versus not helping, and forming connection versus divergence). It is

important to consider both the theoretical and practical implications of this research and how it can better inform the participatory arts engagement experience and relational maintenance.

Theoretical Implications

Research Question 1:

The first research question sought to identify what relational maintenance behaviors care partners and adults with ADRD used while engaging in community participatory art workshops. Results showed that some relational maintenance behaviors appeared in interactions more frequently than others. For example, in alignment with Canary and Stafford's (2003) list of positive relational maintenance behaviors, *positivity*, *shared tasks*, and *networks* played out in interactions for all participants at multiple points. The use of these behaviors was logical given the environment and the role of caregiving.

Shared Tasks. For most participants, the process of making a mask was inevitably a *shared task* as most participants both wanted to work with their partner on the assigned project and had to share tasks given their partner's physical and cognitive limitations. The workshop environment differs from the household setting commonly associated with Canary and Stafford's (2003) typology. Given the participants were in an unfamiliar environment, the way that they shared tasks was not the same as it would be if they were in a house the partners shared. In this setting, participants were required work on the mask during a given period, and the role of the care partner was to assist their partner in the process in some capacity. The fact that the space was not their own and the tasks went beyond household chores, shared tasks appeared in a unique form in this research.

Networks. Similarly, the act of participating in the workshop created a *network* for participants to interact with people in a similar situation to them and all participants took

advantage of that network to varying degrees. In alignment with previous research, much of the care taking process involves patience and kindness toward a loved one suffering from ADRD (Hayes et al., 2009) and participants in this research used positivity to affirm and support their loved one. The prevalence of these relational maintenance behaviors further contributes to the growing research highlighting the utility of relational maintenance. This then explains how people sustain relationships by affirming previous research as initially outlined by Canary and Stafford (2003).

Assurances. Although less prevalent, participants (regardless of whether they were the person with ADRD or their care partner) also used *assurances*, *openness*, *avoidance*, and *anti-social behaviors*. The fact that these behaviors appeared less frequently is important as it better explains the role of care partners in the art-making process and the role of ADRD on a dyad's ability to complete the mask. According to Canary and Stafford (2003), *assurances* aim to affirm to a loved one that the relationship has a future and longevity to it. However, although people with ADRD can live several years past their diagnosis, there is no cure for the disease (Ferri et al., 2005). This creates a unique tension as previous research states that when a person has a debilitating and incurable illness such as ADRD, talking about the future can be a difficult conversation for family and loved ones since there is an immense amount of uncertainty regarding the illness and the person's life expectancy (Hellström & Torres, 2016). Instead, Hellström & Torres (2016) argue that family and friends might focus on the present or challenges they have already overcome instead of focusing on the future. Since *assurances* as defined in this research focus solely on the future and conversation about the present was classified as a different behavior, it is logical that there were few instances of this relational maintenance behavior. When exploring the use and effects of assurances, it is important to

consider the context. This context was not one where participants may have felt welcome or comfortable enough to discuss the uncertainty they have around the person with ADRD's future and therefore effected how the dyads interacted.

Openness. The use of *openness* in the workshop sessions was interesting given the disparity of its use amongst participants. For example, some participants disclosed a great deal of information about themselves or their loved ones during the workshops whereas others did not offer substantial information about themselves, especially without prompting from others. This is interesting considering previous research highlights one of the main issues associated with an ADRD diagnosis is social isolation for both the care partner and the person with ADRD (Burgener et al., 2015; Henson et al., 2004). It stands to reason that people would share parts of themselves with others when creating a social network in activities such as arts engagement.

However, research also notes the uncertainty and vulnerability associated with ADRD particularly as it relates to feeling stigmatized and disconnected from others (Stone & Jones, 2009), which better explains why some people shared about themselves whereas others did not. If a person feels that they will be unfairly stigmatized or will somehow feel alienated from the group, they might have withheld more in an act of self-defense both for themselves and for their partner. Additionally, participants might have withheld certain information about themselves or did not ask other participants to disclose because of the pressure to reciprocate associated with self-disclosure (Perion & Steiner, 2017). For a group of people who already feel stigmatized against and socially isolated (whether the person with ADRD or their care partner), both self-disclosing and reciprocating to someone else's self-disclosure could cause further undue stress (Stone, 2013). Instead, it might be easier to keep conversation light and surface-level to avoid uncertainty and discomfort. Ultimately, the disparity in certain behaviors or actions between

participants shows that the experience of arts engagement with ADRD was different for all dyads and some viewed the experience as more collaborative with the whole class, while others saw the activity as more individual, which altered which relational maintenance behaviors they used and how often.

Avoidance and Anti-Social Behaviors. Additionally, given the collaborative and unfamiliar environment, the lack of prevalence of negative relational maintenance behaviors such as *avoidance* and *anti-social behaviors* is consistent with expectations of people given social norms. Normal social behaviors state that people act kindly and cordially toward one another in public just as most participants did in this research (Griffin, Ledbetter, & Sparks, 2014). If the participants were in their own space or were in a different environment, deviations from normal might have been more expected. When participants did have moments of anti-social behaviors, it was only with their partner and usually came as a result of one person asking their partner a question and the partner not responding. While this changed the workshop environment temporarily between dyads, there was not tension between participant dyads as they worked. These occurrences were sparse and surprising since the environment of the workshops was laid back, collaborative, and welcoming.

Touch. While the ample use of some relational maintenance behaviors and the lack of other behaviors was logical given the environment and unique circumstances of participants with ADRD, the behaviors previously outlined in literature did not fully account for some of the behaviors of participants. In response, the criteria for a relational maintenance behavior for this research expanded to also include acts of *touch* and *reminiscing*. *Touch* as included as a form of relational maintenance because it highlighted certain aspects of non-verbal communication that are not accounted for in relational maintenance research (Canary & Stafford, 2003). For

example, when a care partner would tap their partner with ADRD to encourage them to respond to a question, it was difficult to categorize the behavior since it was not about the future, self-disclosure, a task, or any other specific category, yet it was important to the interaction. Consequently, since the action did not fall into any specific category and previous research supports that touch is highly important to interactions with people with ADRD (Gleeson & Timmins, 2004), the observational protocol used for data analysis needed to be broadened beyond what has been outlined in relational maintenance research to date. Touch was particularly salient as a form of relational maintenance given that ADRD is associated with loss of language and limited communication (Stone, 2013). As a result, nonverbal communication becomes an essential form of communication for people with ADRD, their families, and medical professionals (Gleeson & Timmins, 2004). The fact that it was prevalent in the participant's behaviors is significant because it means that people were intentionally trying to find connection and touch communicated when words failed.

Reminiscing. Similarly, *reminiscing* was highly prevalent in interactions between participants, yet also did not fit into one category given it served as a form of reflection for the participants. As highlighted earlier, *assurances* as a form of relational maintenance look toward the future of the dyads, which can be a difficult conversation and one that most people would not want to have in a public space such as an arts engagement workshop. With that in mind, reminiscing as a form of relational maintenance served to fill the gap in relational maintenance behaviors. Using reminiscing as a tool for interaction has been found to decrease care giver burden and increase the person with ADRD's perception of being loved (Fletcher & Eckberg, 2014). Previous research also supports that the act is an important tool for both care partners and the person with ADRD's connection to one another (Astell, Ellis, Alm, et al., 2010; Fels &

Astell, 2011; Fletcher & Eckberg, 2014). Including reminiscing as a form of relational maintenance was important to this study given the prevalence of the behavior in the workshops, how there was a gap in the categories to account for the behavior, and how previous research has affirmed it as an important tool for people dealing with the negative effects of an ADRD diagnosis. While relational maintenance has been the focal point of several communication studies, this research is unique in that not all behaviors observed fell under the various behaviors outlined by Canary and Stafford (2003). Whether that is because of the ADRD or other factors, this research serves as a call for additional studies highlighting the forms of relational maintenance and whether the framework that currently exists accounts for all behaviors.

Retention of Relational Maintenance Behaviors. The results from research question one highlighted that people use relational maintenance behaviors, whether strategic or routine, in their interactions regardless of their mental capacity. Even the participants who were the most limited in communication as a result of their disease showed signs of relational maintenance inherently through their interactions with their partner. For example, Lewis, who had limited physical capabilities and suffered more severe language deficits, was able to reminisce with his wife about their travels together, he offered several forms of positivity to others, and he shared the whole project with his partner. This is particularly poignant given that one of the main concerns of family and friends of people with ADRD is the barriers to communicate that result as the disease progresses (Stone, 2013). For care partners, results such as this may offer insight into how to better communication with a loved one with ADRD. Just as research has found that yielding the floor and asking questions of a person with ADRD can help with communication and connection (Small & Perry, 2005), this research implicates that engaging in arts engagement and using intentional relational maintenance behaviors on the part of care partners may also

encourage a person with ADRD to reciprocate those behaviors, leading to more frequent and potentially more substantial communication.

Research Question 2:

Research question two sought to understand how the use of these relational maintenance behaviors helped or hindered the arts engagement experience for the partners. Results showed that the use or nonuse of specific relational maintenance behaviors highlighted tensions that the dyads worked to balance throughout the mask-making process. The tensions included balancing between facilitating *social interaction versus vulnerability*, *helping versus dominating versus not helping* in the mask creation, *stimulating cognitive function versus blocking cognitive function*, and *offering a connection versus pursuing independence* for couples.

Social interaction versus vulnerability. Since social isolation has been found to be related to decreased quality of life for both care partners and their loved ones (Burgener et al., 2015), ample research supports that arts engagement can serve as an important activity to allow for social interaction (Stuckey & Nobel, 2010). However, the results of this research also highlight that this social interaction must be balanced to avoid discomfort. Within communication research, the tension of social interaction versus vulnerability may also be known as Baxter and Montgomery's (1996) external relational dialectic of revelation versus concealment. In this dialectic, people must decide between what they share with the outside world versus what they keep between the two of them (Baxter & Montgomery, 1996). While many participants showed an interest in getting to know the other participants in the workshop or having social interaction, there was a constant balance for both the care partner and their loved one with ADRD between what, when, and how often to share personal information or become involved in conversation with others. It is not enough to simply note when participants use a

relational maintenance behavior, but rather it is important to note the various tensions that might be at play in the moment. For example, openness was an underutilized behavior by participants. However, acknowledging how the tension between revelation versus concealment might be at play can better explain why a person did or did not actively engage in relational maintenance behaviors such as openness or assurances.

Helping versus dominating versus not helping. Baxter and Montgomery's (1996) relational dialectics can also apply to better explain the tension that care partners managed between helping versus dominating versus not helping at all as well as the tension of having connection between couples and the activity being separate for dyads. The tension that best connects to this balance is the connection versus autonomy internal dialectic (Baxter & Montgomery, 1996). In this dialectic, partners must manage between how much they rely on one another and how much independence each person possesses. When completing the mask, the care partners held different roles in the workshop. Some were more engaged in helping their partner than others and the dialectic of connection versus autonomy can help explain why. For example, Carol noted that she did not help her partner on a lot of the tasks because he could do the work on his own, especially in comparison to the other workshop participant (Lewis). In this instance, her form of managing this tension is different from Lewis's partner Jan, who helped him with nearly every aspect of the mask. Acknowledging how each person balances this tension better explains why some relational maintenance behaviors were more prevalent than others, especially as it related to an individual with ADRD's desire for both connection with other people and their own autonomy (Fels & Astell, 2011). Carol used fewer positive relational maintenance behaviors in comparison to Jan but that could be because she prioritized her partner's autonomy and interacted with her partner less as a whole because she understood his

capabilities. The understanding of tensions such as these present important considerations for future research on relational maintenance and how populations such as those effected by a life altering disease interact with one another. Additionally, this research opens the door to future exploration regarding tension management in these various contexts. More specifically, it would be interesting to explore whether these relational maintenance behaviors are the strategies care partners and people with ADRD use to manage these tensions or if they are only used to highlight that these tensions exist.

Relationship inequity. One important theoretical implication of this research is that it begins to address the issue of relationship inequity in caregiving for a person with ADRD. Previous research has shown that caretaker relationships are naturally inequitable. When caring for their loved one, caretakers experience grief, caretaker burden, isolation, and both physical and mental stress (Dyck, 2009; Walsh et al., 2004). Additionally, the majority of spouses take care of their significant other with dementia until it becomes too unmanageable (Buhr et al., 2006). Consequently, several spouses or care partners willingly continue in their inequitable relationships fraught with challenges caused by dementia. Since this goes against research on equity in relationships, this study takes a different perspective by examining the experience of a person who is willingly in an inequitable relationship. Due to the unequal relationship between caregiver and their partner with ADRD, an important component to this research is that the burden of managing those tensions fell largely on the care partners. Whether they were managing how they helped their partner, connected with their partner, asked of their partner cognitively, or how much they and their partner interacted with other participants, nearly the entire workshop consisted of the care partners managing both their and their partner's feelings and concerns through relational maintenance techniques such as positivity, networks, and shared tasks.

Balancing tensions. How often and when each person used relational maintenance behaviors can better explain how the care partners were trying to balance all the tensions with and for their care partner. When a care partner used positivity, it was typically correlated with encouraging their loved one to keep working or affirming that they liked what they were creating. When a care partner helped their partner with a task, it was usually to help them avoid frustration or unproductivity. Additionally, relational maintenance behaviors can shed light on the times where the person with ADRD responds to their partner's use of relational maintenance behaviors to help balance those tensions. For example, when Emily did much of the work on the mask (a shared task) but would always consult with Deb as she worked. In this instance, Emily was managing the tension by including her partner and Deb's affirmative responses to Emily showed that the tension was managed effectively.

As highlighted through the findings of research question two, relational maintenance can work to either stimulate or hinder the arts engagement experience for participants. The process of managing the experience for participants can be explained through the concept of face negotiation (Ting-Toomey & Kurogi, 1998). Inherent in each tension outlined through the results is the idea of face, which is the favorable social self that a person wants others to perceive of them (Ting-Toomey & Kurogi, 1998). Whether they are avoiding embarrassing, alienating, or overstimulating their partner, care partners were continually aware of protecting both their own face and their partner's both negative and positive face (Ting-Toomey, 2005). I argue that the care partners did this through their use of relational maintenance behaviors, particularly positivity and networking with the rest of the group.

Through both intentional and unintentional relational maintenance behaviors, care partners were continually protecting their partner's face and managing the various tensions. This

was particularly clear when a care partner would ask their partner if they liked what they were creating. In those instances, care partners were communicating to both the person with ADRD and the rest of the group that they had a say and were competent enough to make decisions even if they could not brainstorm the whole mask or do all of the tasks independently. Implications such as this can help researchers better understand why some relational maintenance behaviors are used more than others and how some dyads interact with one another. It can also better explain why some people enjoyed their experience more than others since they either were or were not successful in managing their face and the tensions associated.

Through connections to face negotiation theory, relational dialectics, networks, and equity theory, this research expands to relational maintenance as a useful frame to understand a wide range of situations with people from unique experiences. Ultimately, there are certain relational maintenance strategies that are more effective or widely used than others, just as the process of engaging in participatory arts engagement is a balancing act of several tensions, particularly for the care partner on behalf of their loved one.

Connections between maintenance behaviors and tensions:

An important consideration in this research is how the findings of related to the use of relational maintenance behaviors in a therapeutic arts environment intersect with those regarding the various tensions present throughout the classes. For example, important insight can be gleaned by exploring why a person might use a given relational maintenance behavior and how it relates to tension management. In some cases, participant's use of relational maintenance behaviors was either proactive in avoiding a tension, reactive in responding to a tension, or created a tension itself. For example, when a participant with ADRD would joke about their illnesses or physical impairments, they were using positivity to proactively avoid the tension

between *social connection versus vulnerability*. In that instance, their choice to disclose that information was a strategic relational maintenance behavior intended to avoid any confusion or tension surrounding their physical capabilities. Additionally, when a care partner would ask their partner if they were okay with what the pair was creating, their act of sharing brainstorming tasks served to ensure that the partner with ADRD did not get upset about the care partner taking over too much of the task (managing the *helping versus dominating versus not helping* tension). Each of these behaviors worked in response to potential tensions that could arise at any moment and were used to proactively decrease the possibility of these tensions occurring.

At other points in time, participants used certain relational maintenance behaviors to react to the creation of a tension. Although less common, this appeared in cases such as when a care partner would try to save or manage both their face and their loved one with ADRD's face (Ting-Toomey, 2005). Care partners were more likely to use relational maintenance behaviors in response to a tension. One example occurred when Charles grew upset during the cognitive testing. Seeing that he was agitated, Sharon used both touch to affirm and positivity with her partner to try and calm him down and keep his focus on the task at hand. She used certain maneuvers such as positioning herself in front of Charles and placing her hands on his legs to try and manage the tension of stimulating cognitive function versus impairing cognitive function. Emily also continually balanced the tension between social connection and vulnerability by continually asking Deb if she could tell a particular story before sharing the whole story with other workshop participants. In this case, she used openness to disclose as a means of balancing between wanting her partner to share information but also knowing her partner had boundaries on what could be shared and what needed to remain private for her own comfort (a tension of *social connection versus vulnerability*).

While the use of these relational maintenance behaviors was at times proactive or reactive, there were also times when the use of certain relational maintenance behaviors actually resulted the various tensions. This was particularly prevalent with regard to negative relational maintenance behaviors used by both care partners and the participant with ADRD. For example, when participants would use avoidance by rejecting help from their care partner, this created a tension between not only how much a care partner could/should help, but also a tension between activity convergence and divergence. In other words, not only did the care partner need to balance between how much they should help their partner, there was also a lack of clarity about how much each person saw the mask making as a shared task versus how much they saw it as a partner activity. These tensions have the potential to confound, creating more ambiguity. Ambiguity in the role between each participant created specific relational maintenance behaviors such as anti-social interactions or avoidance and those, in turn, created more tension. Another example came from when a care partner would use anti-social behaviors with the person with ADRD through sarcastic remarks, as it created more distance between partners as they navigated how much the activity was shared and how much it was independent for the person with ADRD (tension of activity convergence versus activity divergence).

Another important consideration regarding the balance of the tensions associated with the arts engagement process is that prosocial relational maintenance behaviors seemed to manage these tensions whereas antisocial tensions were more likely to create them. When a partner used positive relational maintenance (whether the person with ADRD or the care partner), they seemed much more able to clearly communicate their thoughts, opinions, and preferences. This then increased the amount of communication between partners, while also decreasing any miscommunication and equivocality between partners. Ultimately, this left a smaller amount of

room for tensions to exist between the partners. However, when a partner used negative relational maintenance, there seemed to be a much larger possibility that the two would not be on the same page regarding the task (activity convergence versus divergence), their independent roles (tension of helping versus dominance versus not helping), and how they would interact with others (tension of social connection versus vulnerability). This lack of alignment worked to create and then perpetuate these tensions, particularly for the care partners who then needed to manage the tasks. The clear communication associated with positive relational maintenance worked to help partners collaborate, whereas negative relational maintenance behaviors seemed to create distance between the two. At the very least, it limited the amount of communication that the partners had (since partners who used more negative relational maintenance seemed to communicate less overall), which in turn created more tension for the care partner as they had to try and navigate their partners preferences, needs, opinions, etc. without consistent communication from their partner regarding these important topics.

Overall, the use of specific relational maintenance behaviors served multiple purposes including proactively avoiding tensions, responding to pre-existing tensions, or creating the tensions in an of themselves. The relationship between the use of these behaviors and the associated tensions is very important to further understanding how relational maintenance plays a role in the effectiveness of various activities such as participatory arts engagement.

Arts Engagement as a unique context:

Aside from the known benefits of arts engagement programming as outlined earlier in this research, creating art as therapy is a unique experience for people with ADRD given the mix of both cognitive and physical stimulation they receive (Camic et al., 2014). While other forms of therapy such as physical therapy are highly beneficial to people with ADRD for a variety of

reasons, arts engagement requires a person to engage both with planning and brainstorming as well as with physical acts to create the art. This is important because it asks a person to engage with several skills that AD/HD may threaten or diminish. The physical creation of the mask serves as a way for participants to process their feelings, engage in movement that they might not do routinely, and connect with others in a similar position to them, which increases social support (Borgmann, 2002; Stone, 2013).

The participatory arts engagement context is unique given that it is associated with the conversation of what is private and public information. Best explained by relational dialectic theory's internal versus external tensions (Baxter & Montgomery, 1996) and face negotiation theory (Ting-Toomey, 2005), this research highlights a gap in other relational maintenance behavior research by discussing the implications behind why a person might or might not use a certain relational maintenance given the public context. Most previous relational maintenance research has focused on private settings or contexts, which then allow for certain relational maintenance behaviors to be more prevalent given the limited number of people involved in the interaction. Arts engagement, however, calls for new considerations regarding the tension between balancing that participants want to share with the public versus what they want to keep between themselves. For example, it makes sense that assurances and openness were not common in interactions given that both are associated with intimate parts of a relationship that would be inappropriate to discuss in a public setting such as a mask-making workshop. Additionally, it is logical that networks and positivity were prevalent because people were trying to create a welcoming environment and used the public workshop setting as an opportunity to engage with people in similar situations. Since the idea of what is public and private and how that affects the use of certain relational maintenance behaviors is highly underdeveloped in

communication research, this project serves to stimulate conversation regarding whether there should be different expectations for how relational maintenance behaviors are used given private versus public contexts.

Practical Implications

For participants and therapists. A major implication from this research for participants and therapists is that it highlights the tensions that participants may face in participatory arts engagement. Within this conversation, several important facets exist that therapists need to be aware of and care partners need to consider before signing their loved one up for a class doing an activity such as making a mask.

It is important for participants and program facilitators to note that some relational maintenance behaviors are more effective than others in the context of participatory arts engagement. As seen in this research, participation in art experiences can be overwhelming or demand too much cognitively of a person with ADRD at times. In response to those tensions, certain relational maintenance behaviors work to manage those tensions better than others. Through the participants, it became clear that positivity is a consistently useful tool for both people in a partnership as it can encourage, clarify, assist, etc. While at times they did perpetuate tensions addressed earlier, shared tasks also helped to create an environment where the person with ADRD was not working alone but was not idly sitting by as other people did their project. Anti-social behaviors and avoidance came at times from a care partner's desire to allow their partner to work alone so that they could avoid alienating their partner by taking over the project. Each of these tasks, when done well, served to manage the tensions that care partners faced. Conversely, behaviors such as assurances seemed to have a little to no effect on the situation as people did not talk about their future. For therapists or those planning the programming,

overstepping by dominating a task (as with Deb when Emily was not present) or by asking for too much cognitively from a person with a memory related illness (as with Charles and Sharon) can alienate the very people they are trying to assist. Although these behaviors may be small in nature, the effect that they have on a situation can be substantial.

A second important consideration for participants, particularly care partners and program facilitators, is to know that consistency is key. Several online publications regarding care for a loved one with ADRD reiterate the need for this consistency (“Caring for Someone with Dementia,” n.d.; “Consistency Matters in Dementia Care,” 2017; LaPira, 2015; Wilson, Rochon, Mihailidis, & Leonarda, 2012). Whether that be with the relational maintenance behaviors used, attending class regularly, or setting a clear pattern for how the tasks will be shared during the process, the smaller the ambiguity in each situation, the better participants are able to engage in the art making process. To be consistent in an art workshop setting, care partners and the therapist can keep the setup of the class consistent, have participants sit in the same seat, use the same materials each session, and generally behave the same toward participants with ADRD each week.

A final important consideration is that sometimes external factors affect the arts engagement process and, regardless of the effort or relational maintenance behaviors used, participants do not or cannot engage. In the case of Sharon and Charles, no matter how much positivity or touch Sharon used, she could not get her partner to engage. Whether that was because he was overwhelmed with the research or he was having a rough day, Sharon’s use of relational maintenance behaviors and the therapist’s attempt to assist made no significant difference in their interactions or progress on the mask. This speaks to the limitations of the theoretical framework to explain every interaction between partners. As previous research states

that people with ADRD have both good and bad days (Mace & Rabins, 2001), it is also important to note the limitations of relational maintenance's ability to explain every situation particularly because of the uncertainty associated with ADRD. When looking to participate in arts engagement, it is important for both participants and the program facilitator to know that external factors can alter a person's productivity and mood and that relational maintenance behaviors may explain some interactions, but not all.

For researchers. Beyond the theoretical implications discussed above, the practical implications from this research can help to strengthen future research on arts engagement and people with ADRD. A major consideration for researchers is to limit the intensity of their research design. Throughout the process, several participants in the 2017 workshop noted that the research activities in conjunction with the mask-making tasks were too intense for the participants with ADRD. Gaining important and relevant information is essential, but a fine balance exists between getting rich data from a participant and overwhelming them in the name of research. This appeared to happen in the case of Charles and Sharon. During Charles' cognitive testing, he grew agitated to the extent that Sharon had to assist him in the process. Afterward, he was unable to engage in the mask making process. Sharon noted in a follow-up call that the research was too taxing, and they did not return for another session. An adjustment was made in the 2018 workshops where most of the important demographic and cognitive research was collected on a separate date and time. No one from the 2018 data set noted issues to the research being too demanding. This seemed to optimize the workshop time and allowed participants to engage in their process deeply. Due to the communicative barriers and cognitive limitations of the participants with ADRD, it is important to work with the care partner to protect

their loved one and have realistic expectations of what they can and cannot offer during a single workshop session.

Limitations and future research

Although this research provides important theoretical and practical implications for the consideration of relational maintenance behaviors through participatory arts engagement for care partners and adults with ADRD, two particularly notable limitations stem from this research. First is the small number of participants. Throughout the two different cohorts, only three dyads consistently attended every session. Two dyads only attended the first workshop session and a third dyad attended all four workshop sessions, though both participants were not present at every session. Three other dyads signed up for the class but were unable to attend any of the sessions. Though this methodological approach provided an in-depth look at the experience of care partners and adults with ADRD, the results are not generalizable to a larger population as only twelve participants total were involved in the study. Instead, it touches on the surface of the issue, allowing for important future research with a larger population. In response to this limitation, this study could be replicated with more participants. The involvement of more participants would allow for a more well-informed conversation about the utility of arts engagement for couples dealing with the effects of a significant illness such as Alzheimer's or dementia. To strengthen the research more, a longitudinal study with the same lead researcher would add consistency to the data analysis in a way that this research fell short.

While the researchers had contact and provided important information to one another, having different researchers collect the data for each year was another limitation for the study. The lack of consistency between researchers meant that data was analyzed and conclusions were drawn across cohorts with limited personal interaction with the lead researcher. This is

problematic because it limits the scope and specificity of the data collected from the 2017 cohort. Despite this lack of consistency, several steps were taken to overcome the lack of interaction between the lead researcher and the 2017 cohort, including meetings with the lead researcher from 2017 to learn more about the participants, context, and interactions which were then analyzing in combination with the video footage, researcher notes, and follow-up calls.

A final limitation of this research was the fact that all of the care partners were women and only one of the participants with ADRD was a woman. This is particularly interesting given that two thirds of people living with Alzheimer's disease or dementia are women ("Women and Alzheimer's," n.d.). While it is also true that more than 60% of caregivers to people with ADRD are women ("Women and Alzheimer's," n.d.), the fact that there were no care partners who were male might have altered the data collected as the way that women use relational maintenance might differ from the ways that men use relational maintenance behaviors, especially in a public setting (Ragsdale, 1996). To address this disparity, alterations in programming might be necessary to better engage male care partners. Since men are less likely to access social support programs such as mental health support or medical help (Doward, 2016), programmers might consider creating a workshop specifically for male care partners or recruiting specifically male care partners. Small programming changes such as these could create a welcoming and destigmatized space for male care partners to both help their loved one get involved in programming as well as themselves.

Conclusion

When beginning this research, an impetus for research was to better understand the utility of participatory arts engagement in the lives of people who are not necessarily artists. While only the first step in this process, the observations of and interactions with participants have

highlighted both when arts engagement is fruitful, and where it can be limiting. The unique context of participants with a memory related illness helped me to better understand who can benefit from arts engagement and who might be better suited for a different activity. This research has presented a wide variety of new research ideas related to the topics of arts engagement, relational maintenance, and life-altering illness. As the prevalence and threat of life-altering illnesses seems to grow each day, research looking at a person's individual experience doing different enriching activities can help us understand and mitigate or minimize the heavily negative effects of these illnesses on relationships and communication.

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APPENDIX A: FOLLOW-UP CALL PROTOCOL

Participant #

Interviewer Initials

Caregiver Phone Interview Questions (within the week following the performance):

How was the experience overall? *Probe: What do you and your partner enjoy most about attending the art class? Anything you did not enjoy?*

Tell us about how you interacted with your partner during the art class. *Probes: Did you make any physical contact during the class? Did you talk about the class and what you were doing over breaks?*

Did the way you and your partner usually interact change at all before, during, or after the class? *Probes: What changes happened? How long did these changes last? Were these changes pleasant or unpleasant?*

Did you interact with others at the class? *Probes: Who did you interact with? Were these interactions meaningful? How did they make you feel?*

After the class, did you talk with anyone about your experience? *Probes: Who did you talk to? What was the nature of your conversation? How did you feel during/after this conversation?*

Do you feel that being involved in this class helps you maintain your relationship with your partner? If so, how?

How engaged was your partner during the class? *Probes: What did their attention look like? When did they pay the most attention?*

Did you notice any changes in your loved one's mood, attitude, or memory after the class?

What sorts of activities do you and your loved one do together? How does attending the class compare to these other activities? *Probes: How much did you talk about the experience later as compared to other activities?*

What would you say are the biggest benefits of attending these classes for both you and your loved one? What are the challenges?

APPENDIX B: OBSERVATIONAL PROTOCOL VERSION 1

Strategy	Definition	Sample indicator related to this study
Touch	Making physical contact with another person or object (isolated to the workshop)	<ul style="list-style-type: none"> • Leaning into a partner • High-fiving • Helping partner draw or paint • Hugging • Holding hands • Touching an object such as a feather • Other related actions
Reminiscing	Reflecting on the past, having conversation about past experiences (can occur in workshop or in follow up call)	<ul style="list-style-type: none"> • Asking partner if they remember a person, place, event • Retelling a story about their experiences • Talking about raising children, previous careers • Discussing what life was like before dementia diagnosis • Other related actions
Networks	Surrounding oneself with friends and family who offer support and a shared community (can occur in workshop or in follow up call)	<ul style="list-style-type: none"> • Interacting with other people at the workshop • Talking about family or friends • Taking photos of the mask or process to send to loved ones • Partner without Alzheimer's talking with family/friends about class • Other related actions
Shared Tasks	The equitable sharing of responsibility (isolated to the workshop)	<ul style="list-style-type: none"> • Sharing responsibility instead of one person doing it all • The care partner assisting their loved ones with painting, gluing, or other artistic tasks. • Asking for the other person's opinion on what to do next • Creating a theme for the mask together • Other related actions
Assurances	Expressions of love that imply the relationship has a future (can occur in workshop or in follow up call)	<ul style="list-style-type: none"> • Talking about their families • Talking about how the mask will look good in their house • Talking about other activities they do or will do together • Other related actions
Openness	Discussions people have about their relationship	<ul style="list-style-type: none"> • Talking about how the mask represents their relationship today • Asking partner if they remember something about their recent interaction together • Talking about challenges in their relationship as a result of the dementia • Other related actions
Positivity	Prosocial behaviors such as being	<ul style="list-style-type: none"> • Making jokes, laughing

	encouraging, polite, friendly, and kind to another person	<ul style="list-style-type: none"> • Telling their partner they are doing a nice job • Being upbeat • Commenting on the improved mood or memory of loved one • Other related actions
Avoidance	Not addressing or dealing with a task or conversation that is undesirable or burdensome	<ul style="list-style-type: none"> • Avoiding certain topics of discussion during the mask-making process • Not completing certain tasks necessary to make the mask • Cutting off partner if they mention something the person does not want to discuss • Changing the subject • Rejecting help
Destructive conflict	Behaviors that create distance between partners	<ul style="list-style-type: none"> • Speaking harshly toward or about partner • Controlling partner's behavior when the person could or wants to do something else • Starting an argument between partners
Other	Actions or conversation that does not fit under any category	<ul style="list-style-type: none"> • Anything that is not consistent with the guidelines outlined above.

APPENDIX C: OBSERVATIONAL PROTOCOL VERSION 2

Strategy	Definition	Sample indicator related to this study
Touch	Making physical contact with another person or object (isolated to the workshop)	<ul style="list-style-type: none"> • Leaning into a partner • High-fiving • Helping partner draw or paint • Hugging • Holding hands • Touching an object such as a feather • Other related actions
Reminiscing	Reflecting on the past, having conversation about past experiences (can occur in workshop or in follow up call)	<ul style="list-style-type: none"> • Asking partner if they remember a person, place, event • Retelling a story about their experiences • Talking about raising children, previous careers • Discussing what life was like before dementia diagnosis • Other related actions
Networks	Surrounding oneself with friends and family who offer support and a shared community (can occur in workshop or in follow up call)	<ul style="list-style-type: none"> • Interacting with other people at the workshop • Talking about family or friends • Taking photos of the mask or process to send to loved ones • Partner without Alzheimer's talking with family/friends about class • Other related actions
Shared Tasks	The equitable sharing of responsibility (isolated to the workshop)	<ul style="list-style-type: none"> • Sharing responsibility instead of one person doing it all • The care partner assisting their loved ones with painting, gluing, or other artistic tasks. • Asking for the other person's opinion on what to do next • Creating a theme for the mask together • Other related actions
Assurances	Expressions of love that imply the relationship has a future (can occur in workshop or in follow up call)	<ul style="list-style-type: none"> • Talking about their families • Talking about how the mask will look good in their house • Talking about other activities they do or will do together • Other related actions
Openness	Discussions people have about their relationships or self	<ul style="list-style-type: none"> • Talking about how the mask represents their relationship today • Self-disclosure with partner, group, or therapist. • Other related actions
Positivity	Prosocial behaviors such as being encouraging, polite, friendly, and kind to another person	<ul style="list-style-type: none"> • Making jokes, laughing • Telling their partner they are doing a nice job • Being upbeat • Commenting on the improved mood or memory of loved one • Other related actions

Avoidance	Not addressing or dealing with a task or conversation that is undesirable or burdensome	<ul style="list-style-type: none"> • Avoiding certain topics of discussion during the mask-making process • Not reacting or responding if partner talks to them • Not completing certain tasks necessary to make the mask • Cutting off partner if they mention something the person does not want to discuss • Changing the subject • Rejecting help
Anti-social behavior	Behaviors that create distance between partners	<ul style="list-style-type: none"> • Speaking harshly toward or about partner • Controlling partner's behavior when the person could or wants to do something else • Sarcasm or short responses to partner • Defensive behaviors
Other	Actions or conversation that does not fit under any category	<ul style="list-style-type: none"> • Anything that is not consistent with the guidelines outlined above.