

**Art Therapy with a Group of Dementia Caregivers:  
Exploring Well-being through Social Support and Creative Expression**

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## **ABSTRACT**

### Art Therapy with a Group of Dementia Caregivers: Exploring Well-being through Social Support and Creative Expression

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The purpose of this instrumental case study was to determine how an art therapy intervention affects self-reported measures of social support and creative expression with groups of dementia caregivers. A secondary purpose was to further an understanding of the stressors and burden experienced by caregivers, as well as identifying needs of the caregiving population. This was achieved by conducting a weekly art therapy intervention, over eight weeks.

Nine participants were recruited from constituents of the Alzheimer's Association Delaware Valley Chapter. One group was held in Philadelphia, PA consisting of five participants, and another was held in Marlton, NJ consisting of four participants. Each group met weekly, created artwork related to dementia care, and took part in a group discussion. A modified version of the Psychological Well-being Scale for Caregivers (mPWS-C) was used to track factors well-being.

Pre/post-interviews data suggests an increased awareness of social support, feelings of connectedness, and expression. Results also suggest that well-being is dynamic and constantly changing. This was reflects in artwork produced, as well as measures from the mPWS-C. Further exploration is needed to define the modulating effect of an art therapy intervention on groups of dementia caregivers.

## CHAPTER 1: INTRODUCTION

The purpose of this instrumental case study was to determine how an art therapy intervention affects self-reported measures of social support and creative expression with groups of dementia caregivers. Study outcomes were investigated through interviews and clinical notes, artwork, and quantitative scales. Participants took part in a group art therapy session one hour per week, over eight consecutive weeks. Well-being was examined through participant perceptions of social support, emotional distress, life meaning, and caregiver inadequacy.

The number of people living with Alzheimer's disease in the US is currently estimated at 5.4 million (Alzheimer's Association, 2012). Types of dementia other than Alzheimer's disease include frontotemporal lobar degeneration (FTD), dementia with Lewy bodies (DLB), vascular dementia, mixed dementia, and others. By the year 2050, the number of people with Alzheimer's disease and other related dementias is expected to triple (Alzheimer's Association, 2012). Many organizations describe this rapid population growth as an impending healthcare crisis.

The number of unpaid, dementia caregivers is currently estimated at 15 million nationwide (Alzheimer's Association, 2012). The Alzheimer's Association reports that in 2011 family caregivers provided over 17.4 billion hours in care at a value of over \$210 billion. This report also states that over 80% of care for people with dementia is provided in the home setting, a large portion of which is provided by family members. The total number of caregivers is also expected to grow in response to the increase of the dementia population.

For this study, the operational definition of a caregiver will be defined as a person providing direct, unpaid care to someone in the home who has a diagnosis of Alzheimer's disease or related dementia. Unpaid caregivers are typically comprised of spouses, sons, daughters, extended family, or other individuals providing care in the

community. Well-being will be defined as a state of acceptance and adequate management of both psychological and practical aspects of caregiving, including self-care and use of appropriate coping strategies.

Caring for people with dementia causes significant stress for spouses, adult children, and other individuals in the community who provide direct, primary care. Caregivers provide assistance with activities of daily living (dressing, bathing, toileting, etc.), as well as psychological and behavioral support. Caregiver stress has been associated with several health risks, which increase the occurrence of cardiovascular disease, hypertension, mortality, and a decline in global health (Schulz & Beach, 1999; Shaw, Patterson, Semple, Ho, Irwin, Hauger, & Grant, 1997). In addition to health issues, caregivers are also more prone to developing psychological, social, and financial problems (Brodaty, Green, & Koschera, 2003).

In a telephone survey, 61% of caregivers for individuals with dementia report experiencing high to very high levels of emotional stress and 43% reported experiencing high to very high levels of physical stress (Alzheimer's Association, 2012). Dementia care requires greater assistance in activities of daily living, as well as a longer duration of care than other old-age assistance (Alzheimer's Association, 2012). These factors contribute to feelings of burden, which may result in diminished well-being in caregivers.

Previous interventions have attempted to alleviate the burden experienced by dementia caregivers through providing interventions such as education and training programs, support groups, individual counseling, respite care, or a combination of approaches. (Brodaty et al, 2003; Knight, Lutzky, & Macofsky-Urban, 1993). Several interventions have aimed to minimize caregiver stress, which may have a positive outcome on deterring or postponing stress-related health risks (Shaw et al, 1997). However, these approaches have been shown to have moderate effectiveness (Knight et al, 1993) and few have empirically studied caregiver well-being.

Caregivers also experience a lack of social support due to isolation that occurs from time constraints, depleted economic resources, stigma, etc. (Bullock, 2004; Diehl, Mayer, Forstl, & Kurtz, 2003). Caregivers who perceive that they have adequate social support generally have a higher degree of coping, stress management, and are able to provide care more effectively (Lai & Thomson, 2011; Wilks, 2009; Haley, Levine, Brown, & Bartolucci, 1987).

Group therapy may provide a way to increase perceptions of social support, through interpersonal dynamics that exist in a group setting. Yalom (1983) identifies the positive effects of social support in group therapy, such as the instillation of hope, universality, imparting of information, and altruism. The group component has also been shown to provide supportive empathy and an opportunity to receive helpful suggestions from other caregivers (Diehl et al, 2003).

Diehl et al (2003) notes that many caregivers find it difficult to verbalize emotions, which may be considered unacceptable toward the care recipient. The authors also state that caregivers may experience anger, aggressiveness, and embarrassment, which may result in feelings of shame and guilt. The author also suggests that the inhibited expression of negative emotions related to caregiving may contribute to increased levels of stress.

Art therapy provides an alternative way to express such feelings due to its non-verbal, symbolic, and objective nature. Wadeson (1980) describes the clinical advantages of art therapy. They include the use of imagery and metaphor, decreased psychological defenses, an externalization of internal thoughts and feelings (i.e. objectification), permanence as a record for personal use and research, the use of a spatial matrix which can represent many things at once, and the generation of creative and physical energy.

In studying published works from the field of art therapy, little has been presented regarding group, art therapy interventions for dementia caregivers. Therefore, the research question is: What effects will an art-therapy intervention have on self-reported measures of social support and creative expression with groups of dementia caregivers? This study will not only inform the field of art-therapy, but it will also help define the needs of the dementia caregiver population.

Over the course of the study, caregivers were asked to create artwork around topics that are relevant to dementia caregiving. The group dynamics and discussion, as well as the art elements and context of the artwork produced, was documented for analysis. A modified version of the Psychological Well-being Scale for Caregivers (mPWS-C) was administered before and after each session to track factors of life meaning and social support, caregiver inadequacy, and emotional distress over the course of the intervention period as determinants of well-being.

In addition, simultaneous programming was provided for people with dementia, as respite for study participants and a means for them to attend the intervention. Programming for the person with dementia was coordinated via the Rocket Educational and Community Center (REC Center) and provided through the Alzheimer's Association Delaware Valley Chapter (AADVC). This programming was offered free-of-charge and was available to people in the early to moderate stages of dementia.

Collecting both quantitative and qualitative data regarding dementia caregivers has helped define the mental health needs of this growing population. It also provided valuable information about the general needs of both caregivers and people with dementia. Furthermore, this study provided information about the use of art therapy in a group setting and its effect on the well-being of dementia caregivers.

This study is limited by the small number of participants (n=9). Caregivers are heterogeneous in nature and come from a diverse socio-economic, cultural, and

educational background. The study is also delimited by barriers that may have prevented caregivers from participating, such as access to the site locations or the illness severity of the person with dementia. This study is also subject to volunteer bias, as participants were self-selected.

Results of this study indicated that at the conclusion of the intervention dementia caregiver participants were able to identify more sources and types of support, as well as identifying more ways to express their thoughts and feelings. The study found that caregiver well-being is dynamic and changes over time and under different conditions. Over the course of the eight-week intervention, composite scores of well-being for each case demonstrated a maintenance and positive modulation of well-being through self-reported quantitative measures, interview responses, and artwork produced.

Participants expressed that attending groups and engaging in the creative process was valuable to them. Participants gained insight through the creative process, received support and the instillation of hope from other group members, and were able to share their experience with others. Further research is needed to further define the modulatory effects of an art therapy intervention on the well-being of dementia caregivers.

## **CHAPTER 2: LITERATURE REVIEW**

### **Overview**

Providing care for people with dementia causes a significant amount of stress for spouses, adult children, and other individuals providing primary care. Caregiver stress has been associated with health risks, which may increase the occurrence of cardiovascular disease, hypertension, and mortality. However, studies using measures of stressors, such as activities of daily living (ADL) assistance, occurrence of problematic behaviors, as well as the daily time and total number of years spent caregiving, have not been clearly identified as determinants of the stress experienced by caregivers. Some literature suggests that chronic stress is related to psychological effects, such as anticipatory grief and ambiguous loss, rather than hands-on-care (Dupuis, 2002; Frank, 2008).

Psychological factors that influence feelings of stress and burden may inhibit the care of a person with dementia, as well as having a negative impact on caregiver well-being. The literature suggests that encouraging self-care and coping practices, facilitating restorative mental breaks and psychological uplifts, and enhancing perceptions of social support may deter this effect (Donovan & Corcoran, 2010; Watts & Teitleman, 2005; Acton, 2002; Butcher & Buckwalter, 2002; Clip & George, 1990). Lastly, art therapy will be reviewed as a new and creative way to help facilitate these objectives, while also providing a conduit for self-expression and affect management.

### **Dementia**

#### **Prevalence**

5.4 million people are currently affected by Alzheimer's disease in the United States (Alzheimer's Association, 2012). That number increases when one also factors in types of dementias other than Alzheimer's disease. Alzheimer's disease accounts for approximately 70% of all dementias. While some dementia is treatable, and possibly



reversible, neurodegenerative diseases are progressive and ultimately fatal. Dementia population totals will increase as more of the general population enters an age that is at greater risk for developing symptoms, in addition to the improvement of diagnostic testing, increased access to diagnostic services, and greater community awareness.

### **Definition**

The Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, text revision (American Psychiatric Association, 1994) (DSM-IV-TR) defines dementia due to Alzheimer's disease as the development of multiple cognitive deficits manifested by both memory impairment and one of the following: aphasia, apraxia, agnosia, and/or disturbances in executive functioning. Aphasia, apraxia, and agnosia are defined as the inability to form or understand language, initiate or execute motor movements, or recognize people or objects, respectively. Disturbances in executive functioning entail the inability to engage complex cognitive processes such as planning, decision making, or abstract thinking.

These impairments cause significant difficulties in social and occupational functioning. There is currently no cure or effective treatment for Alzheimer's disease, and it is marked by a gradual onset with a slow decline in cognitive function. Those with Alzheimer's disease may be diagnosed with, or without, significant behavioral disturbances. Dementia is determined by criteria put forth in the DMS-IV-TR. To meet criteria for dementia, symptoms must be severe enough to interfere with daily life and include both a decline in memory and at least one of the following cognitive abilities to:

- 1) generate coherent speech or understand spoken or written language.
- 2) recognize or identify objects, assuming intact sensory function.
- 3) execute motor activities, assuming intact motor abilities and sensory function and comprehension of the required directive.

4) think abstractly, make sound judgments and plan and carry out complex directives.

## **Symptomology**

Alzheimer's disease and other related dementias are neurodegenerative conditions, which cause a gradual decline in global cognitive functioning. Typically, people with dementia first experience problems retaining new information, then experience more difficulty retrieving long-term memories as the disease progresses. Although dementia is most commonly associated with memory loss, there are also other symptoms, which have an impactful effect on both people with dementia and caregivers:

- Challenges in planning or solving problems.
- Difficulty completing familiar directives at home, at work, or at leisure.
- Confusion with time or place.
- Trouble understanding visual images and spatial relationships.
- New problems with words in speaking or writing.
- Misplacing things and losing the ability to retrace steps.
- Decreased or poor judgment.
- Withdrawal from work or social activities.
- Changes in mood and personality.

(Alzheimer's Association, 2012)

Over the progression of the disease, the individual's cognitive and functional abilities decline. In the early-stages, individuals may need prompting or assistance to complete directives, keep a schedule, or express themselves. In moderate to advanced dementia, people need help with basic activities of daily living, such as bathing, dressing, eating and using the bathroom. Those in the final stages of the disease lose their ability to communicate, become bed-bound, and are reliant on 24-hour care.

Alzheimer's disease and other related dementias are ultimately fatal.

Karttunen et al. (2010) examines the influence of neuropsychiatric symptoms on the well-being of people with mild to moderate dementia and their caregiver. 240 caregiving dyads completed several evaluations as part of a rehabilitation program. Frequent symptoms that were noted are apathy, depression, irritability, and agitation. Neuropsychiatric symptoms were associated with a caregiver's assessments of a patient's quality of life, but did not affect the self-assessment of a patient's own quality of life. This suggests that negative neuropsychiatric symptoms may have a greater impact on caregivers, as opposed to the person with dementia.

### **Caregiving**

A review of the literature suggests that there is a significant increase in health risks associated with chronic, caregiver stress. However, the causes of this stress are still undetermined. In addition to the physical burden of caring for people with dementia, the mental health constructs of ambiguous loss and anticipatory grief may also contribute to the stress experienced by caregivers. Enhancing factors of well-being may minimize effects of stress and burden.

### **Demographics**

For the purposes of this review, caregivers are defined as those who provide unpaid care for people with dementia, and are typically comprised of spouses, sons, daughters, extended family, or other individuals providing care in the community. Currently, there are over 15 million people providing care for a person with Alzheimer's disease or other dementias.

The 2009 Behavioral Risk Factor Surveillance System (BRFSS) (Alzheimer's Association, 2012) survey provided a basis for demographic data. Over 6,800 caregivers were surveyed in four states. The survey found that caregivers are likely to be 55 or older, female (70.3%), married (72.8%), and white (81%). It was also noted that almost half of caregivers take care of a parent, while between 6-17% take care of a spouse.

## Well-being

The presence of stress and burden in the caregiver population has been examined extensively. Caregivers report significantly more perceived stress compared to non-caregiver controls on stress scales (20.5 [1.6] v. 13.7 [1.5],  $p < 0.002$ ) (Kiecolt-Glaser, Marucha, Malarkey, Mercado, & Glasser, 1995). Many studies have reported that chronic stress and burden negatively influence both the physiological and psychological well-being of caregivers.

Etters, Goodall, and Harrison (2008) find that caregiver burden is often used to describe the act of caregiving, which has been reported as 'enduring stress and frustration. Several poor outcomes for the caregiver such as depression, illness, and decreased quality of life are associated with caregiver burden. The article defines caregiver burden as "a multidimensional response to physical, psychological, emotional, social, and financial stressors associated with the caregiving experience" (p. 423). Attempts to identify specific stressors have yielded mixed results. Intuitive causes of stress have not been strongly associated with the feelings of burden experienced by caregivers.

Vitaliano, Zhang, and Scanlan (2003) conducted a meta-analysis examining if caring for a family member with dementia is, in fact, a chronically stressful process with potentially negative physical health consequences. This study reviewed 23 samples in 45 reports ( $n = 3,072$ ). The mean age of participants was  $65 \pm 10$  years. 10% were female, and the number of non-white participants was 7.4%. 1,594 caregivers and 1,478 non-caregivers were group matched on age and gender. After comparing results across 11 health categories, the authors found that caregivers exhibited a slightly greater risk for developing health problems as defined in the study, and a strong relationship was found between caregiving and stress hormones, antibodies, and global reported health.

Therefore, the authors indicate it is imperative to develop a theoretical model which relates caregiver stress to physical illness.

Kieolt-Glaser et al. (1995) demonstrate that there is significantly slower wound recovery time in a study of 64 caregivers versus non-caregiver controls (48.7 [2.9] v. 39.3 [30] days,  $p < 0.05$ ). This finding suggests that there may be an underlying deregulation in biological mechanisms, which negatively affect the caregiver's ability to recover from physical injury. This suggestion was supported in other studies involving blood clotting in the caregiver population. Von Kanel et al. (2005) evaluated clotting as a result of stress. D-dimer, a marker of fibrin formation and degradation, is significantly higher in caregivers than controls ( $p = 0.02$ ). Elevated coagulation may be a result of caregiver stress, contributing to the increased cardiovascular health risks in dementia caregivers, which are higher in the caregiving population.

Mausbauch et al. (2007) demonstrates findings that associate caregiving with greater rates of morbidity, mortality, and the development of cardiovascular disease in a study of 165 caregivers and non-caregiver controls. Blood levels of t-PA antigen act as an indicator for cardiovascular health. Caregivers show significantly greater increases in t-PA antigen compared with non-caregiver controls ( $p = 0.02$ ), which places caregivers at greater risk for developing serious cardiovascular problems that may result in greater mortality rates.

Mortality rates were also examined by Schulz and Beach (1999). The authors identified the experience of mental and emotional strain from caregiving as an independent risk factor for mortality in the elderly. Caregivers who reported strain, associated with the act of caregiving, were found to have significantly higher death rates than non-caregiver controls. Those with the highest risk for mortality 1) provide direct care and 2) report experiencing mental and emotional strain. The authors found

caregivers reporting this combination of factors had a mortality rate 63% higher than non-caregiving controls.

To complicate matters, Shaw et al. (1997) examined the treatment of major health events for caregivers. This longitudinal study of 146 caregivers found that there is a trend for caregivers to develop serious health problems. The study finds that caregivers are reluctant to seek necessary medical care when their spouses are most problematic, which may lead to long-term health implications.

Gonzalez, Polansky, Lippa, Walker, and Feng (2011) conducted a study of 121 caregivers and found that 50% (n=60) were considered high-risk, which is defined as reporting at least one diagnosed health problem and having a self-rating of fair or poor health. The study found that developing health-risks is 2.3 times greater for caregivers that had a one unit increase in depressive symptoms, as measured by the Center for Epidemiologic Studies – Depression Scale (CES-D). The authors indicate that, while the literature is limited in examining depression as a predictor of physical health, there may be a connection between depression, poor or disrupted health habits, and increased health risks.

In a study conducted by Kiecolt-Glaser, Glasser, Gravenstein, Malarkey, and Sheridan (1996), caregivers were found to have much higher rates of depression than the general population ( $F = 12.46, p < 0.001$ ), as measured using the Beck Depression Scale. The authors also found that caregiver depressive symptoms were not reliably correlated with caregiving variables, such as years spent caregiving, the number of hours per day consumed by caregiving activities, or the extent of patient impairment. These conclusions suggest that experienced depression may extend beyond problems typically associated with hands-on-care.

Hayley, Levine, Brown, and Bartolucci (1987) also demonstrate a weak link between the objective severity of the stressor, and the perceived impact that stressor

has on caregiver outcomes. In fact, the authors found that the severity of cognitive and behavioral impairment, as well as the duration of the disease, accounted for very little of the variance in caregiver depression, life satisfaction, and general health. This effect is also seen in physiological aspects of stress and burden. Shaw et al. (1999) found that hypertension was not related to the extent of daily living assistance, problematic behaviors, or levels of caregiver distress. Although chronic stress from caregiving had a statistically significant effect on blood pressure ( $p = 0.05$ ), the underlying mechanism of this correlation remains unclear.

Chronic stress from caregiving also has a negative impact on the physical, mental, and emotional well-being of the caregiver themselves. Caregiver stress can be the result of physical strain, psychological or emotional instability, social isolation, and financial difficulties (Frank, 2008). Stress from caregiving can be experienced as both acute, short-term frustration and chronic, long-term negative emotions (Frank, 2008).

Problems related to chronic stress can be exacerbated along several dimensions such as “depressive symptoms, effects of care recipient behavior on the caregiver, role strain, self-esteem, emotional distress, life satisfaction, time spent on social activities, relationship strain, and physical health...Alzheimer’s caregivers often experience a shift in the family role dynamics, loss of intimacy, and feelings of isolation” (Frank, 2008, p. 517). Such changes in traditional familial roles, in combination with other experienced negative effects on personal well-being, can cause a great deal of emotional distress for caregivers.

Two mental health constructs, which have also been identified as central to caregiver stress, are ambiguous loss and anticipatory grief. Ambiguous loss and anticipatory grief are closely related and involve a sense of loss that occurs while the object of loss is still physically present. This may entail losses which are predicted to take place in the future; however, it also involves the loss of functioning in people with

dementia, which may be an ongoing phenomenon involving the past and present as well. Frank (2008) emphasizes this point and states that although many of the losses are anticipated in the future, “it also incorporates losses that have already occurred and those that are presently occurring. In other words, anticipatory grief comprises past, present, and future losses” (p. 517).

Frank (2008) identifies anticipatory grief and ambiguous loss as independent factors contributing to chronic stress. The level of grief was measured using the Marwit-Meuser Caregiver Grief Inventory (MM-CGI). Several major barrier categories and subcategories are identified, such as caregiver role versus personal life, patient related challenges caused by the disease, communication, personal grief and loss, and lack of support. These barriers were found to present particularly difficult challenges to the caregiver. Therefore, anticipatory grief and ambiguous loss may not only cause hardships for the caregiver but may also act as a fundamental barrier to the act of caregiving.

Dupuis (2002) also studied ambiguous loss as a phenomenon that may shift over time. Over the progression of dementia, ambiguous loss can be broken into three stages. Anticipatory loss is the first stage, in which the caregiver is concerned about future losses that may be experienced. The second stage is progressive loss and describes “the pain of watching the deterioration and disintegration” (Dupuis, 2002, p. 95). This is often distinguished by a sense of helplessness as the caregiver tries to maintain some quality of life. Lastly, Dupuis describes the acknowledged loss stage “when adult children with institutionalized parents acknowledge their psychological losses” (Dupuis, 2002, p. 112). A main coping strategy and defense for acknowledged loss were identified as acceptance and avoidance, respectively.

Piiparinen and Whitlatch (2011) suggest that existential loss contributes to negative feelings associated with care. Caregivers experience an intrapsychic threat



from losses they experience. It is noted that both individual and social factors negatively influence a caregiver's ability to integrate the emotional difficulties. The study also speculates that caregivers cope with these emotional difficulties through avoidance or acceptance. Furthermore, the authors suggest that a caregiver's coping strategy may result in the engagement of inequitable (e.g. authoritarian) or equitable (e.g. negotiated) relationship, which has an impact on dyadic well-being.

Other defenses and coping mechanisms have also been described by Oliver and Bock (1990). The authors find that common stress responses exhibited by caregivers can act as barriers to care. It is suggested that stress also inhibits appropriate coping skills for the caregiver. The identified defenses include denial, anger, guilt, self-pity, and depression. All of which are experienced as very negative emotions related to caregiving issues.

Bullock (2004) states that the treatment of Alzheimer's disease and dementia is linked to the caregiver's ability to successfully cope with the challenges of caregiving. Caregivers who experience high levels of burden, and who incorporate poor coping strategies, are more likely to suffer from poor well-being. The author also describes that caregivers often experience social isolation and relationship disruptions as a result of their time spent caregiving. Caregivers often need support from their family and friends, but do not often receive it. Hayley, Levine, Brown, and Bartolucci (1987) found that in measuring life satisfaction, the greatest variable accounting for the variance of caregivers was social support and activity. "Caregivers with a larger number of friends and close relationships had a greater subjective satisfaction with their social networks. Higher levels of social activities with friends, and church attendance, were also correlated with greater life satisfaction" (p. 329).

A longitudinal study (Clip & George, 1990) observed the effect of social support patterns along 6 categories of caregiver needs. "... Burdens associated with providing

care for a family member with dementia may entail a change in network contributions because family and friends differ in their ability and willingness to assist the caregiver” (p. S110). As a correlate, the study also found that support patterns do not influence the duration of the disease process or the severity of the patient’s cognitive or behavioral symptoms. In the result of the study, caregivers that rate their support system as inadequate, tend to rate their financial status as low, have the lowest self-rated health, have the highest use of psychotropic drugs, have the highest stress symptoms, have the lowest positive affect and highest negative affect, and have the lowest life satisfaction.

The stress of being a caregiver for someone with Alzheimer’s disease is long-term and severe. Many of the responsibilities associated with caregiving can have a negative impact on both emotional and physical health. These responsibilities range from managing difficult behaviors to witnessing the cognitive decline of a loved one to navigating financial issues. The authors also note that lacking a confiding relationship may lead caregivers to experiences of depression (Clip & George, 1990).

While evaluating the effectiveness of a psychometric system to measure familial and friend support, Wilks (2009) found that familial and friend support related to lower caregiver stress and greater resilience. This effect has been previously reported for reducing stress and enhancing resilience. Therefore, enhancing social support may be protective against the experience of caregiver stress.

In addition, a telephone survey of 340 family caregivers (Lai and Thompson, 2011) found that higher levels of perceived social support lead to adequately lower levels of caregiver burden. The findings of this survey revealed that the most important correlate to caregiver burden in females, and the second most important correlate in males, was perceived social support. Adequacy of social support accounted for a greater percentage of caregiver burden than the health of the care recipient, in both male and female caregivers. Inversely, caregivers experienced a higher level of burden when

there are lower levels of social support. Therefore, social strain and frustration are generally felt by caregivers who experience a lack of support from family and friends.

Decreased social support, due to family conflict, has been found as a result of caregiving for a person with dementia (Etters, Goodall, & Harrison, 2008). The article calls for the development and implementation of multicomponent interventions to improve health outcomes for caregivers and individuals with dementia. The article states that interventions have demonstrated improvements in caregiver burden, coping skill, depression, and delayed institutionalization for patients. Interventions requiring active participation of the caregiver have demonstrated the greatest improvement.

### **Previous Efforts to Deter Caregiver Stress and Burden**

Several different methods have been explored to reduce caregiver stress and facilitate coping. These range from private and community based support programs and counseling to in-home respite assistance. There are a variety of interventions, respite programs, and educational programs, which have been used to help achieve a reduction in caregiver stress. Two meta-analysis studies will be reviewed followed by a few specific examples of previous programs.

### **Meta-analysis**

A meta-analysis (Brodaty, Green, & Koschera, 2003) reviewed 30 controlled studies involving 2,040 caregivers. The review aimed to examine outcomes of various caregiver interventions, excluding respite care, and to provide recommendations for clinicians. Clinicians have utilized education and training programs, support groups, and counseling.

Successful programs report reduced distress, depression, and psychological morbidity; delayed nursing home placement; and improved psychological well-being. It was found that the group of caregiver interventions had modest but significant benefits on caregiver knowledge, psychological morbidity, and other main outcome measures,

such as coping skills and social support (Brodaty, Green, & Koschera, 2003). They however, did not influence caregiver burden. Despite modest findings in effectiveness, the authors found that caregivers were generally very satisfied with the interventions, noted improved coping skills, identified the intervention as helpful, and said that they would use the training program again.

Unsuccessful programs are identified as short educational programs, support groups alone, single interviews, and brief interventions that are not supplemented with long-term contact (Brodaty, Green, & Koschera, 2003). Variability in the results is attributed to the heterogeneous nature of caregivers; such as range in age, sex, and living arrangements; type and severity of dementia; prevalence of other behavioral or psychological symptoms associated with dementia; and demographic variables such as relationship to the patient, demands on time, and practical and social supports.

Knight, Lutzky, Macofsky-Urban (1993) also conducted a systematic review of 20 studies that focused on a variety of caregiver interventions. They also accumulated quantitative results from the data that was presented across studies, in an effort to determine the effectiveness of the interventions through comparison. The study offered several recommendations for future research in the areas of participant selection, use of a comparison group, issues with measurement, incomplete reporting of outcomes, and differential success of interventions.

They suggest that researchers should have more targeted inclusion criteria due to selection bias, and that samples should be limited to specific kinds of caregivers with outcome data reported separately for each group (Knight, Lutzky, & Macofsky-Urban, 1993). The authors also note that years spent caregiving should always be reported as a covariate in outcome data analysis. Lastly, they also raised the possibility that caregiver interventions may actually cause negative treatment effects (as cited in Strupp, Hadley,

& Gomes-Schwartz, 1977). Therefore, a full exploration of all other outcomes is also encouraged and negative outcomes should be reported more fully.

### **Educational programs**

Gelmini, Morabito, and Braidì (2009) studied 74 caregiver participants over the course of five of educational trainings. Results show that caregivers experienced improvement over six months, measured by the Caregiver Burden Inventory (CBI). The emotional states of caregivers were also found to show improvement after the course in terms of anxiousness, nervousness, dissatisfaction, pessimism, depression, and guilt. Educational programs and trainings are perhaps the most common delivery for caregiver support in the community at large.

There have also been extensive non-traditional, educational programs which have been utilized. These novel programs use a multimodal approach, which helps support the caregiver in several ways. Gitlin, Winter, Dennis, and Hauck (2007) describes the ACT3 project as “different treatment modalities including medical testing, education, problem solving, customized action plans, demonstration and role play using environmental modification are introduced to provide a comprehensive approach to helping families learn new skills to cope with this significant domain of concern.”

### **Respite care interventions**

Hoskins, Coleman, and McNeely (2005) evaluated the effectiveness of interventions provided by a multidisciplinary health team ( $n=26$ ). The findings were that caregivers experienced significantly less strain over a six month intervention time period ( $p = 0.000$ ), measured by the Caregiver Strain Index. They also found a statistically significant relationship between respite care and the reduction of caregiver stress ( $B = 1.705$ ,  $t = 2.586$ ,  $p = 0.0017$ ).

Gaugler et al. (2003) conducted a study to evaluate the effectiveness of adult day services to reduce stress and enhance psychological well-being. In the three month

longitudinal study (n=400), reducing the amount of caregiving hours resulted in “reduced feelings of role overload; decreases in ADL hours... were associated with decreases in worry and strain...” (p. 52). The findings suggest that respite may have a meaningful impact on reducing burden felt by caregivers.

### **Support groups, counseling, and therapy**

Zarit, Anthony, and Boutselis (1987) examined two common interventions for caregivers: family counseling and support groups. Both treatments incorporated education about dementia, behavior management, and identifying potential support systems. Although progress was made by participants over time, and that progress remained stable into the following year, the treatment group did not significantly differ from the waitlist group.

Another intervention was provided in the form of cognitive therapy by Oliver and Bock (1990). This study used Rational-Emotive Therapy (RET), which “specifies the maladaptive cognitions which elicit and sustain maladaptive emotions and behaviors, and provides a model for cognition, affective, and behavioral change” (p.53). The results yielded a greater understanding of defensive mechanism in the caregiver participants.

Deihl, Mayer, Forstl, and Kurtz (2003) studied eight spousal caregivers of patients diagnosed with frontotemporal dementia participated in seven weekly, group sessions lasting 90 minutes. Caregiver’s often feel an emotional reaction, which may be difficult to verbalize because they are considered as unacceptable toward the care recipient. During these meetings participants were encouraged to express their own needs and confront painful emotions, such as aggression, anger, mourning, and guilt. The study notes that caregivers felt relieved by sharing their problems with others. Participants rated the group intervention as useful and said that benefits were sustained after termination. The authors conclude that support group formats for interventions can

be effective, but that these groups should be tailored to the specific problems and needs of caregivers.

### **Enhancing well-being**

Butcher and Buckwalter (2002) examined the process of shaping caregiver frustration into meaningful experiences (n=1). The authors used a hermeneutic phenomenological approach to analyze caregiver narrative. They found that through sharing narratives with other caregivers, both creating and receiving this narrative can contribute to meaning making. They also note that written emotional expression fosters meaning-making, diminishes psychological distress, improves immune function, and promotes health and well-being.

Watts and Teitleman (2005) explored how family caregivers achieve a restorative mental break through a phenomenological research method. A mental break was defined as “distinct periods of freedom from caregiving concerns and conceptualised [sic] them as the essence of respite and as a restorative occupation” (p. 282). 15 caregivers reported over four extensive interviews that they achieved restorative mental breaks through a combination of social support, traditional respite care, relief enhancing conditions, and techniques for momentary stress reduction. This study stresses that mental breaks are within the capability of the caregiver, achievable without formal respite care services, and require a combination of both rest and engagement with pleasurable activities.

Donovan and Corcoran (2010) also used a phenomenological approach with 15 caregivers to develop a description of caregiver beliefs, meaning, and actions. Specifically, positive aspects of caregiving behavior were explored as well as making adjustments in attitudes. The results suggest that promoting positive aspects of care, through learning to make cognitive reassessments of caregiving situations, can contribute to positive outcome on well-being for caregivers and care recipients.

## **Art Therapy**

### **Theory of Art Therapy**

Art therapy is an established form of psychotherapy that has been in practice for over 50 years. Margaret Naumburg was the first to describe the benefits of art creation as a primary, therapeutic tool. She, as well as other practicing art psychotherapists, describes that every individual has the “capacity to project his inner conflicts into visual form” (Naumburg, 1987, p. 1). Through art therapy’s symbolic nature, the patient has a tool for enhanced communication, which is not subject to the difficulties of language and may aid in verbalization. Expression through a visual image is harder to censor and control and may lead to revealed motives that the patient has repressed from consciousness.

Naumburg (1987) also describes the importance of the art therapy relationship. As in traditional psychotherapy, discovering meaning takes place in the context of a symbolized relationship via transference. Art therapy provides a triangular relationship, where transferences are not only experienced through the therapeutic relationship with the art therapist, but through the artwork itself. In addition, countertransference to both patient and artwork provides more information to the therapist regarding unconscious conflicts that may be occurring in the patient and the therapist.

The prevalence of visual images as descriptors of internal unconscious was described first by Freud, adopted in art therapy by Naumburg, and expanded upon by Judith Rubin and others. Rubin(2001) identified two primary goals of psychoanalytic psychotherapy as “first uncovering and thereby discovering repressed material...and second, helping the patient gain insight into the meaning of their behavior in terms of these formerly hidden ideas and feelings” (p.18). The focus on gaining insight over unconscious conflict may be regarded as the catalyst of change for maladaptive behavior.



Art therapy has also been described as an alternative way to express feelings due to its non-verbal, symbolic, and objective nature. Wadeson (1980) describes the clinical advantages of art therapy. They include the use of imagery and metaphor, decreased psychological defenses, an externalization of internal thoughts and feelings (i.e. objectification), permanence as a record for personal use and research, the use of a spacial matrix which can represent many things at once, and the generation of creative and physical energy.

### **Creativity, Adaptation, and Resilience**

Cohen (2011) describes the act of creation as a dynamic interplay between person and environment, which is defined by situational restraints. The act of creation involves exploring discontinuity or the division between what was before and the new. It is a process of reflection which brings about transformation, modification, and paradigm shifts. There are cognitive, emotional, and motivational elements, which allow individuals to make major changes and adapt under adverse circumstances.

Hartley (2007) states that creativity is essential for people to survive extreme adversity. The author suggests that in times of loss, trauma, or bereavement the creative arts can inspire us to carry on. The creative process can be employed to motivate individuals in “doing the next thing” (p. 281). It may also help people to “determine the first step” (p. 281) that they need to take in order to make a change.

People also may learn how to employ courage through creativity to experience that they can “make doing possible” (p.281). Through engaging in the creative process people can realize what they need to do and how they can do it. This process defines resilience, enabling people to bounce back in times of adversity, while also discovering new ways of coping.

## **Research on the Effects of Creating Art**

Curl (2008) explores art-making as a method for achieving cognitive focus and stress reduction in an experimental study with college students. 40 college students were randomly distributed to four treatment groups that used a 2x2 factor of positive/negative-focused and drawing/collage. Changes in stress levels were measured using the State Trait Anxiety Inventory. Results indicate that participants in the positive-focus condition demonstrated a significant decrease in stress, while participants in the negative-focus condition demonstrated a slight increase in stress. The study found art making to influence both thought process and stress, and the author also suggests that the artistic process may offer an alternative way to view caregiving problems and develop potential solutions. It may also be possible for caregivers to use art as means of catharsis, which could facilitate stress reduction. Therefore, making art could be a beneficial coping activity to help caregivers manage emotions, thoughts, and feelings that they may deem unacceptable.

This phenomenon has also been described by Belfiore (1994). The qualitative study focuses on eight medical professionals providing homecare to terminally ill patients. Participants were noted to be at a high risk for stress and felt in danger of burnout syndrome. Participants took part in group, art therapy sessions every week for six months. Results describe the function of imagery in making participants' inner, emotional life accessible to consciousness and providing participants with a more viable mode of relating to others, to the life/work experience, as well as to oneself. Through art therapy it was possible to offer another "language" to the participants to enable them to express the deepest and hidden levels of their personal experience in fulfillment of their duties.

Belfiore (1994) identifies several factors that are direct benefits from making art. These include providing a language for expression and a means of cathartic release of

stress. Imagery can also function as a way to make one's inner life more accessible to consciousness. Through this process, participants were able to develop insight and a greater level of self-understanding. The author also notes, that creating and sharing artwork provided participants with a more viable and concrete mode of relating to others.

### **Creative Arts-based Interventions for Caregivers**

Murrant, Rykov, Amonite, and Loynd (2000) studied enhancing self-care by building self-awareness through the creative process. Workshops on journaling, art, and music therapy were provided to professional palliative care providers (N=75). Enhancing self-care through the creative process in AIDS caregivers, by building self-awareness through creativity. Workshops on journaling, art, and music therapy were provided to 75 professional palliative care providers. A telephone interview confirmed that participants valued the intervention, as well as observations from the facilitator and survey feedback. Participants gained insight into taking better care of themselves as caregivers. Promoting self-care through the creative process may help caregivers identify alternative ways to address their own psychological needs.

Creative arts-based workshops can offer benefits to caregivers. Based on weekend workshop surveys of professional caregivers, participant responses of a survey suggested that they highly valued the experience (Nainis, 2005). However, although the workshop was highly enjoyable, it may not actually facilitate stress reduction in a care setting or apply to unpaid, family caregivers.

McElroy, Warren, and Jones (2006) addressed the need for more information regarding therapies for homebound clients. Both clients and caregivers suggest that art therapy can be of benefit in the in-home environment. These interventions can increase confidence and motivation for caregiver and PWD, while also providing emotional support.

Sezaki and Bloomgarden (2000) also saw the benefits of in-home care. The case study presented explored art making as a joint activity between the caregiver and person with dementia in the home setting. The authors suggest that art therapist can develop goals and objectives in art therapy to help caregivers and people with dementia enhance their quality of life. Findings suggest that the art therapist can help develop goals and objectives, which may enhance the quality of life for the caregiver/care recipient dyad.

A review of the literature reveals that stressors contributing to feelings of burden have been well documented, but have not been found to be directly correlated with any specific factor. Instead, caregiver burden is multidimensional and comprised partly of psychological factors which cannot be aided through hands-on-care alone. Feelings of isolation, loss, and hopelessness may be mitigated through increased social support. Higher appraisals of social support have been found to be directly correlated with a greater degree of well-being among caregivers. This information has informed the rationale of this study, to determine what bearing an art therapy intervention may have on self-reported measures of social support and creative expression.

## **CHAPTER 3: METHODOLOGY**

### **Design of the Study**

This study was conducted using an instrumental case study design. A mixed-method design was chosen as a way to integrate both quantitative and qualitative data. Dementia caregiving causes problems that are embedded in a complex social context. Incorporating both quantitative and qualitative data helped the researcher more clearly understand caregiving by integrating data from multiple methods. The variety of data created by a mixed-method study helped direct the researcher toward more cohesive findings.

The quantitative study design was applied to the study in a pretest-posttest design with a repeated measure. This design is an ABA format with a repeated measure. A pretest and post-test was applied to both the eight-week intervention and to each, individual session. Participants were not randomly assigned to intervention groups and there was not a control group. Quantitative data was collected individually and aggregated for each intervention sub-group.

The qualitative aspects of the study design used a single-case study with repeated measures. Each participant was viewed as a case study unto themselves and each study sub-group was viewed as a case study. A case study design helped isolate important individual and/or group experiences that may have a bearing on study outcomes. This information was gathered through individual interviews and the group process of each art therapy session.

Quantitative data included a self-reported scale measuring various aspects of well-being, including perceived levels of social support, emotional distress, life meaning, and caregiver inadequacy. Instrumentation used a modified version of the Psychological Wellbeing Scale for Caregivers (mPWS-C) (Wu, Cho, Li, Chen, & Tse, 2010). The

instrument was administered before and after the eight week intervention, as well as before and after each individual session.

Qualitative data included semi-structured interviews before and after the eight week intervention, the verbal content of each group session, recurring themes and topics during group processing, expressed emotion, individual and group dynamic behavior, as well as the formal and contextual aspects of the artwork produced. Artwork was produced during the pre/post-interview and in each of the eight sessions.

The creation of artwork was used as a means to facilitate connection with others and enhance self-expression. Artwork was also used to help the group and investigator identify the emergence of common themes. Group discussions focused on the content, as well as the formal aspects, of the artwork created. Artwork was processed with the group and analyzed by the investigator at the completion of the study.

### **Location**

The location of this study was conducted in the offices of the Alzheimer's Association Delaware Valley Chapter (AADVC). Two site locations were utilized in Philadelphia, PA and Marlton, NJ. Sessions were conducted in office conference rooms, which have previously been utilized as art space through other Rocket Education and Community Center (REC Center) programming. These site locations were also convenient, based on accessibility and population density to participants. Other AADVC services of the organization, such as an information and referral hotline, support groups, and educational events, were also offered to the participants and their family member with dementia at the conclusion of the study.

### **Time Period**

This study began May 2012, after approval from the Drexel University IRB and was completed in December 2012. The eight-week intervention was held the week of June 18<sup>th</sup>, 2012 through the week of August 6<sup>th</sup>, 2012. Two weeks prior to the

intervention participants met individually with the researcher to review and give consent, complete the initial interview, and create individual artwork. Two weeks after the intervention participants met with the researcher to complete the final interview and create individual artwork. Data analysis was completed two months after the conclusion of intervention.

### **Enrollment Information**

For inclusion in the study, participants could be male or female, from any socio-economic background, and identify themselves as any ethnicity/nationality. Participants were required to provide primary care to an individual diagnosed with Alzheimer's disease or another related dementia and provide direct care for a minimum of 24 hours per week, which included nighttime care. Due to aspects of the study, which involved verbal communication in a group setting, participants were required to speak English as either their primary or secondary language. Participants were also required to be between 18-85 years of age. Individuals were not permitted to participate in the study if the person with dementia was being cared for in a long-term care facility (i.e. nursing home, assisted living, or continuing care facility).

The study enrolled caregivers who responded to the study flyer, met the enrollment criteria, and gave consent to be enrolled in a study group. The total number of consenting caregivers was 12; however, only nine completed the study. Two groups were established based on geographic convenience of participants to the study sites. Group 1 consists of five consenting participants, and Group 2 consists of four consenting participants. Of the three participants that did not complete the study, two did not meet the minimum attendance requirement and one was prevented from attending due to a hospitalization of the care-recipient.

### **Participant Type**

Caregivers for the study could have included non-professional spouses, adult children, grandchildren, siblings, and neighbors giving direct, primary care to an individual with dementia due to Alzheimer's disease or a related dementia. Caregiving participants were considered healthy volunteers; however, any caregiver may experience stressors due to their role as a caregiver and may also experience symptoms of depression, anxiety, etc.

Caregivers enrolled in this study tended to be spouses, Caucasian, and female. All provided a minimum of 24 hours of direct, unpaid care per week. None were observed to have any major health or psychological problems at the time of the study. However, over the course of the study depression, anxiety, and feelings of exhaustion were discussed as experiences connected to caregiving duties. A more thorough review of participants can be found in the results.

### **Participant Source**

The source of study participants included caregivers who lived in the greater Philadelphia area. Therefore, participants were recruited from the dementia community at large and were comprised of residents of the greater Philadelphia area, which drew from a dementia population of nearly 300,000 individuals. In this geographic area, it is expected that over 600,000 individuals provide non-professional care for people with dementia.

Participants were drawn from constituents of the AADVC, a non-profit organization in the greater Philadelphia area, which services families of people with dementia. The AADVC provides community educational events, support groups, care management services, and a 24/7 information and referral hotline (i.e. Helpline). All potential participants will be given referral and access to these chapter services.



## **Recruitment**

Recruitment materials included hard copy flyers, which were distributed to the dementia community. The hardcopy flyer includes the study title, objectives, inclusion criteria, site locations, and contact information for enrollment. Electronic flyers were sent by AADVC staff. The email contained a brief description of the study (title, research objectives, study information, study site locations, and enrollment information), as well as the study flyer as an attached PDF file.

After the email was sent, any email responses received by the AADVC staff were forwarded to the co-investigator for follow-up. Training was provided to the AADVC staff to establish a protocol for handling these responses. Interested and willing participants called the co-investigator to confirm eligibility and willingness to participate, at which time information from the flyer was reviewed. If the potential participant met the inclusion criteria, an individual appointment was made to sign the consent form.

### **Participant inclusion criteria**

To participate in this study, individuals must:

- be between the ages of 18 – 85.
- provide over 24 hours of dementia caregiving per week, which includes nighttime care.
- speak English as a primary or secondary language.

### **Participant exclusion criteria**

- Individuals may not participate in this study if the person with dementia is being cared for in a long-term care facility (i.e. nursing home, assisted living, or continuing care facility).
- If younger than 18 or older than 85.
- Does not provide over 24 hours of caregiving per week.

## **Investigational Methods and Procedures**

### **Informed consent**

At the first meeting with the potential participant, the informed consent document was reviewed and explained. The participant was then informed of the purpose and procedures of the study, including their rights as a research participant and confidentiality. The participant was asked to repeat the purpose of the study in their own words before signing the consent form. Two copies of the consent form were signed, one which was provided to the participant and the other which was stored in a locked, secure file in the Drexel Creative Arts in Therapy program offices for three years following the end of the study. Gathering of data begin immediately after signing the consent form.

### **Instrumentation**

The Psychological Well-being Scale for Caregivers (PWS-C) was developed in a palliative care setting to create a tool that provides information on well-being for caregivers of those with terminal cancer (Wu, Cho, Li, Chen, & Tse, 2010). The authors found the PWS-C to be a reliable and valid measure for psychological well-being/distress reduction in caregivers. They also suggest that the PWS-C could be used as an outcome measure for psychological interventions tracking well-being.

Caregivers of dementia patients and caregivers of those with terminal cancer suffer from the similar issues such as a need for social support, increased distress, feelings of inadequacy, etc. The PWS-C is an 11 item questionnaire, which consists of five subscales: 1) Life meaning, 2) social support, 3) emotional distress, 4) caregiving inadequacy, and 5) hospital care. The two items measuring hospital care will be excluded from this study, as they primarily served as a control for validation of the measure and because the intervention will not be conducted in a hospital environment.

Each item is listed below in their under their respective subscale:

*Social Support (SS)*

Item 1 - I can share my thoughts and feelings with someone close to me.

Item 2 - I have adequate support from someone close to me.

*Life Meaning (LM)*

Item 3 – I am clear about the meaning of my life (e.g. I have done things for my family and friends in my life).

Item 4 – Each day is a gift (I treasure every day I have now).

Item 7 – I can still enjoy life.

*Emotional Distress (ED)*

Item 5 – I feel distressed about my present condition.

Item 6 – I have fears for my future.

*Caregiver Inadequacy (CI)*

Item 8 – I have a feeling of incompetence in taking care of the person with dementia.

Item 9 – I do not understand the way the patient feels or thinks.

All items were rated on a scale from 0 to 10, 0 being totally disagree and 10 being totally agree. For the interpretation of well-being in this study, higher scores in the subscales of social support (max = 20) and life meaning (max = 30) were considered an indicator of positive well-being, while high scores on the subscales of caregiving

inadequacy (max = 20) and emotional distress (max = 20) were considered an indicator of poor well-being.

### **Interview guide**

The type of interview conducted was an open-ended, responsive interview. The purpose of the open-ended interview was to collect demographic data, information about support systems, information about the expression of caregiver thoughts and feelings, and to get general feedback about the intervention. The co-investigator noted responses to the interview questions for later analysis. The interview questions are outlined below for both the pre/post-intervention interviews.

#### *Pre-Intervention*

1. What is your age?
2. What is your ethnicity?
3. What is your relationship to the relation to the person with dementia?
4. How many years have you been a caregiver?
5. Are you currently receiving respite care (e.g. in-home care, daycare center, etc.)?
6. Are you currently receiving any other support services (i.e. case management, individual counseling, etc.)?
7. In what ways, and from whom, do you receive support?
8. In what ways do you express your thoughts and feelings?

#### *Post-Intervention*

1. In what ways, and from whom, do you receive support?
2. In what ways do you express your thoughts and feelings?
3. What effects has participating in this study had on your life as a caregiver?
4. Do you have any other general feedback or comments about the experience?
5. Would you recommend this intervention to other caregivers?

## **Procedures**

### **Consent.**

The consent forms were reviewed with participants. Prior to giving consent, participants were asked to verbally repeat their understanding of the study to the researcher in their own words. Upon signing the consent form at the initial interview, the participant was asked to attend eight weekly sessions, which lasted 60 minutes each, facilitated by the researcher. Participants also met with the researcher for a final interview. The study participants met with the researcher on 10 occasions. The total time commitment to complete the study required approximately 10 hours.

### **Data collection 1.**

During the first meeting, the researcher and each participant met individually. The meetings took approximately one hour and preceded the eight week art therapy intervention to establish informed consent, establish a baseline for evaluation, and to conduct a brief interview. The participant was also asked to "draw yourself as a tree in weather" and to respond verbally to the drawing they produced.

### **Data collection(s) 2-9.**

During each of the 60-minute sessions, participants met with other dementia caregivers. The first five minutes was dedicated to completing the pre-session evaluation. The group of caregivers were provided time to respond to an art therapy directive. Following the art making, the remaining time was spent discussing the directive and the artwork. The final five minutes were spent completing the post-session evaluation.

### **Data collection 10.**

After the conclusion of the eight week workshop, participants met with the co-investigator for a one-hour debriefing that included an interview, which will be noted for later analysis, a final evaluation, and the opportunity for the participant to provide

feedback about any information that they believed may be relevant. Finally, again they were asked to "draw yourself as a tree in weather", and respond to it verbally.

## **Data collection**

### **Types of collected data.**

- **Hardcopy data** – Consent, mPWS-C forms, artwork, and session notes.
- **Digital data** – Data from all mPWS-C forms, attendance records, digital pictures of selected artwork, and all data analysis linked with the study.

### **Confidentiality.**

All collected data was tracked using a Participant Identification Number (PID Number) and date. The participant tracking form was the only record linking participant identifiers to the corresponding PID Numbers. This information was recorded on a paper hardcopy and locked in the office of the primary investigator, Betty Hartzell, PhD, located in the Creative Arts in Therapies Department in the Bellet Building, 10<sup>th</sup> floor. Data will be kept for three years following the completion of the study.

### **PID Number.**

Each participant was assigned a PID Number. The PID Number used a three digit code; the first numeral corresponding to the site location, the second numeral corresponding to the site-specific group, and the third numeral corresponding to the order that the individual consented to participate in the study. Participants were assigned a PID Number immediately following the signing of the consent form, which was tracked on a data sheet.

### **Data collection timeline.**

Data collection began once the first individual gave consent to participate. The mPWS-C was implemented once during the pre/post-intervention interviews and before and after each of the eight weekly sessions. The first scale was administered immediately after the signing of the consent form and prior to the initial interview

questions and initial art making. Each week participants completed the mPWS-C prior to, and after, the session. The last scale was administered at the beginning of the post-intervention interview, prior to the interview questions and the final art directive.

Throughout the sessions, participants were asked to complete several art directives, which may have been relevant to dementia caregivers. They were provided with art materials, including paper, pictures from magazines, glue, paintbrushes, scissors, oil pastels, colored pencils, watercolor paints, and clay. During art-making, music was played in some sessions to help facilitate relaxation and creativity. Below is a list of art directives to be completed in each session:

- Data Collection 1 - Pre-Intervention – Tree in Weather Drawing
- Data Collection 2 - Session 1 – Needs Collage for Caregivers
- Data Collection 3 - Session 2 – Kinetic Family Drawing
- Data Collection 4 - Session 3 – Altered Relationship Drawing
- Data Collection 5 - Session 4 – The Angry-Caregiver Drawing
- Data Collection 6 - Session 5 – Life as a Garden Drawing
- Data Collection 7 - Session 6 – Positive Aspects of Caregiving Drawing
- Data Collection 8 - Session 7 – The Caregiving Container
- Data Collection 9 - Session 8 – A Perfect Day Drawing
- Data Collection 10 - Post-intervention – Tree in Weather Drawing

During each intervention caregivers had the opportunity to create and share their artwork. Directives are constructed to illicit responses that were possibly relevant to dementia caregivers. Group dynamics, discussion, and emerging themes were noted by the co-investigator in session notes, which were later used in the final study analysis.

### **Data entry.**

All data from the mPWS-C forms was transferred into a digital record by the co-investigator. This data was entered via an excel spreadsheet and was kept in a password protected folder on the researcher's personal computer, which was also protected with a username and password. All data was tracked with the PID Number.

### **Data storage and disposal.**

All hardcopy data was marked with the PID Number and date, and will be locked in the office of the faculty advisor for a total of three years. After three years, this hard copy data will be destroyed. All artwork will be stored in a locked cabinet at the AADVC, to which only the co-investigator will have access. All artwork will also be destroyed at the completion of the study, unless the participant wishes to have their artwork returned at the conclusion of the study.

### **Data Analysis**

Outcomes of this study were analyzed for the following factors:

- **Quantitative:** Descriptive statistical analyses were used to define sample means and calculate changes in well-being throughout the duration of the intervention, over a single session, and between pre/post-interviews.
- **Qualitative:** Interview responses, session notes, and artwork were analyzed for coding of major themes.

Any conclusions that were drawn from the quantitative analysis were compared to the qualitative information. Qualitative data also provided additional information that was not collected via the assessment scales. Both methods of analysis contributed to more a robust and comprehensive evaluation of caregiver well-being.

Data from the mPWS-C was analyzed using descriptive statistics. Statistical analysis was used to determine individual and group means. Raw data scores were recorded in a Microsoft Excel workbook and combined into subscale scores of social



support, life meaning, emotional distress, and caregiver inadequacy for each participant per session. Participant subscale scores for each session were then aggregated into their respective intervention groups.

For the interpretation of well-being in this study, higher scores in the subscales of social support (SS) (max = 20) and life meaning (LM) (max = 30) were considered an indicator of positive well-being, while high scores on the subscales of caregiving emotional distress (ED) (max = 20) inadequacy (CI) (max = 20) were considered an indicator of poor well-being. Therefore, the composite score for each group could range from -20 to 30. The composite scores of well-being for each session were determined by averaging together individual, subscale totals; averaging together the group, pre/post-session subscale averages; and applying the following formula:

$$SS + LM - ED - CI = \text{Composite Well-Being}$$

Interviews, session notes, and artwork were reviewed for themes and art elements related to psychological issues, which may be linked to caregiving. The analysis of the case material is defined by Stake (1995). The data collection in this case study drew on many sources of information, namely interviews responses, observations of behavior and group dynamic, interpersonal interactions between group members, artwork, and the mPWS-C. All collected data was used to help develop a better understanding of each case.

For the identifications of themes in interview questions and session notes, Moustakas (1994) outlines a method for descriptive coding which involves going through the data and noting significant statements, sentences, or quotes that provide an understanding of how the participants experienced the phenomenon. This is known as horizontalization. Next, the researcher develops clusters of meaning from these significant statements and organizes them into themes.

From these themes the researcher then identifies a composite description that represents the most important aspect of the phenomenon. This step highlights the common experiences of the participants. The purpose of identifying these common experiences is to isolate the underlying structure that is shared by the participants.

Both the intake and debriefing interviews, as well as session notes, were prepared for analysis and coded through exploration of the data. The researcher identified significant statements, which were then coded into emerging themes. Themes were then clustered together with like themes to form the composite description. The same set of themes was applied across all participants in the intake and debriefing interviews, while data from each session of the art therapy intervention were coded independently.

For intake and debriefing interviews, the number of occurrences or the frequency that themes were recorded provides a basis for identifying what was most commonly shared between participants. The frequency of emergent themes, compared between pre/post-intervention interviews, also provided information on the effect that the intervention had on various factors.

### **Operational Definitions of Terms, Concepts, Variables**

1. **Caregiver:** A person providing unpaid, direct care to someone who has Alzheimer's disease or another form of dementia. Caregivers provide support with activities of daily living, as well as psychological and behavioral support. In regard to this study caregivers will provide a minimum of 24 hours of support per week.
2. **Caregiver Well-Being:** A state of acceptance and adequate management of both psychological and practical aspects of caregiving, including care for their loved one and self-care practices.

### **Possible Risks and Discomforts to Participants**

Risks associated with this study were considered minimal. However, the participants may have experienced minimal anxiety from discussing artwork that participants create about the topic being studied. Because the study was conducted in a group setting, participants may have also felt discomfort while creating art or discussing the topics in the presence of other participants and/or the researcher.

### **Special Precautions to Minimize Risks or Hazards**

If at any point a participant was uncomfortable, that participant could refrain from the directive or discussion at hand, or elect to leave the room. Participants could have also chosen to drop from the study at any time. It was also emphasized that artistic skill and talent was not needed to participate and that any artwork produced would not be evaluated in the group for its artistic qualities. Also, a list of session topics and directives would have been provided at the time of consent if a participant wished to receive it. Participants could have also been referred to a therapist on a compiled list of therapists in the geographic area.

## **CHAPTER 4: RESULTS**

### **Overview of Results**

The research question asked how an art therapy intervention affects self-reported measures of social support and creative expression with groups of dementia caregivers. Well-being was measured using open-ended interview questions; an instrument for the measurement of social support, life meaning, emotional distress, and caregiver inadequacy; researcher session notes; as well as individual and aggregated, groupwork. Each group was examined as a single-case study. A review of each group's demographics, measures of well-being via the mPWS-C, emergent themes over the course of the intervention, and information regarding intake and debriefing interviews and art assessments were provided.

### **Participants**

An electronic flyer was sent to 4,786 constituents of the Alzheimer's Association Delaware Valley Chapter. 38 respondents expressed an interest in study enrollment. After reviewing the enrollment criteria, 12 participants gave consent to enroll in the study. Three consenting participants did not complete the study. Of the three who did not complete the study, two did not meet the minimum attendance requirements and one withdrew prior to the start of the intervention due to hospitalization of the care recipient. Therefore, nine participants completed the study who met the inclusion criteria and attended the minimum number of required sessions.

### **Rationale for Directives and Art Materials**

Below is a description of each session directive and the rationale regarding the directive and art materials that were used:

- Pre-Intervention – Tree in Weather Drawing

The initial art assessment was given after the interview questions had been completed. Materials used were a 9"x12" piece of paper and a standard set

of 16 oil pastels. The participant was then asked, "Think about your life as a caregiver, and draw yourself as a tree in weather". They were then asked to explain how the tree figure relates to them. Some other follow-up questions were asked if the participant needed further prompting.

Oil pastels were used because they allowed participants to express a wide range of affect while providing a moderate amount control. The art directive and materials were designed to elicit thoughts and feelings regarding caregiving. At the conclusion of the intervention, the caregiver was presented with this directive again for comparison.

- Session One – Needs Collage for Caregivers

The art therapy directive for session one focused on ways for caregivers to identify needs in themselves and the person with dementia. Participants were given an 18"x12" sheet of paper, an assortment of magazines, scissors, and glue. After being instructed to fold the paper in thirds they were asked, "Make a collage showing the person with dementia's needs on the outside, and a collage of your needs on the inside. To make the collage, select and cut out images or words from the magazines and paste them to the paper".

A collage project was chosen for the initial session to help participants become comfortable with making and discussing art in a group setting. The use of magazine images in a collage is less anxiety provoking than creating original images. However, the directive enabled participants to use the image as a metaphor to explore and discuss issues related caregiving.

- Session Two – Kinetic Family Drawing

The art therapy directive for session two was the kinetic family drawing (KFD). Participants were given a 9"x12" sheet of paper and a set of 12 colored pencils. They were then asked, "Draw a picture of yourself and your family

somewhere doing something together". The KFD was used as an appraisal of familial support, offered reminiscence, and gave the researcher insight into family and relationship dynamics.

Colored pencils were chosen as the medium because they offer control, which may have helped participants cope with any anxiety they may have been feeling about producing drawn images in a group setting for the first time. In the same way, it helped participants share about their families and to begin building feelings of connectedness with other participants, while not becoming too overwhelmed with emotion.

- Session Three – Altered Relationship Drawing

The art therapy directive for session three allowed caregivers to reflect on the ways their relationship has changed due to dementia. Participants were given an 18"x12" sheet of paper with a set of 16 oil pastels. After being instructed to fold the paper in half they will then be asked, "In what ways has your relationship changed because of dementia? Draw a picture of your relationship before dementia on the left, and your current relationship on the right."

Oil pastels were used because they allowed participants to express a wide range of affect and provided a moderate amount control. The materials and directive helped caregivers explore feelings of ambiguous loss, role change and role confusion, and other non-specific caregiver stressors. The directive also supported more interactions between participants as they could relate to each other about the losses they have experienced.

- Session Four – The Angry-Caregiver Drawing

The art therapy directive in session four asked caregivers to remember a time that they were angry with the person with dementia, as well as what they experienced prior to and after the event. Participants were given an 18"x12"

sheet of paper with a set of 16 oil pastels. The group was then asked, "Draw a time that you were angry at the person with dementia in the middle panel." After 15 minutes the researcher then asked, "While you continue to draw, consider what happened right before this event and what happened right after this event."

Oil pastels were used because they allowed participants to express a wide range of affect and provided a moderate amount control. The materials and directive helped caregivers explore feelings of anger. The directive also supported more interactions between participants as they could relate to each other about frustrations that they have experienced as a result of caregiving.

- Session Five – Life as a Garden Painting

The session five, art therapy directive asked caregivers to represent their past, present, and future life as a garden. Participants were given an 18" x 12" sheet of paper with a set of watercolor paints. After being instructed to fold the paper in thirds they were then asked, "Paint your life as a garden; past, present, and future." They group created artwork then engaged in group discussion.

Watercolor paints were chosen to elicit more affect from participants. The medium tends to enhance expression, due to its nature as a less structured material. The directive was designed to aid participants in expressing loss, fear of the unknown, and feelings of hope and hopelessness. Due to the difficult nature of the content discussed in the session, this directive was placed in the middle to ensure enough time for the group to build supportive relationships with each other, as well as providing additional support in the following sessions.

- Session Six – Positive Aspects of Caregiving Drawing (or Five Coping Strategies Drawing)

The session six art therapy directive asked participants to consider positive aspects about being a caregiver or to draw five ways that they cope with

stress. Participants were given a 9"x12" sheet of paper with a set of 12 colored pencils. The caregivers were first presented with the following anecdote (Donovan & Corcoran, 2010):

"A caregiver hears dripping in the middle of the night. She walks down into the kitchen to see the freezer door hanging open. All the food inside has melted and spoiled. She has a flash of anger, clenches her fists, and immediately wants to get her husband and show him what he's done. Instead, she takes a deep breath and says to herself 'You know, I've been meaning to defrost and clean that freezer for some time now.' She then sets to work on throwing away the food and wiping down all the shelves and ice trays. After she is done, she looks at the clean freezer and closes the door feeling much better."

A synopsis was provided: "the caregiver in this story was able to turn a negative into a positive experience." After the anecdote was given the researcher asked participants to "Draw at least one positive aspect of being a caregiver."

Members of Group 1 were also given the option to "Draw five ways that you cope with stress". When the original directive was given, two of the three participants voiced that they were having a very difficult week and that they did not feel they could complete the directive. Assessing their feedback, the researcher gave an alternative option to draw five coping strategies. This directive was given to provide an opportunity for them to identify strategies that may prevent future burn out. Both participants were more receptive to this alternative directive.



In both directives, colored pencils were provided because of their structured and controlled nature. After the previous session, which tended to focus on difficult feelings of hope/hopelessness and the unknown, the directive that was given served the purpose of managing stress and reframing caregiving experiences as an opportunity for personal growth.

- Session Seven – The Caregiving Container

The art therapy directive for session seven was to create a clay container. Participants were given a fist-size piece of air-drying, potter's clay. Participants were told, "Working with clay is a good way to work out frustrations. As you need and shape the clay, think about transferring any negative feelings you may be holding into the clay object. Make a container to help you hold any worries that you may have in the future." This directive uses both mindfulness and meditative practices to help caregivers cope with stressors that they may be experiencing.

Clay was chosen as a medium to aid in the cathartic release of frustration and stress. Creating a container also contributed to discussion about the process of holding and letting go of worries. The container also acted as a transitional object that the participants could take home with them during the last week to help facilitate closure.

- Session Eight – A Perfect Day Drawing

The session eight art therapy directive asked the caregiver group to, "Draw a perfect day. Where would you be? What would you be doing? Who would you be with?" Participants were given an 18" x 12" sheet of paper with a set of 16 oil pastels.

Oil pastels were used because they allowed participants to express a wide range of affect and provided a moderate amount of control. Because it was the final group session, themes that were highlighted included self-care practices

and identifying positive life experiences that contribute to well-being. The directive was designed to help facilitate closure, while allowing participants to express their hope in their continued life as a caregiver.

- Post-intervention Interview – Tree in Weather Drawing

This final art assessment was given after the interview questions. Materials used were a 9"x12" piece of paper and a standard set of 16 oil pastels. The participant was then asked, "Think about your life as a caregiver, and draw yourself as a tree in weather". They were then asked to explain how the tree figure relates to them. Some other follow-up questions were asked if the participant needed further prompting.

Oil pastels were used because they allowed participants to express a wide range of affect while providing a moderate amount control. The directive and art materials were designed to elicit thoughts and feelings regarding caregiving. The participant will then be asked how the tree figure relates to them. The final tree will then be compared with the initial tree, to aid reflection on their experiences over the intervention period.

Over the course of the study, 76 pieces of art were produced by participants. Group 1 created 41 pieces of art and Group 2 created 35 pieces of art. The difference in the total number of pieces that were created by each group can be attributed to the different group sizes and the number of attendees in each session. A compact disc containing a note from the researcher and a full archive of the artwork can be found in the inside cover of the thesis located in Drexel University Creative Arts in Therapy Department or Drexel University Hahnemann Library. If you have accessed this thesis electronically, or intend to use any of the study images for any purpose, please contact the researchers regarding dissemination of the study material.

## Data Analysis

### Group 1

#### Description of Group 1.

Five participants were enrolled in Group 1. The mean age was  $54.6 \pm 6.6$  years, ranging from 46-64 years of age. All of the participants were female and there was one non-white participant. Three participants were spouses, one was an adult child, and one was an in-law. Two of the participants were caring for someone with frontotemporal dementia, one for Alzheimer's disease, one for Lewy body dementia, and one for dementia (unspecified). The mean number of years spent caregiving was  $3 \pm 0.8$  years, ranging from under 2 years to 4 years.

At the beginning of the study all of participants in Group 1 were currently receiving one or more forms of respite care. Of that total, three received professional in-home care, two received daycare services, and two received informal respite care. All of the participants in Group 1 were also receiving other support services. Three attended an Alzheimer's Association support group, three saw an individual counselor or therapist, and two used case management/social worker services.

#### mPWS-C-Group 1.

Data collected from Group 1 via the modified Psychological Well-being Scale for Caregivers (mPWS-C) can be found in Table 1 seen below. The scores for each subscale (social support, life meaning, emotional distress, and caregiver inadequacy) are listed over the eight-week intervention. Figure 1 displays a graph of the average scores for each subscale across the intervention period. The subscales appear to be independent of each other and do not trend in a specific direction.

Figure 2 displays the well-being of Group 1 tracked over the intervention period. The composite measures of well-being are given in the final column of Table 1.

Table 1. Group 1 Data from mPWS-C

Session	Social Support	Life Meaning	Emotional Distress	Caregiver Inadequacy	Composite
<b>0a</b>	13	20	13	8	<b>12</b>
<b>1</b>	14	20	13	8	<b>13</b>
<b>2</b>	15	22	14	8	<b>15</b>
<b>3</b>	15	19	13	8	<b>13</b>
<b>4</b>	15	18	13	9	<b>11</b>
<b>5</b>	14	19	11	9	<b>13</b>
<b>6</b>	10	19	15	11	<b>3</b>
<b>7</b>	14	20	12	10	<b>12</b>
<b>8</b>	16	19	12	10	<b>13</b>
<b>0b</b>	14	20	13	9	<b>12</b>

Key:

Social Support (SS) (min= 0, max = 20)

Life Meaning (LM) (min = 0, max = 30)

Emotional Distress (ED) (min=0, max = 20)

Caregiver Inadequacy (CI) (min=0, max = 20)

Composite scores of well-being were calculated using the following formula, and scores can range from -20 to 30:

$$SS + LM - ED - CI = \text{Composite Well-Being}$$

Figure 1.

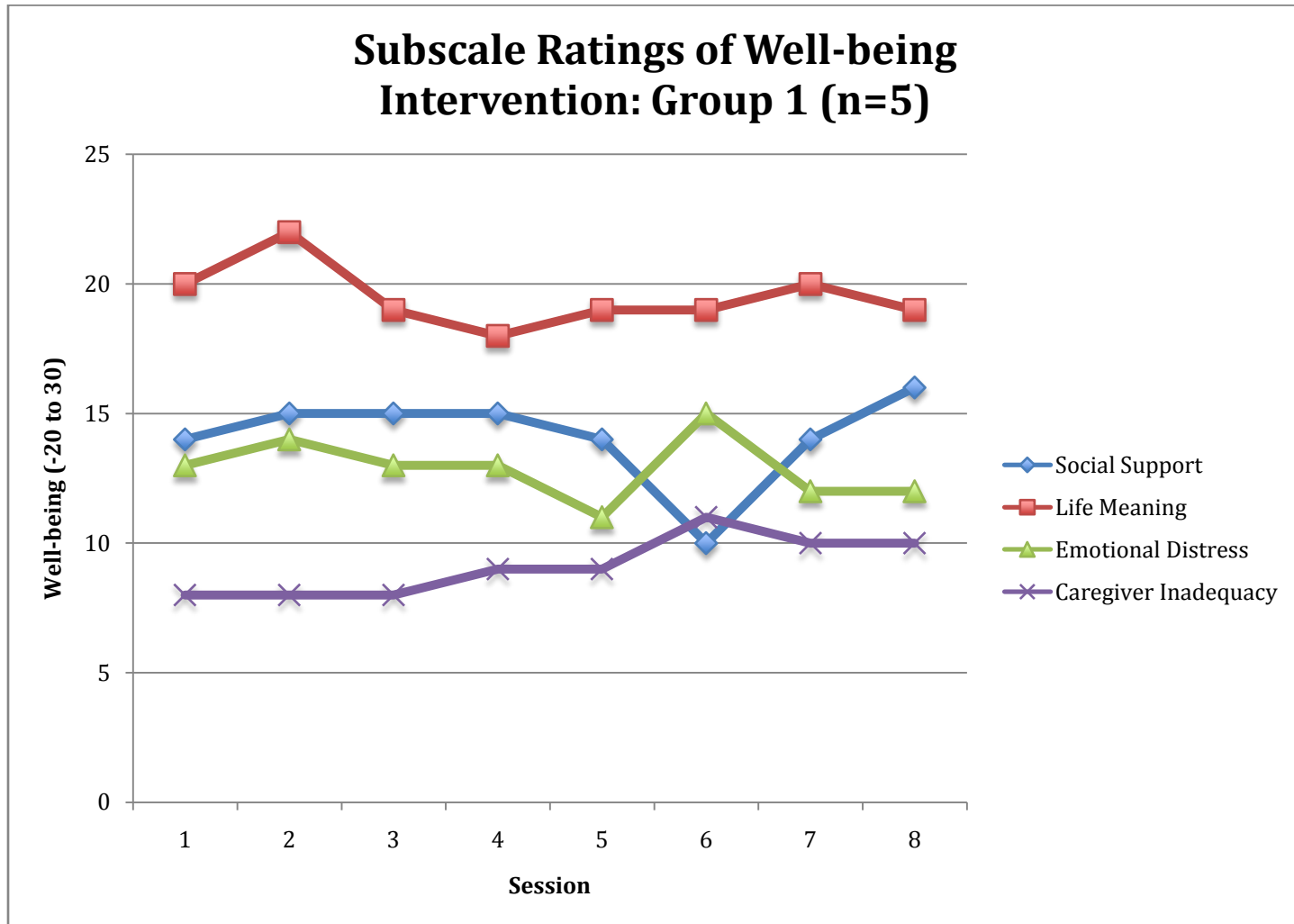
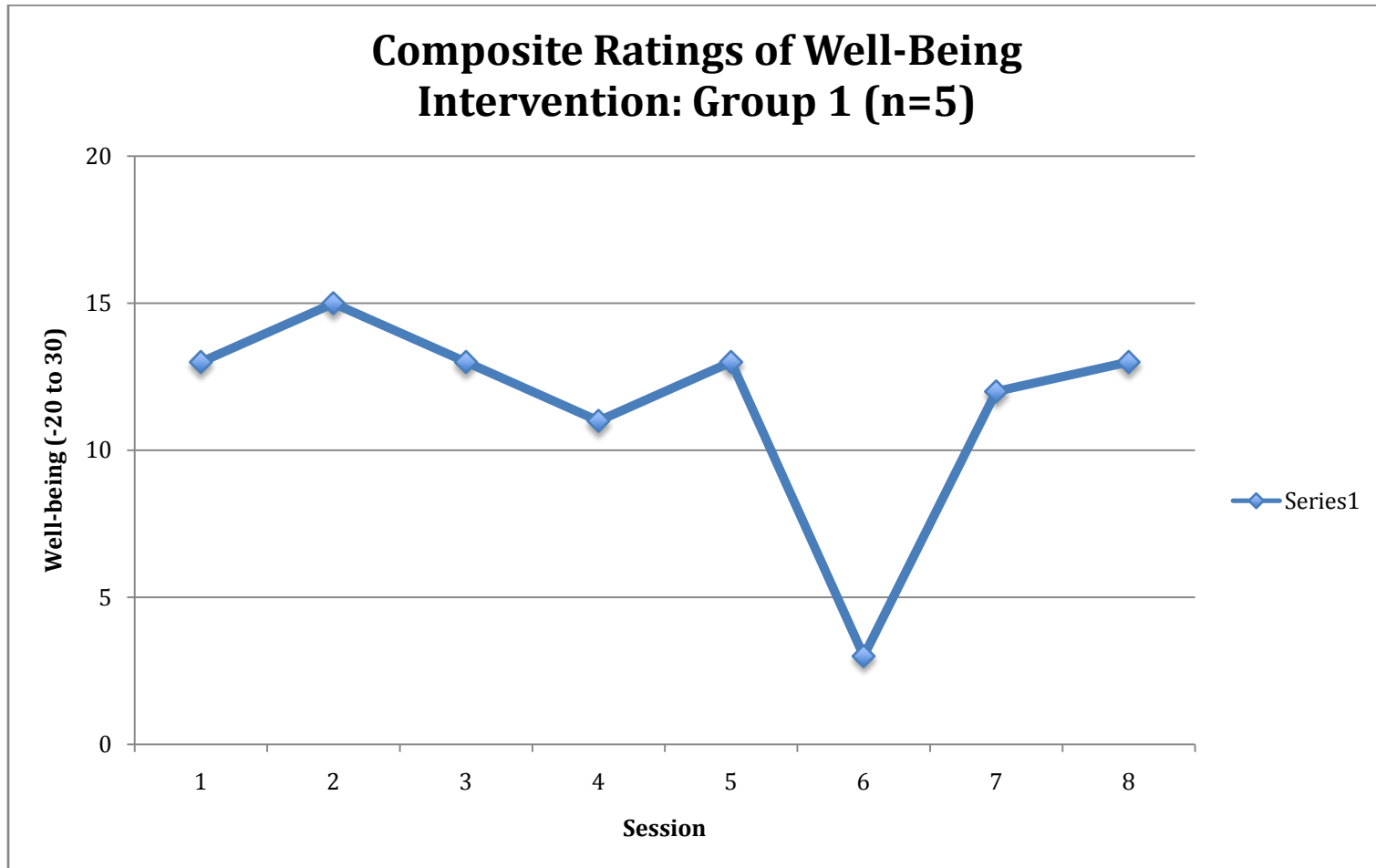


Figure 2.



Composite measures for Group 1 range from 3 to 15 on a scale from -20 to 30, with an average, composite score of 12 over the entire intervention.

The data suggests that the composite measures of well-being for Group 1 was dynamic and changed throughout the intervention. These changes may be dependent on a number of unknown factors. However, over the course of the intervention it was observed that participants were able to express themselves and receive support. Measures of well-being at the conclusion of the intervention were comparable to those during the initial session.

### **Intervention - Group 1.**

Table 2 presents data from each of the intervention sessions. The table includes art materials used, the directives, number of participants in attendance, art elements, themes in group discussion and artwork, dynamics in the group, as well as subscale and composite measures of the mPWS-C. A list of art elements that emerged from the artwork can be found below the table. Changes in well-being between the pretest and posttest within a single session may demonstrate therapeutic effects of the discussion, group dynamics, or art-making.

To represent the changes in well-being graphically, Figure 3 shows the pretest and posttest scores across the intervention period. Points describing average pretest and posttest scores for each session are shown. Three of the eight sessions had a positive effect, three had a negative effect, and two had no effect on Group 1 well-being.

Social support was increased in two sessions, remained the same in five sessions, and decreased in one session. Life meaning decreased in four sessions, increased in three sessions, and remained the same in one session. Emotional distress was found to decrease in four sessions and have no effect in four sessions. Caregiver

	Art Materials	Prompt	n	Art Elements (# out of n)	Themes	Dynamics	Subscales				Well-being
								pre	post	change	
1	- 18"x12" sheet of paper - Assortment of precut magazine images - Scissors - Glue	"Make a collage with the PWD's needs on the outside, and a collage of your needs on the inside. To make the collage, select and cut out images or words from the magazines and paste them to the paper."	3	- Full use of space: 3 - Full use of color: 3	- Family as support - Being in the here-and-now - Need for a restorative break	- Little group interaction					Pre: 10 Post: 15  <u>Change:</u> +5
							SS	13	14	+1	
							LM	20	20	0	
							ED	14	12	-2	
						CI	8	8	0		
2	- 9"x12" sheet of paper - Set of 12 colored pencils	"Draw a picture of yourself and your family somewhere doing something together."	4	- Full use of space: 4 - Full use of color: 3 - Underdeveloped figures: 2 - Floating figures: 3	- Need for a restorative break - Dependency - Being thankful for small things - Family as a support - Difficulty asking for help from others - Letting go and acceptance	- Worked quietly - Little group interaction					Pre: 15 Post: 14  <u>Change:</u> -1
							SS	14	15	+1	
							LM	23	22	-1	
							ED	14	14	0	
						CI	8	9	+1		
3	- 18"x12" sheet of paper - Set of 16 oil	"In what ways has your relationship	4	- Full use of space: 4 - Full use of color: 3 - Underdeveloped	- Additional role and increased responsibilities	- More group interaction - Worked		pre	post	change	Pre: 16 Post: 10



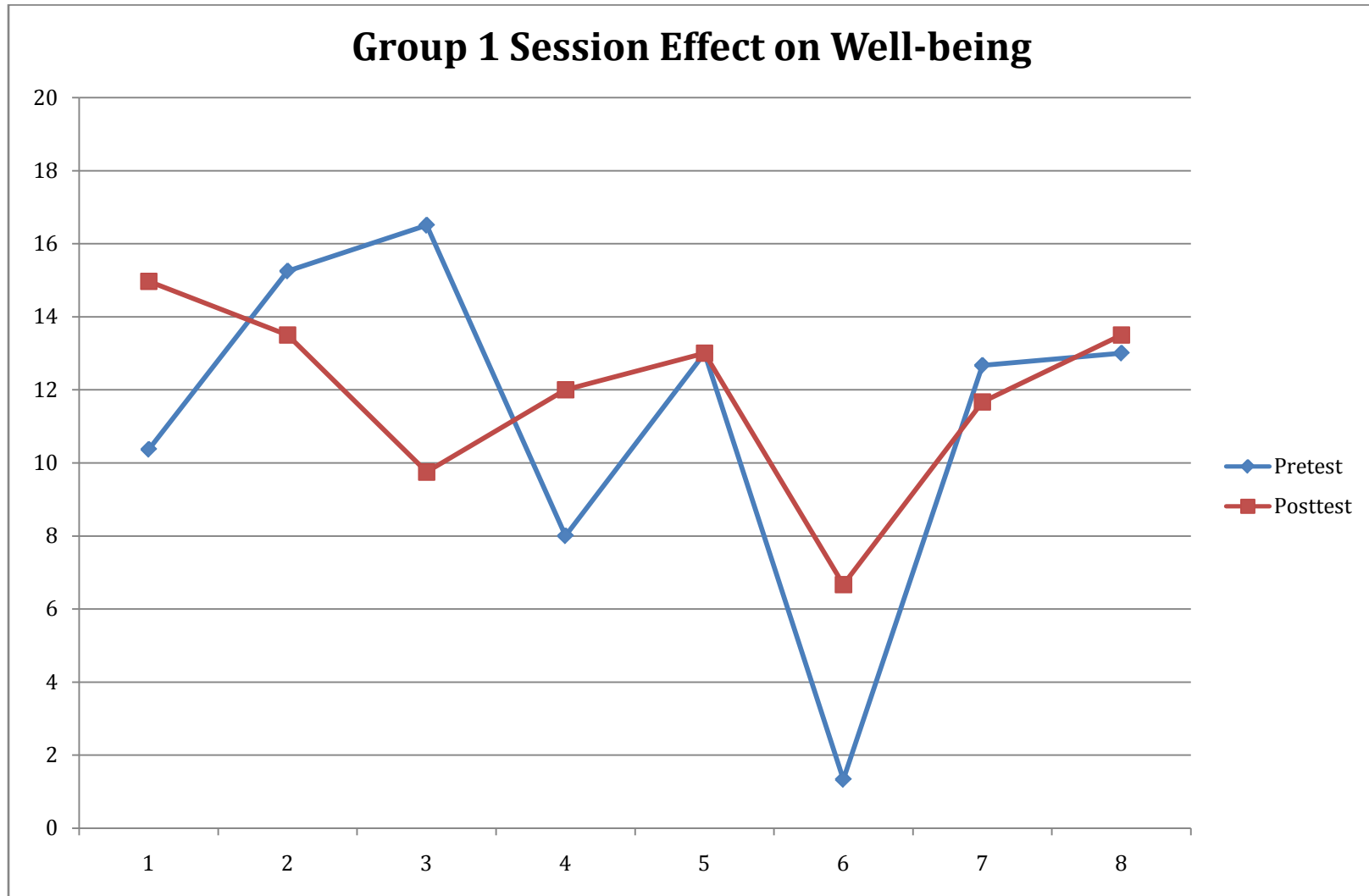
	pastels	changed because of dementia? Draw a picture of your relationship before dementia on the left, and your current relationship on the right."		figures: 2 - Floating figures: 4	- Loss of/need for companionship - Intellectual v. emotional process - Coping: sublimation and withdrawal - Defenses: avoidance and isolation of affect	quietly - Late ending (+15)	SS	15	14	-1	<u>Change:</u> -6
							LM	22	17	-5	
							ED	13	13	0	
							CI	8	8	0	
4	- 18"x12" sheet of paper - Set of 16 oil pastels	"Draw a time that you were angry at the person with dementia in the middle panel." After 15 minutes the therapist will then ask, "While you continue to draw, consider what happened right before this event and what happened right after this event."	4	- Full use of space: 4 - Full use of color: 2 - Underdeveloped figures: 2 - Floating figures: 4	- Tension and frustration in the CG/PWD dyad caused by burden and dependency - Coping: catharsis - Defenses: Avoidance and displacement	- 2 participants arrived late (+15/+30) - Work quietly and diligently - More group interaction - Participants openly asked each other questions - Imparting of knowledge - Universalization - Ended late		pre	post	change	Pre: 9 Post: 12 <u>Change:</u> +3
							SS	15	15	0	
							LM	17	18	+1	
							ED	14	12	-2	
							CI	9	9	0	
5	- 18" x 12" sheet of paper - set of watercolor	"Paint your life as a garden; past, present, and future."	4	- Full use of space: 4 - Full use of color: 4 - Ground line: 0 - Underdeveloped	- Loss of former life - The future unknown - A desire for	- Started late (+15) - 1 late arrival (+20)		pre	post	change	Pre: 13 Post: 13 <u>Change:</u>
							SS	14	14	0	

	paints - Watercolor paint brushes			figures: 1	normalcy/new beginning - Helplessness	- Worked silently - Imparting of knowledge - Universalizati on - Offered each other emotional support - Ended late (+30)	LM	19	20	+1	0
							ED	11	11	0	
							CI	9	10	+1	
6	- 9"x12" sheet of paper - Set of 12 colored pencils	After an anecdote is presented. "Draw at least one positive aspect of being a caregiver." OR "Draw 5 coping strategies."	3	- Full use of space: 2 - Full use of color: 3 - Floating figures: 2 - Underdeveloped figures: 1	- Helplessness - Feeling depleted - Coping: Mindfulness practices, catharsis, sublimation; negative coping strategies - Defenses: Avoidance, displacement, isolation of affect	- 1 participant early to session - Imparting of information - Worked quietly and diligently - Done artwork early, time to sit - Less group interaction		pre	post	change	Pre: 1 Post: 7  <u>Change:</u> +6
							SS	10	10	0	
							LM	19	20	+1	
							ED	17	13	-4	
							CI	11	10	-1	
7	- Fist-size piece of air- drying potters clay - Sculpting tools	"Working with clay is a good way to work out frustrations. As you knead and shape the clay,	3	*Creation of sculptures - art elements not applied	- Coping with worries - Sublimation - Isolation of affect - Catharsis - Need for down	- Started late (+15) - Late arrival (+25) - Worked diligently and		pre	post	change	Pre: 13 Post: 11  <u>Change:</u> -2
							SS	14	14	0	

		think about transferring any negative feelings you may be holding into the clay object. Make a container to help you hold any worries that you may have in the future."			time	silent - Differentiation - Expression of group mourning	LM	21	19	-2	
							ED	12	12	0	
							CI	10	10	0	
8	- 18" x 12" sheet of paper - Set of 16 oil pastels	"Draw a perfect day. Where would you be? What would you be doing? Who would you be with?"	4	- Full use of space: 4 - Full use of color: 4 - Floating figures: 1 - Underdeveloped figures: 2	- Loss of friendships and companionship - Role change - Family as a support - Unmet needs of CG	- Started late (+20) - Late arrival (+15) - Worked diligently and quietly - Imparting of knowledge - Ended late		pre	post	change	Pre: 13 Post: 13  <u>Change:</u> +0
							SS	16	16	0	
							LM	20	19	-1	
							ED	13	12	-1	
							CI	10	10	0	

- Emerging art elements:
- Range of color
    - o Full v. sparse
  - Use of space
    - o Full v. less-than-full
  - Development of figures
    - o Underdeveloped (e.g. fragmented or stick figures)
  - Floating figures v. groundline

Figure 3.



Inadequacy remained stable in five sessions, increased in two sessions, and decreased in one session.

Upon reviewing the data, the therapeutic effect (i.e. change in the composite score of well-being or subscale of well-being during pre/post-session testing) does not seem to be correlated with the art materials used, the number of participants in attendance, with specific themes or dynamics.

The week one collage addressing needs, week four drawing about anger, and week six drawing of positive thinking and coping yielded a positive effect on the composite well-being of the group. The week two kinetic family drawing, week three drawing of changes in the caregiver/care recipient dyad, and week seven sculpture of a clay container resulted in a decrease of composite well-being. The week five painting of “your life as a garden; past, present, and future” and week eight drawing of “your perfect day” did not cause any change in composite well-being.

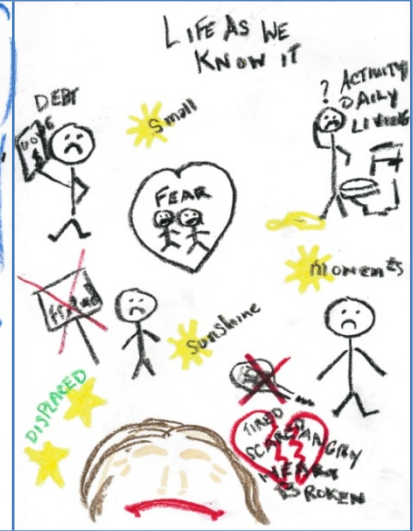
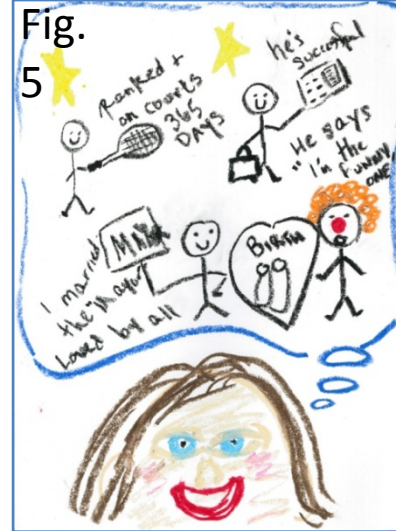
The artwork created during these sessions provides further insight into the experience and lives of the caregivers in Group 1. Over the course of the intervention participants created artwork which reflect their own needs, experienced losses, dyadic interactions between caregiver and care recipient, coping mechanisms and strategies, etc. Data will be presented from three sessions in Group 1. These sessions were selected because they most clearly represent issues that were relevant to Group 1.

Figures 4-7 are drawings created during session 3, which asked participants to draw how their relationship has changed due to dementia. Three participants were spouses and one participant was an in-law. All of the images produced reflect a loss of companionship, indicating that dementia has a disruptive effect on relationships. This loss was indicated in both the imagery and reported in the group discussion.

Figure 5 demonstrates the emotional effect this loss has had on the participant; once happy and beaming with pride for her spouse, now saddened and fearful. The

# Group 1 – Session 3

- “In what ways has your relationship changed because of dementia? Draw a picture of your relationship before dementia on the left, and your current relationship on the right.”



participant explained that she feels she is “living loss” and “miss[es] the man”. Her only relief is the small moments of “sunshine”, which are ambiguous and non-descript.

Figure 6 and 7 most clearly reflects the burden felt by caregivers, who must take on the additional responsibilities that were traditionally fulfilled by their spouse. As an ancillary effect, the person with dementia is depicted as having a decreased capacity for functioning and increased dependency. Burden is then two pronged, meaning that being a caregiver requires learning and managing the role of the diagnosed, while also requiring a greater level of assistance in caring for the person with dementia.

The discussion yielded information about coping and defense mechanisms, which may be incorporated by participants to manage feelings of loss and burden. Specifically, participants talked about channeling frustrating energy into their work life and in the management of household directives.

However, they also mentioned the desire to withdraw and isolate themselves in order to receive a break from their responsibilities. The need for a restorative break was discussed in several sessions. Avoidant behavior was also observed when loss was addressed directly. The subscales demonstrated a one point decrease in social support, a five point decrease in life meaning, and no change in caregiver inadequacy or emotional distress.

Session four asked participants to draw a time they were angry with the person with dementia, and to reflect on what had happened before and after that moment of anger. Three participants were spouses and one participant was an adult child. All moments of anger, displayed in Figures 8 through 11, resulted from feelings of disruption experienced by the caregiver from the actions or needs of the care recipient. Figures 9 and 10 involved assistance with activities of daily living, Figure 8 involved an expectation for normalcy, and Figure 11 involved the need for psychological space and down time.

# Group 1 – Session 4

- “Draw a time that you were angry at the person with dementia in the middle panel”. After 15 minutes the facilitator then asked, “While you continue to draw, consider what happened right before this event and what happened right after this event, and draw those scenes along side the middle panel.”

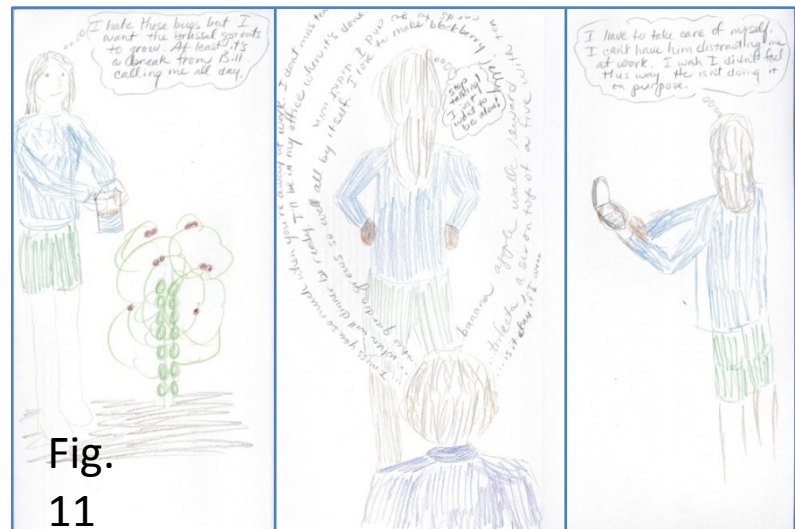
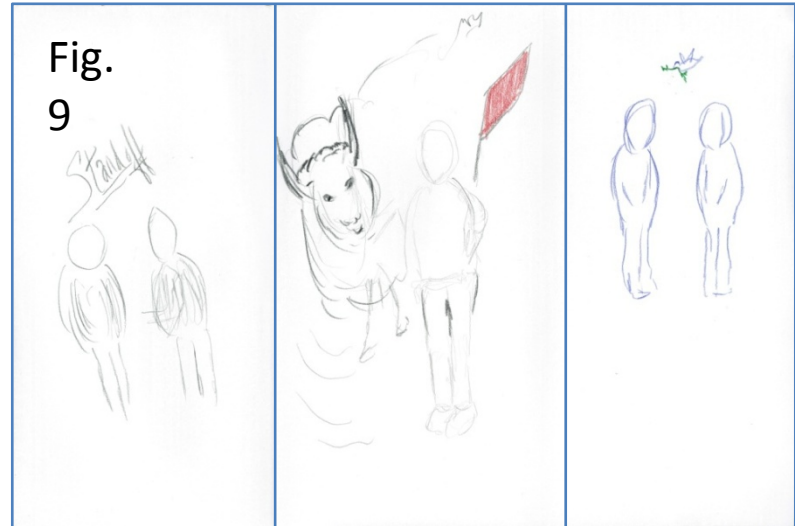




Figure 11 is of special interest due to the dynamics involved. All day the participant had been receiving calls at her office from her husband with dementia. She reported that it would not be unusual for her husband to call 30-40 times a day. After feeling that her work had been disrupted all day, she returned home and chose to stay in her car for a few minutes of silence to collect herself.

Seeing the car in the driveway, the husband came out to greet her. Going into the garden, she proceeded to gas bugs on a plant, while she tried to ignore the constant and incoherent verbalizations of her husband. The participant depicts herself with her back turned toward her husband wishing for a moment of time alone. Pictorially she demonstrates her avoidant behavior.

In the final pane, the participant shows herself deleting the office number from her husband's cellphone. In the thought bubble, she has written the following thoughts: 1) I have to take care of myself, 2) I can't have him distracting me at work, 3) I wish I didn't feel this way, 4) he isn't doing it on purpose. This thought process exemplifies a psychological dilemma that caregivers experience. The subscales of well-being indicate a two point decrease in emotional distress, a one point increase in life meaning, and no change in social support or caregiver inadequacy.

Group 1 worked with clay during session 7. They were asked to make a container, or worry jar, to hold any worries that they have. During the beginning of the session participants were also told to imagine transferring negative thoughts and emotions into the clay as they worked with it. Group discussion was then conducted to reflect on process of creating the artwork, as well as the final product.

During the process of working with the clay the researcher observed the act of sublimation including slamming and rolling of the clay. This behavior may be an indicator of frustrations and anger that is involved in caregiving. The cathartic act of slamming the

# Group 1 – Session 7

- “Working with clay is a good way to work out frustrations. As you knead and shape the clay, think about transferring and negative feelings you may be holding into the clay object. Make a container to you hold any worries that you may have or may have in the future.”



Fig.  
12



Fig.  
13

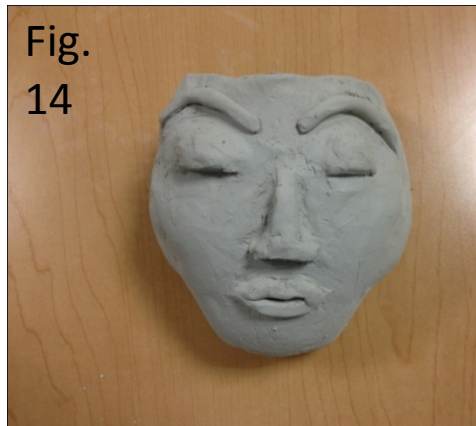


Fig.  
14

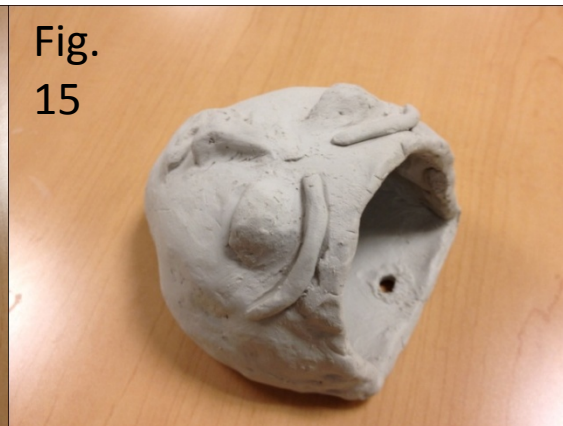


Fig.  
15

clay may lead to a diffusion of these negative feelings. These qualities are inherent in the media.

Figures 12 – 15 present the final products. The participant in Figure 13 created a garbage disposal to get rid of her worries. The participant noted that sometimes it is difficult to externalize the worry that she feels. She also noted that she has used journaling to help in the past. A fellow participant offered a supportive statement that she saw a blooming flower in the participant's sculpture, which was well-received.

Figure 12 is a container with a lid. The participant stated that she once she put the worry in, she did not want it to come out again. She also stated that rather than keep them she would prefer to get rid of them. The researcher offered the suggestion that even if she could not get rid of the worry, perhaps she could put it there and revisit it at a time that she felt she could handle it better. Finally, the participant stated that she wanted to make the handle like a rollercoaster, to reflect the ups and downs of caregiving.

The final participant made the figure of a head to hold the worries, in Figure 14 and 15. She shared that her intent was for the face to be both serene and whimsical, to remind her to stay calm and see the humor in situations of worry. Upon reflecting on the product she also remarked that the placement of the worries in the head may also be related to dementia itself, since most of her worries are being caused by a neurological disease which causes the degeneration of brain tissue.

The group then discussed what causes them worry in general. Participants identified both concrete and ambiguous causes of worry. They included being unable to prepare their house for sale, being unable to manage finances well, and having “nebulous” fears about the present and future. One of the participants expressed that being a caregiver has taught her to worry less. Lastly, the group expressed a need for down time to attend to both concrete and ambiguous worries. Subscale scores showed a

two point decrease in life meaning and no effect on social support, emotional distress, or caregiver inadequacy.

In the artwork, participants tended to use the space provided for them and an array of color. Session Five produced the most color which was in line with the goals of the session to trigger an affective response. There were also a number of figures that were not grounded. One or two members in the group also had a tendency to create underdeveloped or fragmented figures.

### **Intake and debriefing interviews - Group 1.**

In the intake and debriefing interviews, participants were asked to answer questions regarding social support and expression of their thoughts and feelings. Responses regarding support can be seen in Table 3 and Table 4.

Table 3 displays coded data from intake and debriefing sessions in the pretest and posttest columns, respectively. Help with the management of responsibility was the most mentioned type of support at intake and debriefing. Feeling support through connectedness was the second highest response rate. Sharing knowledge as a form of support showed the greatest increase in Group 1. However, gains in feelings of connectedness and help with responsibilities also increased significantly. None of the factors regarding support type decreased from intake to debriefing.

Sources of support are displayed in Table 4. Support from friends and family was the most mentioned source of support for Group 1 at intake and debriefing. The second highest response for support source was for the community at large, including neighbors, church congregation, coworkers/company, etc. The source of support that appeared to change the most between the intake and debriefing was support groups. Professional support, including care aids, therapists, counselors, and ministers, also increased. No factors of support decreased.

Table 3. Group 1 Types of Support Received (n=5)				
		pretest	posttest	change
Communication	Listening to CG	4	5	1
	Talking	0	1	1
	Listening to others	0	1	1
	Verbal Support	1	0	-1
	TOTALS	5	7	2
Connectedness	Comparison w/other CG (inst of hope)	0	3	3
	Emotional Support	2	4	2
	Universalization	0	2	2
	Companionship for CG	1	1	0
	Visiting	0	0	0
	Companionship for PWD	3	2	-1
	TOTALS	6	12	6
Existential factors	Self	0	1	1
	Through Prayer	1	0	-1
	TOTALS	1	1	0
Knowledge	Sharing Coping Strategies	0	3	3
	Problem Solving and Decision Making	1	2	1
	Imparting of information/knowledge	0	0	0
	TOTALS	1	5	4
Responsibilities	Respite	0	5	5
	Management of Job Responsibility	2	5	3
	ADL assistance	3	4	1
	Household Tasks	2	1	-1
	General Awareness of PWD	2	1	-1
	TOTALS	9	16	7

Table 4. Group 1 Sources of Support (n=5)		pretest	posttest	change
Support groups	SG	1	6	5
	TOTALS	1	6	5
Community	Coworkers/Company	2	3	1
	Community (church, neighbor, etc.)	3	2	-1
	TOTALS	5	5	0
Existential factors	Self	0	1	1
	Faith	1	0	-1
	TOTALS	1	1	0
Family & friends	Family	5	9	4
	Friends	3	5	2
	Pet	0	0	0
	TOTALS	8	14	6
Professional support	Therapist/Counselor/Minister	0	2	2
	Professional Aids	2	3	1
	TOTALS	2	5	3

Table 5. Group 1 Types of Expression (n=5)		Pretest	Posttest	Change
Catharsis	Laughing	0	1	1
	Talking	5	5	0
	Slamming things	0	0	0
	Crying	2	1	-1
	Joking	2	1	-1
	Scream/Yelling/Cursing	3	0	-3
	TOTALS	12	8	-4
Mindfulness	Visualizations	1	0	-1
	Prayer	1	0	-1
	Meditation	1	1	0
	TOTALS	3	1	-2
Negative Coping	Eating	1	2	1
	Inhibition	0	0	0
	Withholding help	0	0	0
	TOTALS	1	2	1
Sublimation	Art-making	0	3	3
	Writing	2	3	1
	Physical Exercise	1	1	0
	Working	1	0	-1
	TOTALS	4	7	3

Table 5 examines responses regarding the expression of a caregiver's thoughts and feelings. Acts of catharsis are the most frequently mentioned at intake in Group 1 and comprise the majority of responses. At debriefing, reporting of cathartic expression decreased. The reporting of sublimation, including art making, writing, physical, exercise, and redirecting energy into work increased from intake to debriefing. Incorporating mindfulness practices decreased by a factor of two, and negative coping increased by a factor of one.

Means of baseline and post-intervention scores for Group 1 can be seen in Figure 16. Results for life meaning and emotional distress are relatively stable, with an increase in feelings social support and caregiver inadequacy. Measures of well-being between individual participants varied greatly and from week-to-week.

The assessments of well-being pre/post-intervention were comprised of the mPWS-C scores, self-reported interview responses, and the artwork itself. Composite scores for well-being on the mPWS-C are not consistently correlated with self-reported responses or artwork. However, there is a consistency between the self-reported responses and the artwork produced.

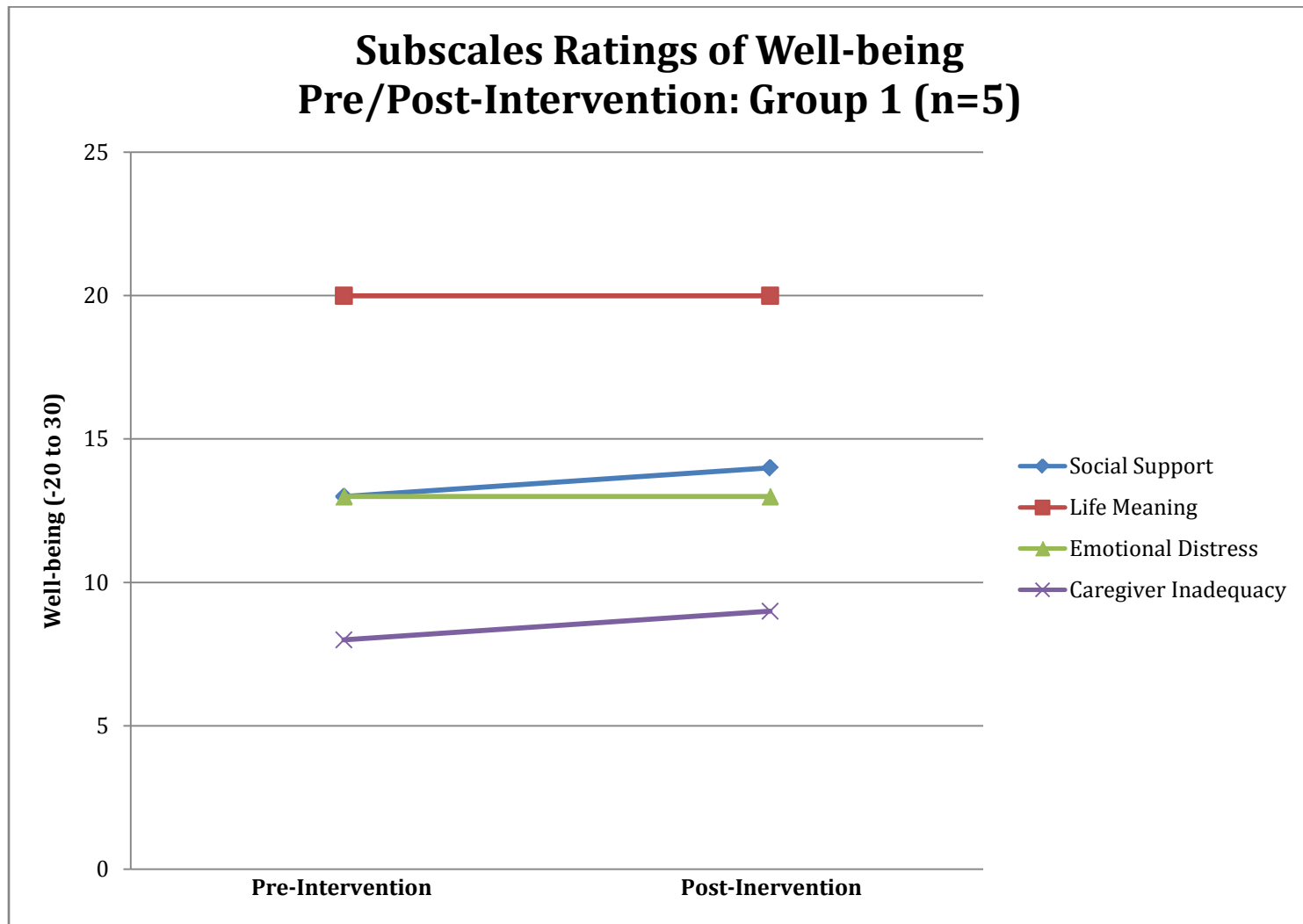
For example, in self-reported interview responses, the participant in Figure 21 and 22 noted feelings of stagnation, as well as increased frustration and depression despite receiving an increase of eight points on her composite score of well-being. The participant's artwork however, reflects little to no change, although she stated that she wanted to add bushes, representing "the little bit of help" that she has been receiving.

Figures 23 and 24 represent a separation of caregiver/care-recipient enmeshment. Special consideration should be given to assessments that represent a possible enmeshment. Although Figure 24 appears less healthy, the interview revealed that the caregiver felt resilient, being able to grow and flower despite being "gnarled".



The artwork and interview seem to represent a more accurate assessment of a participant's experience, and contextualizes their well-being, much better than the mPWS-C. Three art assessments show a moderate change, one shows a decrease in well-being, and one shows an increase. Also, the tree figure may represent the self, the care recipient, or identification with the care recipient. Themes such as loss, isolation, and stress are also present in the artwork and interview responses. Other factors such as enmeshment, superficiality, and intellectualization may also occur.

Figure 16.



# Group 1 – Tree in Weather

- “Think about your life as a caregiver, and draw yourself as a tree in weather.”

Fig 17

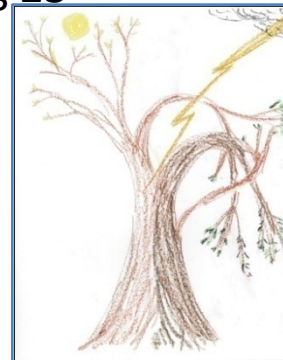


-8  
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Fig 18



Fig 23



-6  
→

Fig 24



Fig 19



Fig 20

-18  
→

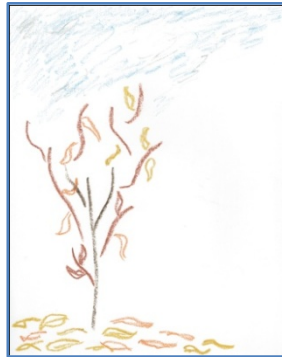
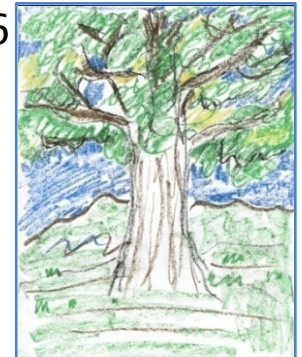


Fig 25



Fig 26

-7  
→



+8  
→



Fig 21

Fig 22

## **Group 2**

### **Description of Group 2.**

Four participants were enrolled in Group 2. The mean age was  $62.5 \pm 16.3$  years, ranging from 44-81 years of age. Three of the participants were female and all participants were Caucasian. The relationship to the person with dementia included two participants who were a spouse and two who were adult children. Two of the participants were caring for someone with dementia (unspecified) and two were caring for someone with Alzheimer's disease. The mean number of years spent caregiving was  $3 \pm 4.6$  years, ranging from under three months to 10 years.

At the beginning of the study three participants were currently receiving one or more forms of respite care in Group 2. Of that total, three received professional in-home care and two received daycare services. Two participants were also receiving other support services. One participant in Group 2 attended an Alzheimer's Association support group and one reported using a faith-based support service (i.e. minister).

### **mPWS-C-Group 2.**

Data collected from the mPWS-C scale for Group 2 can be found in Table 6 seen below. Individual scores had a tendency to vary from session-to-session. Composite scores for well-being of Group 2 range from 12 to 19 on a scale from -20 to 30, with an average, composite score of 15.

Figure 27 displays a graph of average scores for each subscale over the duration of the intervention period. Figure 28 displays the well-being of Group 2 tracked over the eight week intervention. The data suggests that factors of caregiver well-being are dynamic and change over time and under different circumstances, the causes of which may be unknown. Group 2 also demonstrates that well-being can also remain stable. Social support increased then stabilized in sessions four through eight.

Table 6. Group 2 Data from mPWS-C

<b>Session</b>	<b>Social Support</b>	<b>Life Meaning</b>	<b>Emotional Distress</b>	<b>Caregiver Inadequacy</b>	<b>Composite</b>
<b>0a</b>	15	24	11	8	<b>20</b>
<b>1</b>	14	21	11	9	<b>15</b>
<b>2</b>	15	23	13	12	<b>13</b>
<b>3</b>	16	20	9	10	<b>17</b>
<b>4</b>	15	20	11	11	<b>13</b>
<b>5</b>	15	22	12	12	<b>13</b>
<b>6</b>	15	19	9	9	<b>16</b>
<b>7</b>	15	22	10	11	<b>16</b>
<b>8</b>	15	19	9	9	<b>16</b>
<b>0b</b>	14	21	12	8	<b>15</b>

Key:

Social Support (SS) (min= 0, max = 20)

Life Meaning (LM) (min = 0, max = 30)

Emotional Distress (ED) (min=0, max = 20)

Caregiver Inadequacy (CI) (min=0, max = 20)

Composite scores of well-being were calculated using the following formula, and scores can range from - 20 to 30:

$$SS + LM - ED - CI = \text{Composite Well-Being}$$

Figure 27.

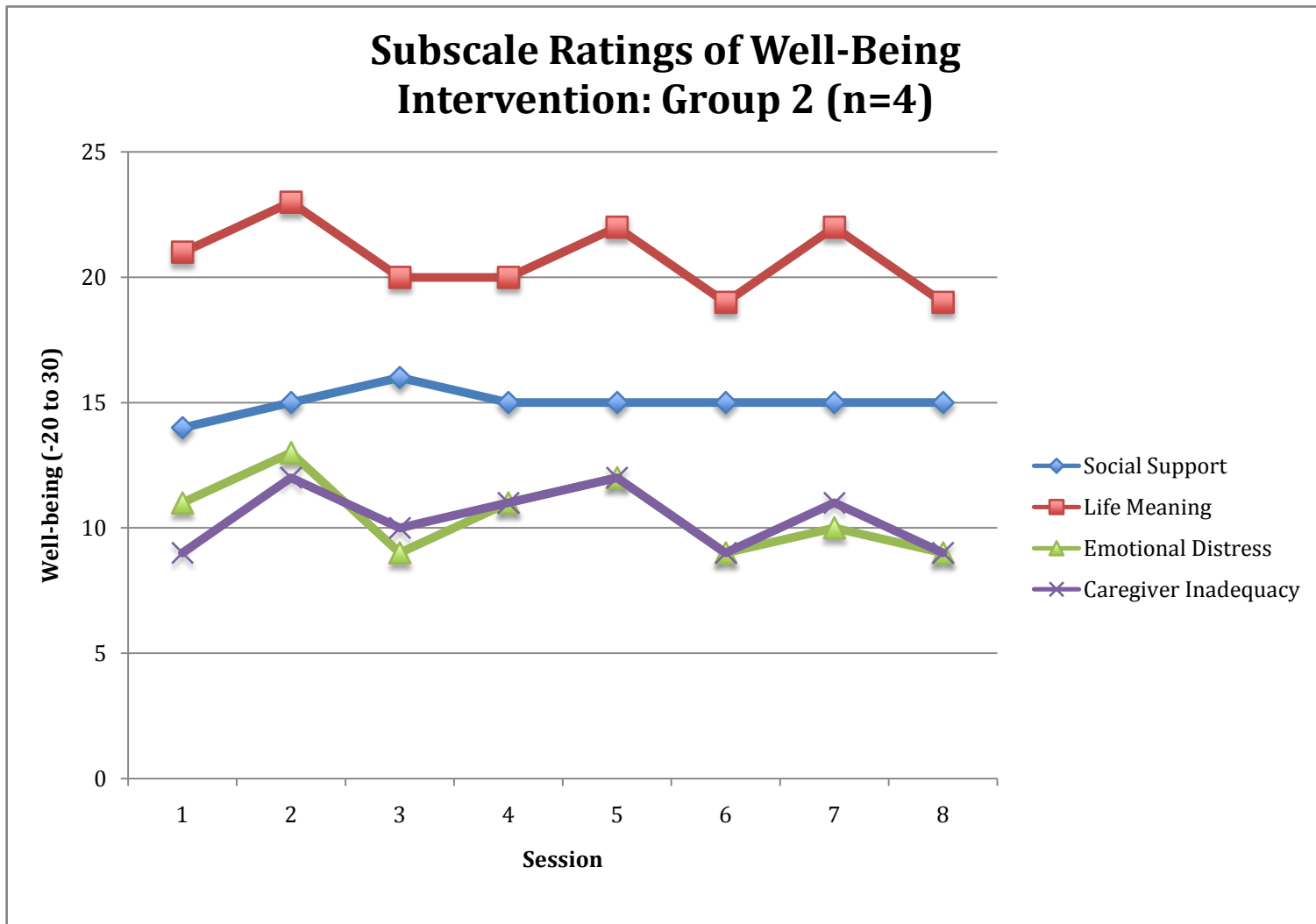
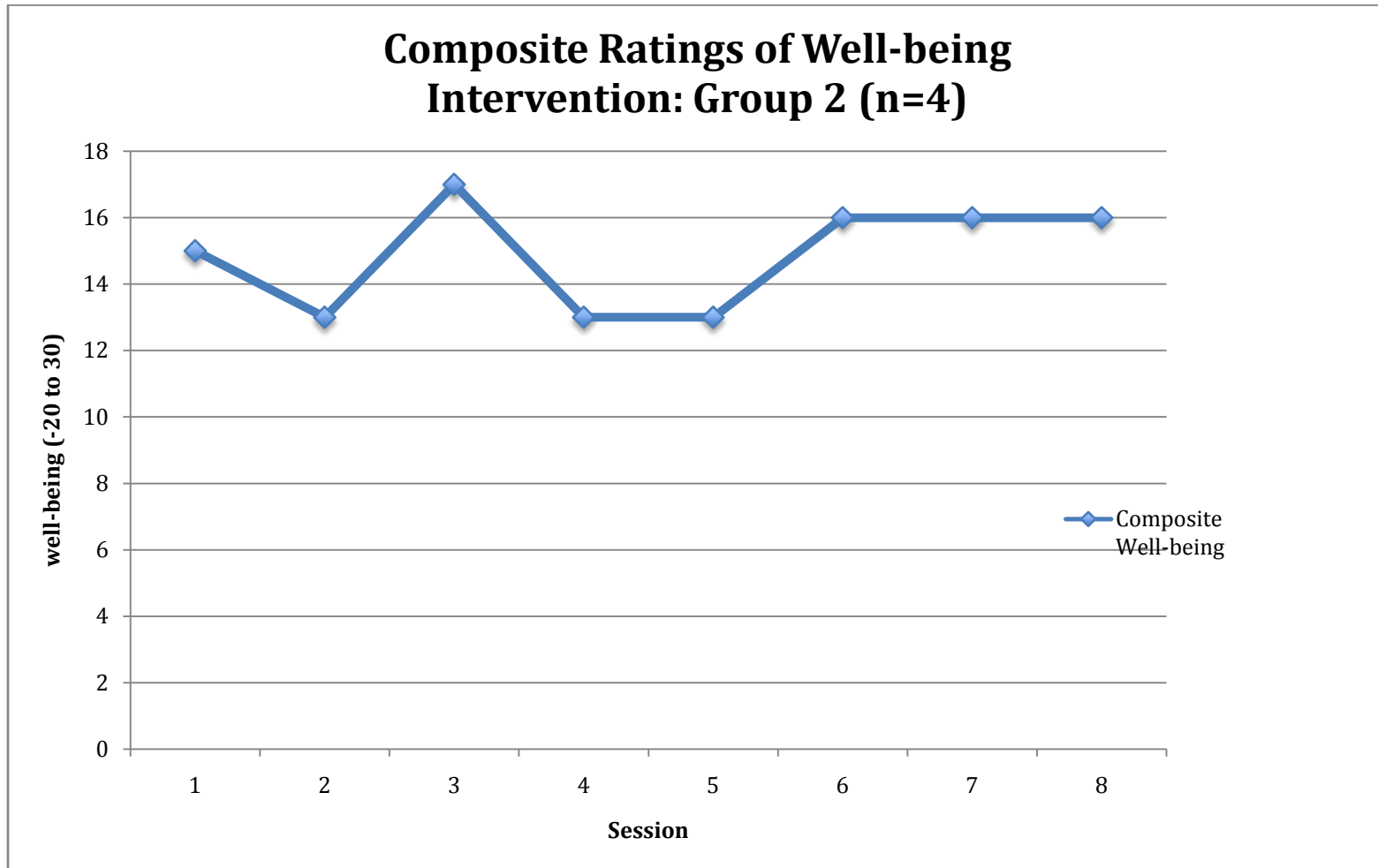


Figure 28.



## **Intervention - Group 2.**

Table 7 presents data from each of the intervention weeks. The table includes art materials used, the directive, number of participants in attendance, emerging art elements, themes in group discussion and artwork, dynamics in the group, and measures of the mPSW-C. Changes in well-being between the pretest and posttest may demonstrate the therapeutic effects of each individual session, which may also be correlated to the other items on the table.

To represent the changes in well-being per session graphically, Figure 29 shows the pretest and posttest scores across the intervention period. Points describing average pretest and posttest scores for each session are shown. Four of the eight sessions had a negative effect, two had a no effect, and one had a positive effect on Group 2 composite scores of well-being. The needs collage, draw a time you were angry, paint your life as a garden, and draw a positive aspect of caregiving resulted in a decrease in well-being. The draw a perfect day, kinetic family drawing, and draw a change in your relationship resulted in no change to measures of well-being. Working with clay resulted in an increase in well-being.

Social support was increased in one session, remained the same in six sessions, and decreased in one session. Life meaning decreased in four sessions, remained the same in three sessions, and decreased in one session. Emotional distress was found to increase in three sessions, have no effect in three sessions, and decrease in two sessions. Caregiver inadequacy decreased in five sessions, increased in two sessions, and decreased in one session.

The artwork created during these sessions provides further insight into the experience and lives of the caregivers in Group 2. Over the course of the intervention participants created artwork which reflect their own needs, experienced losses, dyadic



	Art Materials	Prompt	n	Art Elements (# out of n)	Themes	Dynamics	Subscales				Well-being
								pre	post	change	
1	- 18"x12" sheet of paper - Assortment of precut magazine images - Scissors - Glue	"Make a collage with the PWD's needs on the outside, and a collage of your needs on the inside. To make the collage, select and cut out images or words from the magazines and paste them to the paper."	3	- Full use of space: 3 - Full use of color: 3	- Need for a restorative break and balance - Burden of constantly attending to physical and psychological needs - Unknown and uncertainty	- Imparting information - Universalization - Differentiation					Pre: 15 Post: 15  <u>Change:</u> 0
							SS	14	14	0	
							LM	22	20	-2	
							ED	11	11	0	
						CI	9	8	-1		
2	- 9"x12" sheet of paper - Set of 12 colored pencils	"Draw a picture of yourself and your family somewhere doing something together."	3	- Full use of space: 3 - Limited color: 2 - Floating figures: 3 - Underdeveloped figures: 2 - Labeling: 2 - Poor organization: 1	- Increased difficulty organizing family gatherings - Story telling/life review	- 1 late arrival - Ended late (+15)					Pre: 12 Post: 12  <u>Change:</u> 0
							SS	14	15	+1	
							LM	23	23	0	
							ED	13	14	-1	
						CI	12	12	0		
3	- 18"x12" sheet of paper - Set of 16 oil pastels	"In what ways has your relationship changed because of dementia? Draw a picture of your relationship before dementia on the left, and	3	- Full use of space: 0 - Limited color: 2 - Floating figures: 3 - Underdeveloped figures: 3 - Labeling: 1 - Poor	- Loss of companionship - Story telling/life review - Additional role and responsibility - Feelings of	- Increased interactions between participants - Asked each other questions - Ended late					Pre: 18 Post: 19  <u>Change:</u> +1
							SS	17	15	-2	
							LM	21	19	-2	
							ED	10	7	-3	

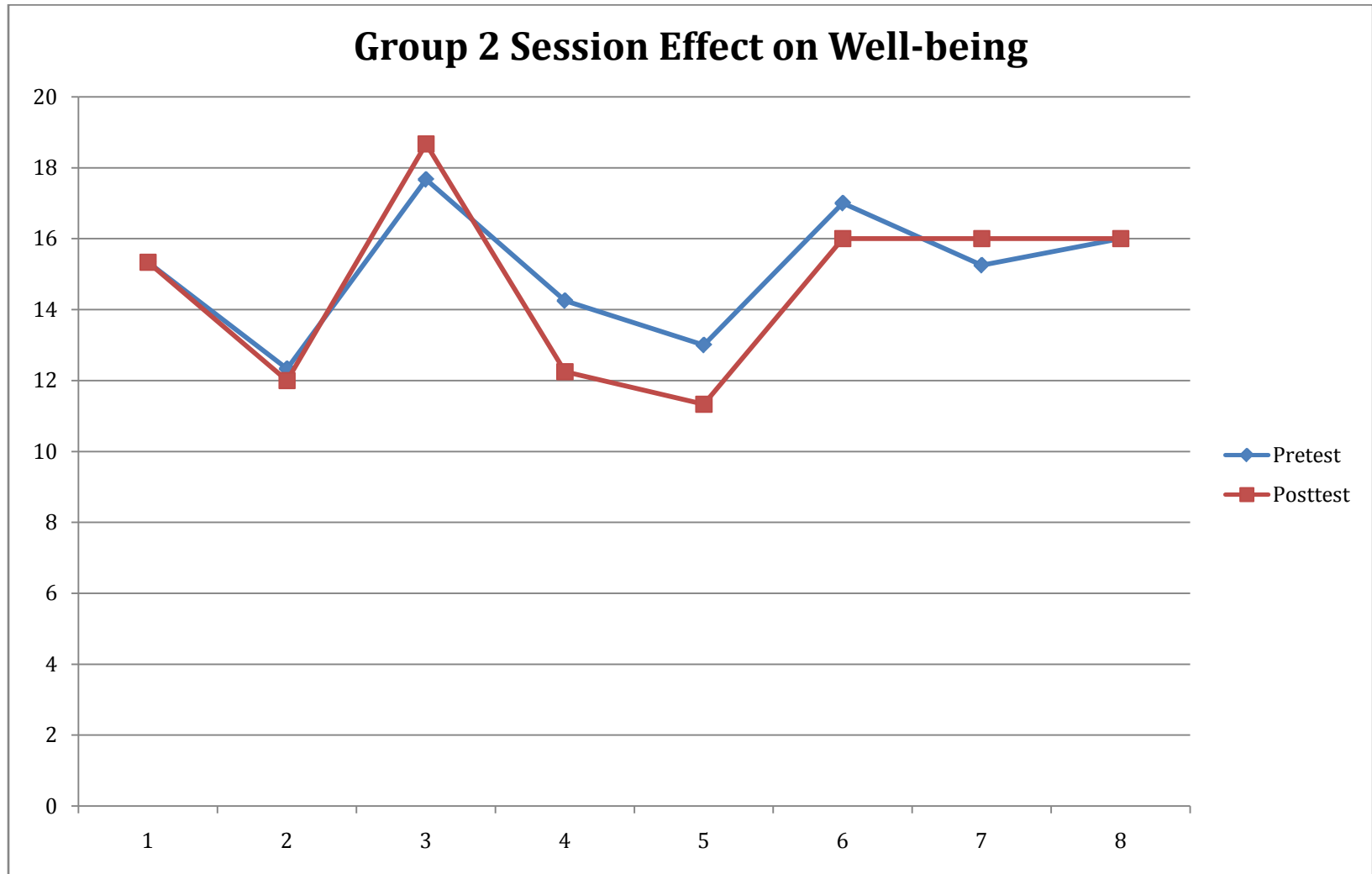
		your current relationship on the right."		organization: 1	inadequacy or uncertainty - Asking others for help		CI	10	9	-1	
4	- 18"x12" sheet of paper - Set of 16 oil pastels	"Draw a time that you were angry at the person with dementia in the middle panel." After 15 minutes the therapist will then ask, "While you continue to draw, consider what happened right before this event and what happened right after this event."	4	- Full use of space: 0 - Limited color: 2 - Full use of color: 1 - Floating figures: 4 - Underdeveloped figures: 4 - Labeling: 2 - Poor organization: 1	- Feeling of inadequacy or uncertainty - Helplessness and hopelessness - Physical burden of ADLs - Coping: Sublimation, acceptance - Defenses: Displacement and isolation of affect - Need for a restorative break	- 1 late arrival - Worked quietly and diligently - Imparting information - Ended late (+15)		pre	post	change	Pre: 14 Post: 12  <u>Change:</u> -2
							SS	15	15	0	
							LM	21	19	-2	
							ED	10	11	+1	
						CI	12	11	-1		
5	- 18" x 12" sheet of paper - set of watercolor paints - Watercolor paint brushes	"Paint your life as a garden; past, present, and future."	3	- Full use of space: 3 - Full use of color: 3 - Groundline: 1 - Underdeveloped figures: 1	- Identification - Differentiation - Loss - Return to normalcy - Hopelessness and helplessness - Unknown - Defenses: Avoidance - Coping: Isolation	- 1 late arrival - increased group interaction - support from group members - Ended late (+15)		pre	post	change	Pre: 13 Post: 12  <u>Change:</u> -1
							SS	15	15	0	
							LM	22	22	0	
							ED	12	12	0	
						CI	12	13	+1		

6	<ul style="list-style-type: none"> <li>- 9"x12" sheet of paper</li> <li>- Set of 12 colored pencils</li> </ul>	<p>After an anecdote is presented. "Draw at least one positive aspect of being a caregiver."</p>	2	<ul style="list-style-type: none"> <li>- Full use of space: 2</li> <li>- Full use of color: 1</li> <li>- Floating figures: 2</li> <li>- Underdeveloped figures: 1</li> <li>- Transparency: 1</li> </ul>	<ul style="list-style-type: none"> <li>- Ambiguous loss</li> <li>- Hopelessness and helplessness</li> <li>- Death and dying</li> <li>- Psychological burden and depletion</li> <li>- Unknown and uncertainty</li> <li>- Caregiver inadequacy</li> <li>- Pride in caregiver role</li> <li>- Coping: Catharsis, existential factors</li> </ul>	- 1 early participant		pre	post	change	Pre: 17 Post: 16  <u>Change:</u> -1
							SS	15	15	0	
							LM	20	19	-1	
							ED	9	9	0	
							CI	8	10	+2	
7	<ul style="list-style-type: none"> <li>- Fist-size piece of air-drying potters clay</li> <li>- Sculpting tools</li> </ul>	<p>"Working with clay is a good way to work out frustrations. As you knead and shape the clay, think about transferring any negative feelings you may be holding into the clay object. Make a container to help you hold any worries that you may have in the future."</p>	3	<ul style="list-style-type: none"> <li>- Death and dying</li> <li>- Shame/inadequacy</li> <li>- Story telling/life review</li> <li>- Warning signs</li> <li>-Coping: Existential factors, acceptance, sublimation</li> </ul>	<ul style="list-style-type: none"> <li>- Differentiation</li> <li>- More group interaction</li> <li>- Preparation for end of the group</li> </ul>		pre	post	change	Pre: 15 Post: 16  <u>Change:</u> +1	
						SS	15	15	0		
						LM	21	22	+1		
						ED	10	11	+1		
						CI	11	10	-1		

8	- 18" x 12" sheet of paper - Set of 16 oil pastels	"Draw a perfect day. Where would you be? What would you be doing? Who would you be with?"	2	- Full use of space: 2 - Full use of color: 1 - Groundline: 2 - Underdeveloped figures: 1	- Story telling/life review - Returning to normalcy - CGing as a barrier to individual needs - Need for a restorative break - Coping: Catharsis	- Worked diligently and quietly - Ended early		pre	post	change	Pre: 16 Post: 16
							SS	15	15	0	<u>Change:</u> 0
							LM	19	19	0	
							ED	8	9	+1	
							CI	10	9	-1	

- Emerging art elements:
- Range of color
    - o Full v. sparse
  - Use of space
    - o Full v. less-than-full
  - Development of figures
    - o Underdeveloped (e.g. fragmented or stick figures)
  - Floating figures v. groundline

Figure 29.



interactions between caregiver and care recipient, coping strategies, and defense mechanisms. Two sessions of Group 2 will be presented for review.

During session 3, Group 2 created artwork regarding the change in relationship with the person with dementia. Two participants were spouses and one was an adult child. The adult child depicted that there had been a role reversal in Figure 30. She stated that she had consulted her father for guidance in finances and general advice, which garnered respect for her father. Since a diagnosis of dementia she now plays the role of providing guidance and support when her father feels lost and confused.

Figure 31 depicts the loss of companionship in late-stage Alzheimer's disease. One participant, the spouse of a person with dementia, shows their life together earlier in the relationship and the loss that has occurred due to the progression of Alzheimer's disease. The caregiver and spouse appear happily hand-in-hand in the first pane, while the caregiver is depicted as saddened as his wife is now bed-bound in the second pane. The graphic indicators of the drawing also suggest depression and isolation of affect. Lastly, the participant expressed feelings of helplessness and hopelessness.

In Figure 32, the participant depicts herself driving and doing the family accounting, which were directives formerly fulfilled by her husband. Rather than a role reversal, the participant describes this as an additional role that she has assumed. Due to the loss of her companion, she also described feelings of inadequacy and uncertainty in making decisions regarding finances and other household matters. She stated that she still feels an obligation to include her husband in decision making although he no longer has the ability to offer advice or assistance.

Themes of the session include feelings of inadequacy or uncertainty, helplessness and hopelessness, the physical and emotional burden of activities of daily living. Coping and defense mechanisms identified are sublimation, acceptance,

# Group 2 – Session 3

- “In what ways has your relationship changed because of dementia? Draw a picture of your relationship before dementia on the left, and your current relationship on the right.”



Fig. 31

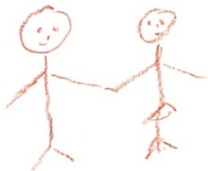
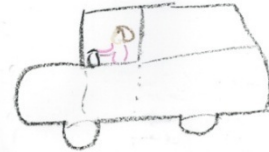


Fig. 32



# Group 2 – Session 5

- “Paint your life as a garden; past, present, and future.”





displacement, and isolation of affect. The group also expressed a need for a restorative break. Social support and life meaning decreased by two points each, emotional distress decreased by three points, and caregiver inadequacy decreased by one point.

Session five asked Group 2 participants to draw their life as a garden; past, present, and future. Three participants, two spouses and one adult child, were in attendance. All three participants identified that there was an experience of loss in their lives. While two of the three participants discussed being able to envision a future, the adult child identified with her mother's condition and could see "no future beyond the darkness" (Figure 35), alluding to feelings of hopelessness. Evaluating the potential to see a future, may have a meaningful impact on preserving caregiver well-being.

The themes in session five exemplify identification and differentiation, losses that are both concrete and ambiguous, hopelessness and helplessness, a fear of the unknown, and a desire to return to normalcy. Coping and defense mechanisms identified are avoidance, isolation, and compartmentalization. Compartmentalization is most evident in Figure 34, which depicts beauty and peace through "flower beds" that the participant describes as being filled with happiness and color in the past, a rocky and dry garden with painful thistles and cactuses in the present, and the reemergence of color and hope in the future. Caregiver inadequacy increased by one point. Social support, life meaning, and emotional distress remained the same.

The artwork produced by Group 2 filled up most of the space and used a range of color. There were many occurrences of floating figures with no ground line. There were also underdeveloped figures that lacked details, were minimal, or were fragmented. In general, Group 2 was less invested in their work and was quick to finish the product. This, however, is in sharp contrast to Group 1 which was intentional and contemplative about their art-making.

Table 8. Group 2 Types of Support Received (n=4)		pretest	posttest	change
Communication	Listening to CG	1	5	4
	Listening to others	0	2	2
	Verbal Support	1	1	0
	Talking	4	3	-1
	TOTAL	6	11	5
Connectedness	Companionship for PWD	0	3	3
	Companionship for CG	1	4	3
	Universalization	0	3	3
	Comparison w/other CG (inst of hope)	0	2	2
	Emotional Support	1	1	0
	Visiting	1	1	0
	TOTAL	3	14	11
Existential factors	Through Prayer	1	1	0
	Self	0	0	0
	TOTAL	1	1	0
Knowledge	Problem Solving and Decision Making	1	4	3
	Imparting of information/knowledge	0	3	3
	Sharing Coping Strategies	0	1	1
	TOTAL	1	8	7
Responsibilities	Respite	0	1	1
	Household Tasks	0	0	0
	General Awareness of PWD	0	0	0
	Management of Job Responsibility	0	0	0
	ADL assistance	4	2	-2
	TOTAL	4	3	-1

Table 9. Group 2 Sources of Support (n=4)		pretest	posttest	change
Community	Community (church, neighbor, etc.)	1	4	3
	Coworkers/Company	0	0	0
	TOTAL	1	4	3
Existential	Faith	1	1	0
	Self	0	0	0
	TOTAL	1	1	0
Family & friends	Family	5	8	3
	Friends	3	5	2
	Pet	1	0	-1
	TOTAL	9	13	4
Professional support	Professional Aids	3	3	0
	Therapist/Counselor/Minister	0	0	0
	TOTAL	3	3	0
Support groups	SG	0	5	5
	TOTAL	0	5	5

Table 10. Group 2 Types of Expression (N=4)		pretest	posttest	change
Catharsis	Talking	4	3	-1
	Crying	1	2	1
	Scream/Yelling/Cursing	1	0	-1
	Slamming things	1	0	-1
	Joking	0	0	0
	Laughing	0	0	0
	TOTAL	7	5	-2
Mindfulness	Visualizations	0	0	0
	Prayer	0	0	0
	Meditation	0	0	0
	TOTAL	0	0	0
Negative Coping	Inhibition	2	1	-1
	Withholding help	1	0	-1
	Eating	0	0	0
	TOTAL	3	1	-2
Sublimation	Art-making	0	1	1
	Physical Exercise	1	0	-1
	Writing	0	0	0
	Working	0	0	0
	TOTAL	1	1	0

## **Intake and debriefing interviews - Group 2.**

In the intake and debriefing interviews, participants were asked to answer questions regarding social support and expression of their thoughts and feelings. Responses regarding support can be seen in Table 8 and Table 9. Responses were coded and clustered into meaningful categories.

Table 8 displays coded data from intake and debriefing sessions. Communication with others was the most mentioned type of support at intake for Group 2. At debriefing the most significant change was an increase in feelings of connectedness. Support in the management of responsibilities was the second highest response rate at intake, but dropped to the least frequent response at debriefing. Sharing knowledge as a form of support showed the greatest increase in Group 2.

Sources of support are displayed in Table 9. Support from friends and family was the most mentioned source of support for Group 2. The second highest response for support source was for professional support, namely professional aids (e.g. in-home nurse, hospice provider, etc.). The source that appears to change the most between the intake and debriefing was support groups. Support from various sources from the community at large also increased. No factors of support source decreased.

Table 10 examines responses regarding the expression of a caregiver's thoughts and feelings. Acts of catharsis are the most frequently mentioned at intake in Group 2. At debriefing, reporting this type of expression decreased from the initial interview. The responses involving negative coping strategies, such as inhibiting emotion, withholding help, or overeating decreased. Factors of sublimation and mindfulness neither decreased nor increased.

Means of baseline and post-intervention scores for Group 2 can be seen in Figure 36. Results show a decrease in life meaning, social support, an increase in

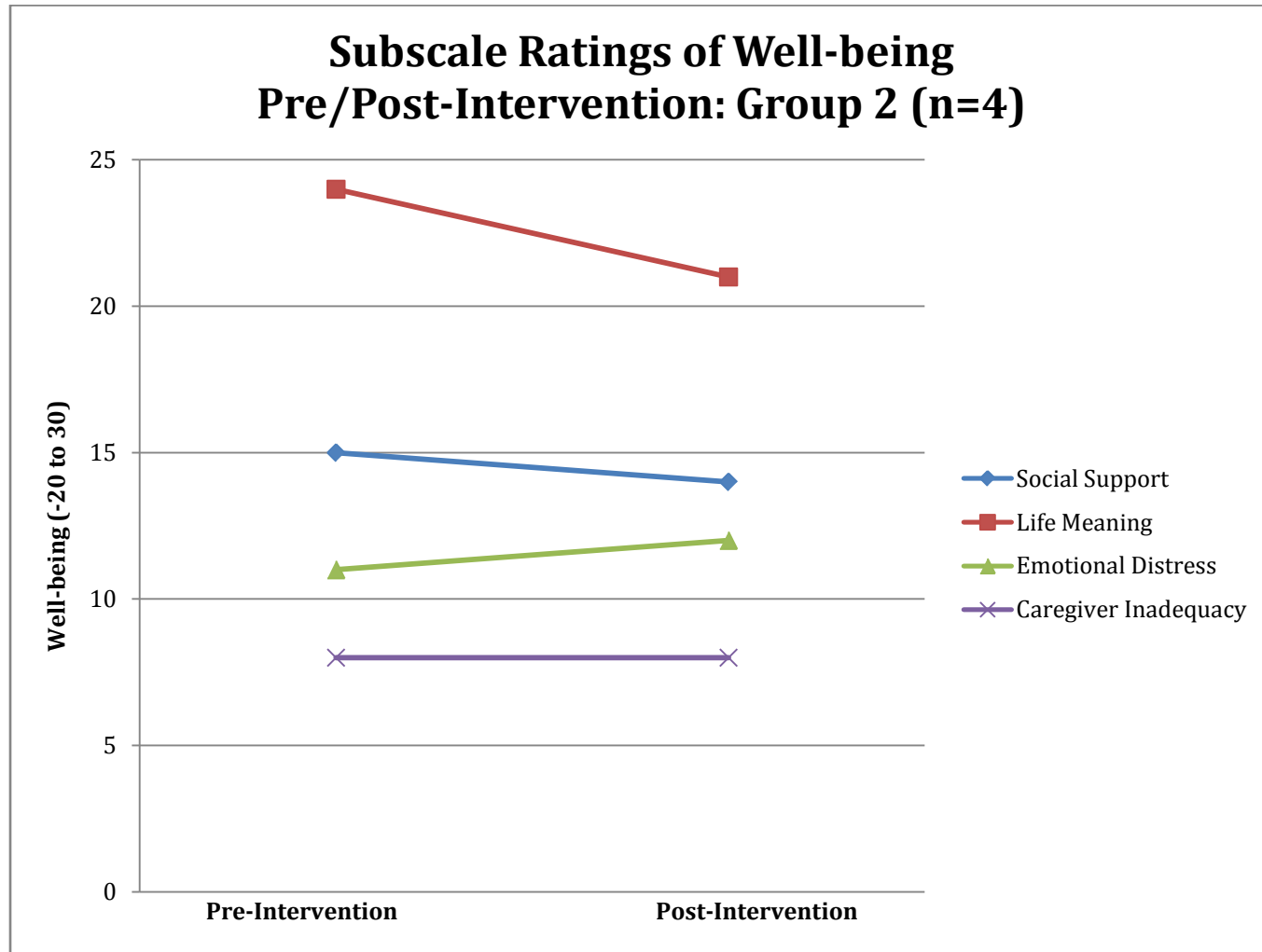
feelings of caregiver inadequacy, and stable ratings of emotional distress. Measures of well-being between individual participants varied greatly, as well as from week-to-week.

The assessments of well-being pre/post-intervention were comprised of the mPWS-C scores, self-reported interview responses, and the artwork itself. Composite scores for well-being on the mPWS-C are not consistently correlated with self-reported responses or artwork. However, there is an inconsistency between the self-reported responses and the artwork produced.

For example, in self-reported interview responses, the participant in Figure 43 and 44 noted feelings of increased depression and more fragile emotionality since intake. She described her experience as “just trying to survive”. Despite these responses, this participant scored +22 points on the mPWS-C. An additional consideration should be made in regard to the intake art, as the participant described that the scene in Figure 43 as what she “hopes for”, but confirmed that it did not reflect her experience of caregiving. Therefore, special recommendations should be given for artwork that may demonstrate superficiality.

Figures 37 and 38 may represent the enmeshment and subsequent individuation of the caregiver/care recipient dyad. Figure 38 should also have special consideration, because the participant indicated that the two trees pictured represent her positive feelings of change before and after the intervention. However, her score on the mPWS-C indicated a decrease of -21 points, which is counterintuitive to her self-report. Again, art assessments containing enmeshment may need special consideration when evaluating well-being.

Figure 36.



# Group 2 – Tree in Weather

- “Think about your life as a caregiver, and draw yourself as a tree in weather.”

Fig 37



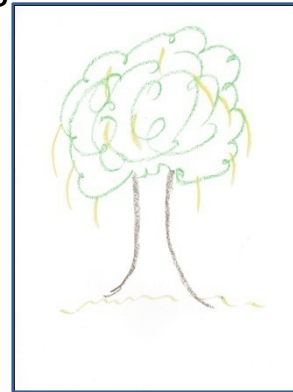
-21



Fig 38



Fig 41



-15



Fig 42

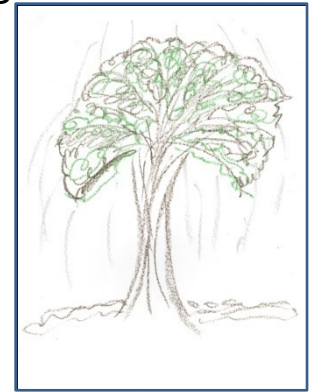


Fig 39



-2



Fig 40

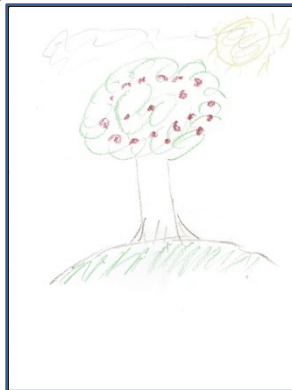


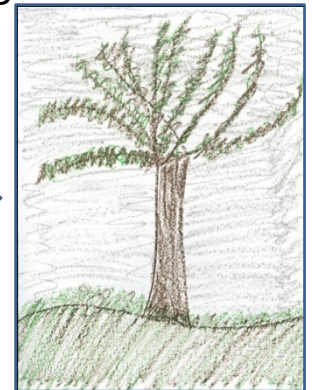
Fig 43



+22



Fig 44





Changes in the art assessment from baseline represent a more accurate assessment when placed in context. Two art assessments suggest an increase in well-being, one art assessment shows a moderate change, and one shows a decrease in well-being. The scores on the mPWS-C suggest that three participants decreased in well-being and one increased.

It was found that the tree-figure may represent the self, identification with the care recipient, or both. A depiction of the weather, while not correlated with scores on the mPWS-C, does match self-reported affect. Themes such as hope and hopelessness, feelings of depression, fear of the unknown, feeling stuck or stagnant, and issues regarding ADLs are also present in the art assessment and interview responses. Other factors such as enmeshment and superficiality may also occur.

### **Combined Feedback and Recommendations**

At the conclusion of the study participants in both groups were asked to provide feedback about ways that the study has impacted their life as well as other general thoughts or recommendations. This information is provided in Tables 11 and 12.

Table 11 shares information about the impact that the study has had on the lives of participants. The most reported impact regards establishing feelings of connectedness. Participants reported this despite the range in the age, family role, or differential diagnosis/stage of the person with dementia. The second highest rating includes the management of affect including being more patient, experiencing less frustration, remaining calmer, increased acceptance, and being more flexible.

Participants also expressed an appreciation for the opportunity to communicate with others, express themselves through creativity and using creative thinking. Three participants mentioned enjoyment of the sessions, and three described an increased focus on self-care. One participant reported increased feelings of empowerment, another

<b>Table 11. Impacts of the Study on Participants (n=9)</b>						
Affect management	Patient	3		Enjoyment	Looked forward to it	2
	Acceptance	1			Enjoyable	1
	Less frustration	2			TOTAL	3
	Calmer	1				
	Flexible	1		Negative	Stressful	1
	TOTAL	8			More depressed	1
					TOTAL	2
Communicate	Discuss	4				
	Complain	1		Self Care	Time for self	1
	TOTAL	5			Talking to self more	1
					Focus on leisure	1
Connectedness	Be/connect/with others	5			TOTAL	3
	More outgoing	2				
	Sympathize	1		Knowledge	Understanding of PWD	1
	Less isolated	1			Ideas	1
	Help from others	1			TOTAL	2
	Group listened	1				
	Universalization	1		Empowerment	More empowered	1
	Instillation of hope	1			TOTAL	1
	Normalizing	1				
	TOTAL	14				
Creativity	Creative outlet	2				
	Creative thinking	1				
	TOTAL	3				

<b>Table 12. Other General Feedback (n=9)</b>	
Art aided discussion and self reflection	7
Needed more time	5
Connecting w/group was important	5
No cost	4
Differences did not detract	3
Scheduling	3
Difficult planning to attend	2
Wish to continue	2
Added insight to Alzheimer's Assoc.	2
Safe place	1

participant reported increased understanding of the person with dementia, and one reported valuing the sharing of ideas to assist with caregiving.

One participant reported feeling more depressed, and another participant reported that attending the intervention was a stressful process. These reports seemed to be confirmed by both the art assessment and interviews, but only in one case of the mPWS-C scores. Potential negative impacts of participating in an art therapy intervention should also be explored.

General feedback and recommendations about the study yielded the results listed in Table 12. The most frequent feedback was that art-making aided in group discussion and self-reflection. Several participants stated that the directives were appropriate and thought provoking. Participants also stated that participation in a group setting with other caregivers was especially important.

In terms of scheduling, participants seemed to be split between feeling that sessions should be offered more or less frequently than once per week. In addition, participants also valued that the study was provided free of cost. Several participants noted that individual sessions should be scheduled for longer than one hour. This would also be the recommendation of the researcher, as most groups went over time by an average of 15 – 20 minutes. Some participants noted that attending sessions proved to be difficult at times due to a variety or range of reasons.

The role of the researcher was also mentioned throughout the final interview. Participants stated that the researcher aided the group by asking relevant questions and by helping the group stay on topic. Providing additional information, making suggestions, and facilitating group interactions was also attributed to the researcher. It was also noted that participants felt that the group was a safe place to share their feelings and experiences.

Lastly, two participants expressed a desire to continue with future art therapy sessions if they were to be offered. All participants reported that they would recommend participating in an art therapy, group intervention to other caregivers. Running the group also had an effect on helping to inform participants of the services offered by the Alzheimer's Association Delaware Valley Chapter.

## **CHAPTER 5: DISCUSSION**

### **Overview**

The purpose of this instrumental case study was to determine how an art therapy intervention affects self-reported measures of social support and creative expression in two groups of dementia caregivers. The study gathered information over an intake interview, an eight-week intervention, and a debriefing interview. This chapter will outline research findings, clinical applications, limitations, and implications for future research.

This study is the first known to the researcher to conduct a measure of dementia caregiver well-being using the PWS-C. This study addressed measures of caregiver well-being over time, and provides information about the validity of this instrument for the population of interest. It also provides a discussion of the use of the PWS-C in conjunction with art therapy group sessions and art therapy assessments.

The field of art therapy has little knowledge about interventions or approaches for working with dementia caregivers. Therefore, a presentation of results will hopefully inform the field about working with this population, as well as informing practicing art therapists about caregiver needs and other major considerations. A review of frequent themes and caregiver dynamics, art therapy directives and materials, and effects on well-being may provide grounds for future exploration.

### **Research Findings**

#### **Participants**

The participants in this study, although a small sample size, may reflect the dementia caregiver population. In terms of demographics, a majority of participants in this study were spouses, while previous studies such as the 2009 Behavioral Risk Factor Surveillance System (BRFSS) reported a higher number of adult children (Alzheimer's Association, 2012). This finding may also reflect another feature of the study population, which produced a younger average age than previously reported in the BRFSS. The

majority of participants were female, which may reflect a demographic that would be more likely to electively participate in an art therapy intervention.

The rate of recruitment and retention of participants should also be taken into consideration. Two site locations yielded a total of nine participants who completed the study, compared with twelve who had given consent. This resulted in a 75% retention rate. However, 12 consenting participants, who were drawn from a population of 4,786 constituents, resulted in a recruitment rate of 2.5%. Logistical issues such as geographic considerations and the demands of caregiving may act as a barrier to participating in a group therapy intervention, resulting in low rates of recruitment.

### **Well-being and the mPWS-C**

This study is the first, known to the researcher, to conduct a measure of dementia caregiver well-being using the PWS-C. This study addressed measures of caregiver well-being over time and also provides information about the validity of this instrument for this population of interest. In addition, empirical data on well-being has the potential to be used statistically in conjunction with art therapy assessments and interventions.

The advantages of the PWS-C included that it was self-administered and it could be completed in a brief period of time as noted by the authors (Wu, Cho, Li, Chen, Tse, 2010). At the debriefing interview some confusion was voiced about item eight, which measured caregiver inadequacy. The amount of effort needed to administer the instrument was low, but the data analysis proved to be relatively technical, sophisticated, and labor-intensive.

Reliability of the measure is hard to determine in the studied population. The items presented in the instrument are subject to the variability of the subject's experience. From session-to-session it is possible that a caregiver's experience of the subscale measures (i.e. social support, life meaning, emotional distress, and caregiver

inadequacy) could vary greatly. To test the reliability it would be beneficial to apply the measure to a non-caregiver control group over the same testing protocol.

Another concern for the mPWS-C is validity. The measure was originally developed in Hong Kong for caregivers of cancer patients receiving palliative care (Wu, Cho, Li, Chen, Tse, 2010). Although dementia is also a terminal illness resulting in many of the same custodial and psychological effects for caregivers, the specific experience of being a dementia caregiver may alter the validity of the measure. There may also be a reduction in validity due to variance caused by translation of the items or cultural differences.

In addition, the items selected for determining well-being may not hold up to content validity, meaning that the items in the measure may not be relevant to the intervention. For example, the subscale items of social support regard factors that are external to the group (i.e. "I feel support from someone close to me" and "I can share my thoughts and feelings with someone close to me"). An intervention may have little bearing on these items and therefore would be an invalid measure of effect for this specific intervention.

Caregivers may also incorporate protective defenses of denial and avoidance, which may mitigate accurate ratings (Oliver and Bock, 1990). Over time, as the intervention increases attention and understanding for the participants and as trust through the therapeutic relationship is developed between participants and the researcher, caregivers may more accurately rate their well-being and disclose information about their struggles, negative feelings, etc. As a way of testing this effect, one could administer the measure to a non-caregiver group in the same testing protocol.

Measurements of well-being over eight weeks may have yielded different results if the same group of people did not receive the intervention. To test this, a control group of caregivers could complete the mPWS-C using the same testing protocol. Comparison



of the control group to the treatment group could yield a greater understanding of the therapeutic effect of the intervention.

### **Art Therapy Intervention**

Over the intervention, several themes were identified as central to the caregiver's experience. These themes can be reviewed in Tables 2 and 7 (pg. 63 and 88).

Addressing the specific factors that are relevant to caregivers may improve effectiveness of future art therapy interventions and improve the therapeutic impact of art directives.

Throughout, caregivers expressed the need for a restorative break. Perhaps the most effective way to alleviate stress and burden of caregivers is to, in fact, provide respite care for the person with dementia. This finding supports information revealed in the literature review, which was one of the only interventions that resulted in a significant alleviation of stress (Hoskins, Coleman, & McNeely, 2005).

Another prominent theme was that of loss, which was reflected by Frank (2008) and Dupuis (2002) in the literature review. Caregivers mentioned loss of their companion, as well as losses they have experienced personally, as a result of caregiving. It seems that loss is multidimensional, meaning that not only are caregivers dealing with the functional loss in the care-recipient caused by the disease, but they also must cope with the loss of a companion, a partner, and a loved one. To compound this situation, spouses are particularly vulnerable to the loss of a partner, which results in an additional shift of traditional familial roles and the responsibilities associated with that role being taken on by the caregiver in addition to the burdens of custodial and psychological care.

Not only do caregivers have difficulty grieving past loss and managing current loss, they also have fears of the future and the unknown. Session five most clearly emphasizes the fear of the future and the unknown. Many participants expressed feelings of hopelessness and helplessness in regard to both the immediate and

extended future. This theme was also exemplified by participants' desires for a "new beginning" or a return to normalcy, before their lives were affected by dementia.

However, the intervention also allowed participants to share common ways of coping and strategies used to alleviate stress and burden. These themes include asking for help and assistance, spending time with family and friends, finding an appreciation for small successes, acceptance and "letting go". Participants also share methods for converting frustrations experienced by caregiving into a positive and productive outlet through sublimation.

Creating artwork in a group setting proved to be a valuable way for participants to express themselves creatively. In post-intervention interviews, many of the participants remarked that creating artwork helped them see their situation differently, aided in thinking or problem-solving, and also aided the group discussion. Creating artwork was also identified as a way to activate sublimation, which may have a minimizing effect on feelings of frustration and/or stress. Lastly, the creation of artwork enhanced communication between group members and the self, as it revealed aspects of the participant's experience that may not be consciously known to them.

This connection between revealing unconscious conflict, as a catalyst for change supports the foundational theory of Naumburg (1987) and Rubin (2001). Findings also support art therapy theory that creation of artwork aids in the verbalization of patients between the therapist, other group members, and the self. Lastly, virtually all benefits described by Wadeson (2010), were observed over the course of the intervention.

Coping strategies and defense mechanisms, which may be unknown to participants, include denial, avoidance, isolation of affect/compartmentalization, identification, and displacement. These mechanisms were revealed through discussion, behaviors, group and interpersonal interactions, and artwork. While these strategies are primarily protective, it may be possible that they also act as a barrier to care, as noted in

the literature review (Oliver and Bock, 1990). This negative effect on treatment is seen within single sessions that address difficult topics and over the intervention as a whole, which may contribute to the decrease in measures of well-being.

Group dynamics also played an important role in the intervention and allowed for the imparting of information, story telling/life review, universalization and differentiation, the instillation of hope, and supportive empathy, as indicated by Yalom (1983). Although measures of social support on scales of well-being decreased over the course of the study, participants expressed their appreciation and support that the group offered them. Participants also stated that they felt the only people who can truly understand their plight are other caregivers.

### **Clinical Applications**

In working with this population, the researcher would first like to acknowledge the logistical difficulties to participants in attending a group intervention outside the home. For caregivers, who already have a litany of responsibilities and obligations surrounding the demands of care, an empathetic and supportive approach should be utilized to encourage attendance. In addition, validation of participant efforts to better their life and well-being through therapy, should be a primary focus of treatment. It would also be beneficial to relate self-care and coping practices of the caregiver as a way of ultimately bettering the care of the person with dementia.

Art therapists should also support positive coping and defenses, while challenging negative thinking and self-destructive, maladaptive coping. Creating a safe environment and trust through modulating group dynamics and therapeutic relationship is essential to circumventing barriers of denial and avoidance. While caregivers should be given the opportunity to reflect on their lives to gain perspective and process difficult stressors, a delicate balance must be struck in order to protect caregivers from experiencing negative and threatening effects of challenging psychological defenses.

## **Defense Mechanisms**

Defense mechanisms present a particular problem to working with this population. The most prominent defense mechanisms, which were apparent over the course of the study, included denial, avoidance, isolation of affect/compartmentalization, identification, and displacement. Tapping into these defense mechanisms in therapy may be threatening and/or unnerving to participants. There seemed to be a desperate need to express and explore feelings of frustration and unconscious conflict; however, this process was often deterred by feelings of confusion experienced in the present, fear of the future, as well as grieving the loss of their past life and/or companion.

It should be noted that at the beginning of therapy the therapeutic process may be difficult and challenging to participants, which may activate these defense mechanisms. As a therapist, one must work through these barriers with the client to help them achieve more awareness about unconscious conflicts that they may be experiencing. Resolving these conflicts can lead to more adaptive coping strategies and better affect management. Improving these factors may also have a direct impact on improving a caregiver's ability to adequately care for the person with dementia.

This is clearly demonstrated in the first few sessions in Group 1. In early sessions, participants rated their pre-session well-being higher with a large gulf between the pre/post-session measures (Fig. 3). These pre-session ratings of well-being were possibly an inaccurate assessment of their own feelings, which may reflect the defense mechanism of denial. However, during the second half of the intervention, the participants' self-awareness increased and they were much more accurate regarding their self-assessments in both pre/post-session measures.

Increasing a caregiver's awareness about their own needs and empowering them with coping strategies may lead to the maintenance of well-being. In the case of Group 1, as pre/post-session ratings became closer toward the final weeks of the intervention,

the ratings of well-being tended to increase. Therefore, the accuracy of well-being appraisal and the increase in the measure of well-being may be correlated.

As participant awareness about their unresolved conflict increases, they become more fluent in sharing about their experiences, receptive to learning from others, better able to manage and coping with difficult circumstances, and are able to engage in an experience that brings about personal growth. In therapy success should not be equated to happiness. Instead, it is a process that contributes to an individual understanding of “the self” over time and enables resiliency.

### **Resilience**

Acknowledging caregiver resilience is a meaningful source of hope for caregivers in difficult times. Promoting coping skills and growth, can help caregivers adapt to adverse circumstances and bounce back during times of significant burden and stress. Although caregivers may tend to feel depleted at times, they have the ability to engage in a restorative break and regain their physical energy, emotional and cognitive stability, and a renewed sense of purpose. In this sense, a caregiver well-being is more fluid and dynamic, rather than being on one static trajectory.

Creating artwork not only offers a tool to aid in developing insight, awareness, and introspection, but it also acts as a metaphor for the process of working through. It may also aid in cathartic release of frustrations and negative emotions. In addition, participants were able to simultaneously reminisce about the importance of their past relationship, while gaining awareness about changes and losses they have experienced in their current relationship due to dementia.

### **Therapeutic Goals**

Both art directives and art materials may have a significant impact on modulating the experience of dementia caregiver groups in an art therapy intervention. Not only should the art therapist give these decisions thoughtful consideration, but they should

also be incorporated into assessing participant needs and developing therapeutic goals. In post-intervention feedback, both the directives and materials were mentioned by participants as having a bearing on their experience in the intervention.

In regard to art directives, the directives put forward in this study were exploratory and designed for the purpose of researching the population. However, in practice, rather than developing a directive prior to the intervention, it may be better for clinicians to create directives based on their knowledge and experience with the participants. If an assessment is completed on intake, goals can be derived and adjusted over the course of the intervention.

Knowledge and incorporation of caregiver specific themes is essential to clinical application. Familiarization with areas such as loss and grief, role change, hope and hopelessness, the unknown, and burden and stress to name a few, contribute greatly to case conceptualization of participant and group needs. These concepts can provide structure to an art therapist's approach; however, because caregiver well-being has been determined to be dynamically changing, the use of directives and art materials should also be equally flexible.

For example, in Group 1 session six participants expressed that they were having a very challenging week and did not feel they could complete the requests directive to "Draw one positive aspect of caregiving". Therefore, the researcher provided an additional art directive to "Draw five ways that you cope with stress". Not only did it better suit the participant's current affective state, but it yielded the most significant change in well-being recorded over a single session. Therefore, while therapist should still operate within certain structure, defined by parameters and understanding about themes and issues related to caregiving, a certain amount of flexibility should also be practiced in regard to art directives and materials.

## **Areas of Concentration**

These key findings have led to the following suggested as areas of concentration for working with groups of dementia caregivers in an art therapy intervention, in an effort to make caregiving a more manageable and sustainable process:

- 1) Encouraging and sharing effective self-care practices
  - a. Using creativity as a positive coping strategy
  - b. Promoting health and resilience through creativity
  - c. Sharing ways to implement a restorative break
  - d. Setting healthy limitations and boundaries
- 2) Identifying and activating social support
  - a. Identifying sources and types of support
  - b. Asking for help without feelings of guilt
  - c. Enhancing meaningful communication
- 3) Increasing knowledge and understanding of the future
  - a. Establishing clear expectations of decline and increased dependency
  - b. Aiding in future oriented planning and decision making
  - c. Enhancing flexibility in regard to an on-going shift in role dynamics
  - d. Facing existential issues of death, loss, and loneliness

Transferences were played out within the group dynamic. Recapitulation of the family dynamic was seen in behaviors and interpersonal interactions. The researcher sought to encourage and promote positive dynamics such as support and validation, while minimizing negative dynamics such as destructive entitlement and enmeshment. Neutrality was practiced as a way to deter favoritism. A transference effect may also have been observed in interpersonal reactions between the researcher and participants. The researcher, a 27 year-old, Caucasian male, may have activated other significant

relationships in participant's lives, such as son or grandson, friend, or partner. The facilitator exercised anonymity to minimize these transference effects.

Countertransference effects are particularly meaningful to the implementation of this intervention. As a therapist, identification with the caregiver is inevitable. It should be expected that the therapist will struggle with feelings of hopelessness and helplessness, feelings of inadequacy, frustration over group dynamics and ineffective or ambiguous results, and emotional distress. Therapists should actively practice self-care, set firm boundaries and limitations, and seek supportive, clinical supervision. Remaining conscious of these effects will aid facilitators in working with this population.

This instrumental case study examined the effects of an art therapy intervention on self-reported measures of social support and creative expression with groups of dementia caregivers. The study yielded several implications for clinical work. In general, clinicians should be supportive and empathetic, knowledgeable about dementia and the prominent issues that exist for caregivers, as well as maintaining a flexible approach to delivering therapy in order to more appropriately address the specific needs of participants.

### **Limitations and Delimitations**

Limitations of this study include a small number of participants who are delimited to geographic area and demographic type. These factors may prevent the generalization of findings to the entire population. In addition, the mPWS-C and other measures of well-being may lack validity and/or reliability. The study is also limited by the specific participants who comprise the sample group, and may not reflect the heterogeneous nature of dementia caregivers.

Delimitations of the study include professional caregivers, as well as unpaid caregivers who provide less than 24 hours of care per week. Also, because this study is inclusive of all types of dementia, results may not be applied to specific types of



dementia such as Alzheimer's disease, frontotemporal degeneration, dementia with Lewy bodies, or dementia (unspecified), although all are represented in the study.

### **Future Research**

This study presented several opportunities for future research. The field of art therapy currently has little information regarding either a) group art therapy with dementia caregivers, or b) art therapy assessment with dementia caregivers. The following is a list of potential ideas for future research in art therapy with dementia caregivers:

- Evaluate specific directives and/or use of art materials to reduce feelings of stress or burden related to dementia caregiving through sublimation.
- Creating artwork to help dementia caregivers share information, problem-solve, and learn coping strategies with other dementia caregivers.
- Creation of artwork to promote verbalization and sharing, while deterring defense mechanisms in dementia caregivers.
- Further analysis of dementia caregiver artwork for prominent themes, graphic indicators, and other formal elements.
- Creating artwork to aid in processing existential factors such as death, loss, and loneliness in dementia caregivers.

## CHAPTER 6: CONCLUSIONS

The study was conducted to determine how an art therapy intervention affects self-reported measures of social support and creative expression with groups of dementia caregivers. Primarily, the study served the purpose of further defining prominent factors contributing to stressors and burden of the dementia caregiver. It also helped to more clearly identify the needs of this growing population. Effects on well-being, as measured by the mPWS-C, indicate the dynamic nature of well-being in the composite scores over the intervention for both groups. This dynamic change was also observed in subscales of social support, life meaning, emotional distress, and caregiver inadequacy.

A comparison of intake and debriefing interviews indicated that participants gained knowledge about types and sources of support, as well as means of expressing their thoughts and feelings in a positive and meaningful way. Further cultivating this understanding with participants in an art therapy intervention may contribute to feelings of support, enhance coping strategies, and better affect management.

The group component also had a positive outcome on participants as they expressed an appreciation for an opportunity to connect with other caregivers and to share their experiences. Because the nature of dementia is one that can be isolating and ostracizing, participants seemed to value the connections and social support that was facilitated through group dynamics and processing.

Furthermore, art therapy offered a valuable tool in helping to administer this group intervention. It aided in self-understanding through developing insight in individual participants, enhanced communication and story-telling between participants, and added to the facilitator's understanding of participant needs and a contextualization of prominent themes relevant to a group of dementia caregivers.

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**DREXEL UNIVERSITY  
COLLEGE OF MEDICINE**

**Office of Regulatory Research Compliance  
APPROVAL OF PROTOCOL**

May 15, 2012

Elizabeth Hartzell, Ph.D.  
Creative Arts and Therapy  
Mailstop: 950

Dear Dr. Hartzell,

On May 15, 2012 the IRB reviewed the following protocol:

Type of Review:	Initial
Title:	Art Therapy with a Group of Dementia Caregivers: Exploring Well-Being through Social Support and Creative Expression
Investigator:	Elizabeth Hartzell, Ph.D.
IRB ID:	1204001225
Funding:	Internal
Grant Title:	None
Grant ID:	None
IND, IDE or HDE:	None
Documents Reviewed:	Application Form, Consent Form, Proposal and Advertisement

According to 45 CFR 46.110, this study is Approved Expedited Categories 6 and 7. This study will enroll 50 subjects recruited from The Alzheimer's Association of Delaware Valley Rocket Education and Community Center.

The IRB approved the protocol from May 15, 2012 to May 14, 2013 inclusive. Before May 14, 2013 or within 30 days of study close, whichever is earlier, you are to submit a completed Continuing Review Progress Report and required attachments to request continuing approval or closure.

If continuing review approval is not granted before the expiration date of May 14, 2013 approval of this protocol expires on that date.

In conducting this protocol you are required to follow the requirements listed in the INVESTIGATOR MANUAL.

Sincerely,

Danyelle S. Gibson

1601 Cherry Street, 3 Parkway Building, Suite 10444 • Philadelphia, PA 19102 • Phone 215-255-7857 • Fax 215-255-7874  
www.research.drexel.edu • www.drexelmed.edu

**24/7 Helpline**  
800-272-3900  
www.alz.org/desjsepa

**Delaware Valley Chapter Headquarters**  
399 Market Street, Suite 102  
Philadelphia, PA 19106

**Delaware Regional Office**  
Tower Office Park  
240 N. James St., Ste. 100-A  
Newport, DE 19804

**South Jersey Regional Office**  
3 Eves Drive, Suite 310  
Marlton, NJ 08053

215-561-2919  
215-561-4663f

302-633-4420  
302-633-4494f

856-797-1212  
856-797-1818f

**alzheimer's  association®**

February 13<sup>th</sup>, 2012

Betty Hartzell, Ph.D., ATR-BC, LPC  
Assistant Director of Art Therapy Department  
Creative Arts in Therapy Department  
Drexel University  
1505 Race St 10<sup>th</sup> Fl, MS 905  
Philadelphia, PA 19102-1192

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To Whom It May Concern:

Let this letter serve as a notice that the Alzheimer's Association Delaware Valley Chapter has approved the Philadelphia and Marlton offices as sites for Scott Reid to conduct thesis work, pending the approval of the Drexel University IRB.

Locations of each office can be found below:

**Philadelphia Office**  
399 Market St, Suite 102  
Philadelphia, PA 19106

**Marlton Office**  
3 Eves Dr, Suite 310  
Marlton, NJ 08053

These sites have been approved in a concordant timeframe with the studies IRB approval for research conducted during the calendar year 2012. Should the study extend beyond one year, the investigator shall seek additional approval.

Thank You,



**Claire Day**  
**Vice President Constituent Services**

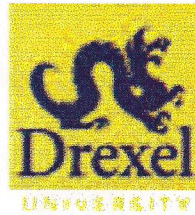
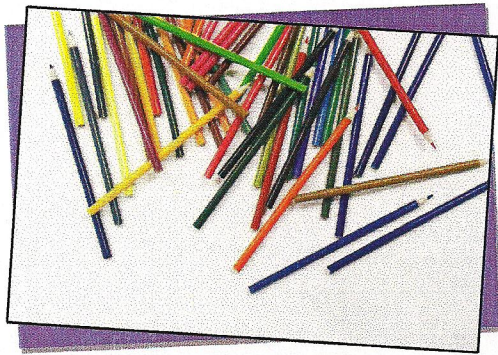
Alzheimer's Association  
Delaware Valley Chapter  
399 Market St, Suite 102  
Philadelphia, PA 19106

Helpline 1.800.272.3900  
Office 215.561.2919 (x352)

**President & CEO**

Wendy L. Campbell

The official registration and financial information of Alzheimer's Disease and Related Disorder Association Delaware Valley Chapter may be obtained from the Commonwealth of Pennsylvania's Department of State by calling toll-free within Pennsylvania, 800-732-0999, and from New Jersey by calling the Attorney General of the State of New Jersey at 973-504-6215. Registration does not imply endorsement. —United Way Member Agency In Delaware — Member Community Health Charities of Pennsylvania



Drexel University  
Recruiting Volunteers for a Research Study

## Art Therapy with a Group of Dementia Caregivers: Exploring Well-being through Social Support and Creative Expression

### Research Objectives

Take part in a study that will explore the use of art therapy with dementia caregivers. The study will focus on how creating artwork and discussing it with others may affect feelings of well-being.

### Study Information and Participant Eligibility

Participants in this study will meet with other caregivers to create artwork and talk about the caregiving experience. These group sessions will be held once per week for 8 weeks, with each session lasting a total of 60 minutes. Participants will also be asked to take part in two, one-hour interviews. The total time commitment to participate in the study is approximately 10 hours.

Each of the 8 weeks, participants will complete a brief rating-scale at the beginning and end of the session, create artwork in response to an art-directive, and discuss their experience with the other caregivers in the group. These sessions will be facilitated by an art therapist Master's level student, who is also on staff at the Alzheimer's Association Delaware Valley Chapter.

You may participate in the study if you...

- are between the ages of 18 - 85
- provide over 24 hours of dementia caregiving per week, which includes nighttime care
- speak English as a primary or secondary language
- You may not participate in this study if the person with dementia is being cared for in a long-term care facility (i.e. nursing home, assisted living, or continuing care facility)

### Programming for the person with dementia

Free programming will be provided during the study sessions if a participant cares for someone with dementia who cannot stay at home alone. The REC Center of the Alzheimer's Association Delaware Valley Chapter will provide this on-site service for those in the early to moderate stages of dementia. However, taking part in REC Center programming is not a requirement for participation in the study; nor is participation in the study required for participation in REC Center programming.

### Study Locations

Philadelphia Office  
399 Market St, Suite 102  
Philadelphia, PA 19106

Marlton Office  
3 Eves Drive, Suite 310  
Marlton, NJ 08053

If you are interested in participating in this study,  
please contact **Scott Reid** at **215.561.2919 (x 352)**

APPROVED  
OFFICE OF REGULATORY RESEARCH COMPLIANCE

Protocol No. 1204001225

App. Date 5/15/12

Exp. Date 5/14/13

**DREXEL UNIVERSITY  
CONSENT TO TAKE PART IN A RESEARCH STUDY**

1. **PARTICIPANT NAME:** \_\_\_\_\_
2. **TITLE OF RESEARCH:** Art Therapy with a Group of Dementia Caregivers:  
Exploring Well-being through Social Engagement and Creative Expression
3. **INVESTIGATORS' NAME:** Betty Hartzell, PhD, ATR-BC, LPC, Principal Investigator  
**CO-INVESTIGATOR:** Scott Reid
4. **RESEARCH ENTITY:** Drexel University
5. **CONSENTING FOR THE RESEARCH STUDY:** This is a long and important document. If you sign it, you will be authorizing Drexel University and its researchers to perform a research studies, with you as a participant. You should take your time and carefully read it. You can also take a copy of this consent form to discuss it with your family member, attorney or anyone else you would like before you sign it. Do not sign it unless you are comfortable participating in this study.
6. **PURPOSE OF THE RESEARCH:** You are being asked to participate in this research study. The purpose of this study is to examine the effects of a group, art therapy intervention on the well- being of dementia caregivers. Due to the stigmatization of Alzheimer's disease and other related dementias, caregivers may experience isolation and a lack of social support.  
  
This may have an effect on a caregiver's opportunity to express their thoughts and feelings about caregiving with others. Therefore, this study seeks to bring a group of dementia caregivers together and provide an opportunity to express their thoughts and feelings through creativity and discussion.  
  
You are being asked to participate in this study because you are a dementia caregiver providing over 24 hours of direct care per week, are between the ages of 18-85, and because you speak English as your primary or secondary language. Previous art-making experience is not required.  
  
This study is being conducted as partial fulfillment for the completion of a master's degree in Creative Arts in Therapy.
7. **PROCEDURES AND DURATION:** You understand that the following things will be done as a participant in this research study:
  - You will be expected to meet with the co-investigator on 10 occasions.

APPROVED Office of Regulatory Research Compliance Protocol # 1204001225 Approval Date: 05/14/12 Expiration Date: 05/13/13
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Participant's Initials: \_\_\_\_\_

- The first occasion will take approximately one hour and precede the 8 week art therapy workshop. The purpose of this meeting is to review this informed consent form, establish a baseline for evaluation, and conduct a brief interview.
  - Upon signing the consent form you will then be expected to attend 8 weekly sessions, which will be 60 minutes each, facilitated by the co-investigator who is also a staff member at the Alzheimer's Association Delaware Valley Chapter.
  - During each of the 60 minute sessions, you will meet with other dementia caregivers. The first 5 minutes will be dedicated to completing the pre-session evaluation. The group of caregivers will then be given an art task and 25 minutes in response to that task, 25 minutes will be spent discussing the topic and reviewing the art. The final 5 minutes will be spent completing the post-session evaluation.
  - Should you miss a session due to illness, transportation problems, or any other reason, you may continue on with the remaining sessions and final debriefing.
  - After the conclusion of the 8 week workshop, you will be expected to meet with the co-investigator for a one hour debriefing that includes an interview, final evaluation, and the opportunity for you to provide general feedback.
- 8. RISKS AND DISCOMFORTS/CONSTRAINTS:** Risks associated with this study are considered minimal. However, you may experience minimal anxiety discussing artwork that you create. This study does not require an artistic talent or background. The artwork will not be evaluated or critiqued.

If at any point you are uncomfortable, you may refrain from the task or discussion, or leave the room. You may drop out of the study at any time if you wish.

- 9. UNFORESEEN RISKS:** Participation in this research study may involve unforeseen risks. If unforeseen risks should occur, the Office of Regulatory Research will be notified at 215-255- 7857, as well as the Principal Investigator, Dr. Betty Hartzell at 215-762 -3767.
- 10. BENEFITS:** There may be no benefits from participation in this research study. However, participants may experience an increase in feelings of well-being as a result of the intervention which aims to promote social engagement and creative expression.
- 11. ALTERNATIVE PROCEDURES:** If you choose to not participate in this study, you and/or the person with dementia will still be eligible to receive Rocket Education and Community (REC) Center programming from the Alzheimer's Association Delaware Valley Chapter (AADVC), as well as taking part in any of the Chapter's other programs and services.

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Office of Regulatory Research Compliance  
Protocol # 1204001225  
Approval Date: 05/14/12  
Expiration Date: 05/13/13



Participant's Initials: \_\_\_\_\_

- 12. REASONS FOR REMOVAL FROM STUDY:** You may be required to stop the study before its conclusion for any of the following reasons:
- If all or part of the study is discontinued for any reason by the co-investigator, or university authorities.
  - If you fail to adhere to the requirements for participation established by the researcher.
- 13. VOLUNTARY PARTICIPATION:** Participation in this study is voluntary, and you can refuse to be in the study or stop at any time. There will be no negative consequences if you decide not to participate or stop participation. You, or the person with dementia, will not be excluded from any services or programs offered by the AADVC.
- 14. RESPONSIBILITY FOR COST:** There are no costs associated with participation in the study.
- 15. IN CASE OF INJURY:** If you have any questions or believe that you have been injured in any way as a result of participating in this research study, you should contact your primary physician. However, the investigators, Drexel University, nor the AADVC will make payment for injury, illness, or other loss resulting from your participation in this research project. If you feel you have been harmed as a result of this study please contact the Office of Regulatory Research Compliance at 215-255-7857.
- 16. CONFIDENTIALITY:** In any publication or presentation of research results, your identity will be kept confidential, but there is a possibility that records which identify you may be inspected by authorized individuals at the Institutional Review Board (IRB), or Drexel University employees conducting peer review activities.

Your identity will be protected by a Participant Identification Number (PID Number). Each participant will be assigned a PID Number. The key will be recorded on a paper hardcopy, which will be locked with consent forms, hardcopy evaluations, and interview audiotapes in the office of the primary investigator, Betty Hartzell, PhD, in the Creative Arts in Therapy Department, of Drexel University.

All other collected or recorded data, including artwork, attendance information, and evaluations will be tracked using your PID Number. Evaluations will be transferred into a digital record and will be kept in password protected on the co-investigators computer hard drive, which is also protected by a username and password. Artwork will be stored in a locked cabinet at the AADVC.

Consent forms, interview notes, evaluation scales, as well as artwork produced, will be dated and marked with the PID Number and kept in a locked cabinet in the aforementioned locations. After 3 years, the consent forms, interview transcriptions, and evaluation scales will be destroyed. You may have your artwork returned to you at the conclusion of the study.

APPROVED Office of Regulatory Research Compliance Protocol # 1204001225 Approval Date: 05/14/12 Expiration Date: 05/13/13
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Participant's Initials: \_\_\_\_\_

Artwork may be photographed, or reproduced, to include in the final master's thesis. However, any discussion of participants, or their artwork, will make use of a pseudonym and not be linked to your identity.

**17. OTHER CONSIDERATIONS:** As a research participant, you have the right to withdrawal from this study at any time for any reason. If you would like further information on your rights as a research participant, please contact the Office of Regulatory Research Compliance at 215-255-7857.

**18. CONSENT:**

- I have been informed of the reasons for this study.
- I have had the study explained to me.
- I have had all of my questions answered.
- I have carefully read this consent form, have initialed each page, and have received a signed copy.
- I give consent voluntarily.

DO NOT SIGN THIS INFORMED  
CONSENT AFTER THIS DATE 5/13/13

\_\_\_\_\_  
**Participant or Legally Authorized Representative**

\_\_\_\_\_  
**Date**

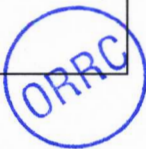
\_\_\_\_\_  
**Investigator or Individuals Obtaining this Consent**

\_\_\_\_\_  
**Date**

**List of Individuals Authorized to Obtain Consent**

<b>Name</b>	<b>Title</b>	<b>24 Hour Phone #</b>
Betty Hartzell, Ph.D	Principal Investigator	215-762-3767
Scott Reid	Co-investigator	215-561-2919 (ext. 352)

APPROVED  
Office of Regulatory Research Compliance  
Protocol # 1204001225  
Approval Date: 05/14/12  
Expiration Date: 05/13/13



Participant's Initials: \_\_\_\_\_

Modified Psychological Well-being Scale for Caregivers (mPWS-C)

PID Number:

Session: /

1. I can share my thoughts and feelings with someone close to me.

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

2. I have adequate support from someone close to me.

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

3. I am clear about the meaning of my life (e.g. I have done things for my family and friends in my life).

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

4. Each day is a gift (I treasure every day I have now).

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

5. I feel distressed about my present condition.

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

6. I have fears for my future.

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

7. I can still enjoy life.

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

8. I have a feeling of incompetence in taking care of the person with dementia.

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral

9. I do not understand the way the patient feels or thinks.

Totally disagree 0 ---- 1 ---- 2 ---- 3 ---- 4 ---- 5 ---- 6 ---- 7 ---- 8 ---- 9 ---- 10 Totally agree  
Neutral