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A Visual Communication Intervention for Caregivers of Spouses with Alzheimer's Disease

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Recently, my grandmother died after living with Alzheimer's Disease (AD) for nearly a decade. My grandfather died two months later from health complications precipitated by, most likely, a broken heart. My grandparent's relationship provided an impetus for my formulation of an art therapy intervention for caregivers and spouses with AD. When formulating the intervention, I viewed my grandparent's tumultuous relationship quality as hindering the care received by my grandmother with AD. As the disease progressed, my grandfather visibly mourned the loss of his fully functioning wife and often spoke of losing a sense of connectedness with her prior identity. No longer able to take care of himself and his wife, he employed full-time caregivers.

The death of my grandmother resulted in a second, stronger wave of grief that was too much for my elderly grandfather to withstand. Although my grandfather grieved my grandmother's link to her prior identity, it was clear that my grandmother's presence was in part keeping him alive. If the pure presence of a loved one could influence the life or death of a spouse, what would be the effect of increasing the quality of the relationship of a couple dealing with AD in terms of caregiver wellbeing?

Based upon my grandparent's relationship and struggle with AD, I formulated an art therapy intervention for use with caregivers and spouses with AD. The intervention was based on the visual communication, in which couples were encouraged to communicate visually. The intervention was created to increase relationship quality in caregivers and spouses with AD by creating increased positive interaction through the creation of art by the couple. The

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effectiveness of the intervention was studied by conducting two single case studies on the use of the intervention with couples dealing with AD.

Justification for Intervention

Alzheimer's Disease (AD) is a progressive illness that results in memory impairment, cognitive disturbances, and difficulties with social and occupational functioning (American Psychiatric Association, 2000). Providing care for a loved one with AD is a challenging undertaking. Caregivers were found to frequently experience a decrease in wellbeing due to the demanding nature of the task (Ott, Sanders, & Kelber, 2007). Caregivers were found to have an increase in depression as a result of the emotional and physical stress of providing full-time care (Williamson & Schulz, 1993). It was found that caregivers of individuals with AD were six times more likely to have an onset of dementia than the general population (Norton, Smith, Østbye, Tschanz, Corcoran, Schwartz, Piercy, Rabins, Steffens, Skoog, Breitner, Welsh-Bohmer, & The Cache County Investigators, 2010). However, relationship quality between caregiver and spouse was found to mitigate negative outcomes (Williamson & Shaffer, 2001).

Caregivers were found frequently to experience a change in perceived quality of the relationship with their spouse with AD progression (Chesla, Martinson, & Muwaswes, 1994). The degree to which a caregiver could connect to their spouse's prior identity, before disease progression, determined the quality of the relationship throughout the disease. As caregivers lost a sense of their spouse's identity, they became increasingly emotionally detached. As a result, relationship quality decreased. Caregivers who were able to view their spouse as continuous with their prior identity were found to enjoy a higher quality relationship. Caregivers with a higher quality relationship were found to have better outcomes emotionally and physically than those in emotionally disengaged relationships (Archbold, Stewart, Greenlick,

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& Harvath, 1990). Caregivers in high quality relationships reported more rewards in their relationship, lower levels of depression, lower caregiver strain, and lower feelings of burden (Archbold et al., 1990; Williamson & Schaffer, 2001). As a result, caregivers in higher quality relationships were able to provide higher quality care (Norton, M.C., Piercy, W., Rabins, P., Green, R., Breitner, J., Ostbye, T., Corcoran, C., Welsh-Bohmer, K., Lyketsos, C., & Tschanz, T., 2009). Individuals with AD who were being cared for in high quality relationships were found to have slower cognitive decline than those being cared for in lower quality relationships.

Alzheimer's disease results in difficulties with memory and verbal communication, both of which create a challenge for caregivers in maintaining a meaningful relationship with their spouse (American Psychiatric Association, 2000). Lack of meaningful interaction was found to be a major barrier to spousal caregivers trying to maintain their relationship (Williamson & Schulz, 1993). This limited positive interaction was found to negatively affect the spouse's feelings about their relationship.

Art therapy intervention was found to be effective in increasing memory and verbal communication in interactions between caregivers and spouses with AD (Bloomgarden & Sezaki, 2000; Witucki & Twibell, 1997). Individuals with AD were found to maintain the ability to communicate nonverbally longer than by communicating through words. Additionally, sensory stimulation with individuals with AD was found to increase "memory and cognitive ability, and increase verbalization" (Witucki & Twibell, 1997, p. 10). The literature suggests that by increasing the quality of the relationship through art therapy intervention, the progression of AD could be slowed, the quality of care increased, and caregiver strain decreased (Archbold et al., 2009).

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Formulation of the Intervention

I designed an art therapy to meet the needs of spousal caregivers and individuals with AD. The context is that caregivers were found to struggle as a result of increases in isolation and lack of connection with their spouses. Individuals with AD were found to struggle with recalling and asserting their identity in their relationships (Chesla, Martinson, & Muwaswes, 1994; Williamson & Schulz, 1993). Visual communication was found to improve areas in which caregivers and spouses with AD had challenges. Improvement through visual communication included increased shared experience, communication, and equality in interaction (Winnicott, 1974).

Winnicott (1974) created an intervention to encourage visual communication of couples. The intervention involved one individual drawing a mark, and the other individual responding to that mark on a sheet of paper. Couples often worked to make an image with their marks (Eisdell, 2005). The directive was created to allow both individuals participating to assert their identity equally through mark-making (Winnicott, 1974). Visual communication was also utilized by Bloomgarden and Sezaki (2000) in providing art therapy for a spousal caregiver and spouse with AD. Visual communication was found to be effective in increasing positive interactions for the couple.

Considering the work of Winnicott (1974) and Bloomgarden and Sezaki (2000), I developed an art therapy intervention focusing on visual communication. Three distinct art directives were established for the intervention, with each requiring couples to create artwork in a back-and-forth manner mirroring the back-and-forth nature of a verbal conversation. It was hypothesized that an art intervention based on visual communication would provide an increased relationship quality by increasing positive interactions between caregiver and spouse.

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Methodology

Two case studies were conducted to investigate the use of this art therapy intervention, based on visual communication. Each case study was conducted over a five-week period, with interventions lasting thirty minutes and spaced a week apart. The intervention was conducted in the homes of the couples. The intervention based on visual communication involved three directives.

The first directive was a scribble chase, performed using scented markers. In the scribble chase, one individual created scribbles on a sheet of paper as the leader, while the other individual worked to follow the marks. After the first scribble chase, the couple switched the roles of leader and follower. The couple then worked together to create an image from the scribbles.

The second directive involved the creation of salt dough by the couple. The couple alternated adding and mixing ingredients to make salt dough. The couple then passed the dough back and forth, taking turns to create new forms from the dough each time the dough was passed.

The final art directive involved the use of a series of art cards with fine art images. One individual was asked to hold up cards, while their spouse chose cards that were preferred. The couple then alternated, so that both individuals had chosen preferred cards. The caregiver and spouse then selected from the preferred cards of their partner, creating a single set of cards that were preferred by both individuals. The couple then worked together to create a collage from the preferred cards.

Case One

Case one was composed of a Caucasian couple identifying as lesbian. The caregiver in the couple is referred to as “M,” and the individual with AD referred to as “L.” The individual

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with AD was officially diagnosed with AD at 72 years of age and was in the moderate stage of the disease during the study at age 74. L exhibited language disturbances, in which it was difficult for her to find the words she needed to communicate. Issues with communication were a growing source of difficulty for the couple, with each often becoming frustrated from an inability to effectively communicate about a wide variety of topics. The spousal caregiver M was 71 years old. M shared that the activities she engaged in with her spouse were limited by disease progression that led to feelings of isolation.

Scribble Chase Directive

In the scribble chase directive, caregiver M chose an orange marker. L, the individual with AD, decided she would like to use the orange marker as well. After repeating the prompt for the couple to choose individual colors, M chose the color brown. L had difficulty deciding which to choose and as a result decided to smell each marker. L finally chose the color blue.

M took the role of leader in the first scribble chase. L followed slowly and had difficulty following the lines of M. In the second scribble chase, L decided to change her marker to orange and then scribbled quickly with M struggling to keep up with the fast pace. L noted drawing quickly was revenge after having to follow M, and the couple laughed. The couple then worked together to create an image from the scribble. The couple worked together to create an image of a rainbow flag, garden, and octopus from one of their scribble drawings (Figure 1).

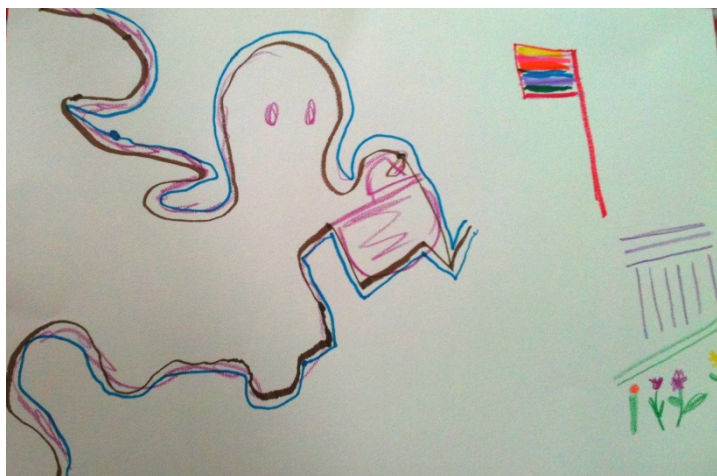


Figure 1. M and L collaborative drawing.

L decided to draw the outline of the flag, fence, and flower forms beside the scribble. M worked to fill in the outlines created by L. M noted she was glad L was getting the chance to take a leadership role for a change. She said prior to disease progression, L often took more of a leadership role in the relationship.

Salt Dough Directive

In the second directive, the couple worked together to make salt dough. Both L and M noted that creating the dough reminded them of memories making bread. The couple passed the dough back and forth, with M first making the shape of a turtle. On being handed the dough, L pounded the dough over and over.

The couple jokingly discussed L's need for a punching bag. M pointed out that the couple had been in disagreement earlier in the day, and L was voicing her anger through pounding the dough. L continued to pound shapes formed by M including a stingray and phallus shaped form. After pounding the stingray, L took the dough and made a coil and a circle. M then created a phallic shape, and L added a hole to make a volcano (Figure 2). The couple then created a rabbit collaboratively from the volcano form.



Figure 2. L and M's volcano using salt dough.

Art Card Directive

At the beginning of the third meeting, the couple was in disagreement. However, they were able cooperate to make art. In the final directive, the couple used art cards to create a collaborative collage. The couple chose images that they preferred. L had difficulty asserting which cards she liked, but M noted she had no difficulty vocalizing the cards she disliked. M chose images by Van Gogh because she said knew L previously liked his work.

M and L each picked images they liked from the other's pile. L picked the Van Gogh from M's pile. The couple used the preferred images to create a collage (Figure 3). The couple worked together to decide where to place the cards.

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Figure 3. L and M's final art card piece.

Interpretation

M initially took a leadership role in the scribble chase directive by being the first to choose a colored marker and leading in the first scribble chase. L desired to mimic M's choice of marker and was glad to follow since she was initially hesitant. However in the second chase, L seized the opportunity to take a leadership role in scribbling and noted she was getting revenge for having to follow M's lead. The scribble chase directive allowed more equality in interaction, with L able to more fully assert her identity in artmaking.

The salt dough and art card directives both enabled the couple to work out aggression from prior disagreements. L forcefully pounded forms created by M, and M retaliated by making aggressive symbols such as a stingray and phallus form in the salt dough directive. Through visual communication, the couple reconciled by creating a more peaceful rabbit form. In the art card directive, M chose Van Gogh images in an effort to please L after disagreement earlier in the day. The visual gesture was well received by L, who chose the images as preferred when choosing from M's pile. The art-making was able to again effectively end disagreement of

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the couple that had occurred prior to the session. The couple noted they enjoyed interventions for providing a source of greater equality, recreation, and socialization.

Case Two

Case two was composed of a Caucasian couple identifying as heterosexual. The caregiver was referred to as “N” and individual with AD referred to as “B.” The individual with AD was age 79, officially diagnosed with AD at age 72. B additionally had essential tremors caused by a nerve disorder and was hard of hearing. As a result, B had difficulty both in utilizing and understanding verbal language. He also exhibited difficulties with motor activities due to hand tremors. The spousal caregiver was age 76 and noted that her activities with her spouse were limited by B’s disease progression. N often noted frustration that her spouse had growing difficulties with memory and overall functioning.

Scribble Chase Directive

In the scribble chase directive, both individuals chose their markers quickly. B began as the leader. When asked if the couple noticed any images within the scribbles, N said she saw winding roads, and B said he saw “cow titties” (Figure 4). N explained that B grew up working on a dairy farm. N then took the role of leader in the scribble chase, with B following slowly.

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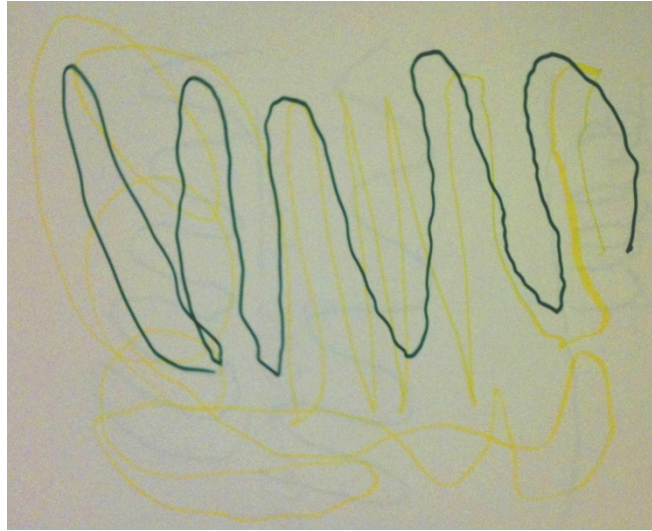


Figure 4. B and N's scribble chase.

The couple alternated making marks in creating another piece of artwork since they had difficulty in creating a single image from the scribbles. B continued to draw a wavy line motif, which he referred to as “cow titties.” N visibly became frustrated and began to draw smiley faces. She then instructed B in what to draw. In a final collaborative drawing, N began to draw and B mimicked her marks on the opposite side of the paper.

Salt Dough Directive

The couple worked together in the second directive to make salt dough. N recounted she used to enjoy baking. The couple was asked to form all of the dough into a ball. N said she wanted it to be yellow, but the color green of B's dough dominated. They passed it back and forth to make different shapes. B formed the dough into a coil shape and said it was a “wiener” or a “cow tit.” N added yellow and red food coloring to represent mustard and ketchup (Figure 5). Following the addition of the food coloring mustard and ketchup, N added a smiley face. When leaving, N said she enjoyed the visits. She said it brightened her day.

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Figure 5. B and N's collaborative salt dough creation.

Art Card Directive

In the final art card directive, N held up fine art cards from which B could choose. B worked slowly to choose images, which N said was frustrating for her. B chose the image of the Mona Lisa because he said it looked like the Virgin Mary. N chose her cards quickly, noting she liked the image of the farmer and wife.

The couple then worked to select cards that were preferred by both. When arranging the cards for a final collage, the couple worked separately on opposite sides of the paper (Figure 6). B's cards, which were on the left side of the page, were rotated to face his direction.



Figure 6. B and N's collaborative collage of fine art cards.

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Interpretation

In the first scribble chase directive, B became fixated on a wavy line motif, which he referred to as “cow titties.” Anytime B exhibited this fixation, N became visibly frustrated and would respond visually with smiley faces. Smiley faces appeared in both the salt dough and scribble chase directive. For N, the wavy line motif symbolized B’s disease progression. N worked to control the interaction when B began to repeat the motif. In the final drawing of the scribble chase directive, N had regained control of the interaction with the couple’s marks completely separate with B mimicking the marks of N.

The art card directive was in line with the prior two directives. Equality was effectively created through the art process, making B’s visual marks were more visible. When his marks became more visible, N became more frustrated because she could notice signs of disease progression.

The final collage in the art card directive showed the couple working in a separate fashion, with B’s cards fully rotated in his direction. However, the couple was able to express their identity as a couple. B chose the image of the Mona Lisa, which could be seen as representing his wife. N chose an image of a farmer and wife, which could be seen as representing her relationship with her husband. The couple said they enjoyed the art intervention for providing a source of socialization and recreation.

Case One and Case Two Analyses

In case one, caregiver M was found to have taken a leadership role in her relationship due to her partner’s disease progression. The interventions allowed L to take more of a leadership role by allowing her to communicate more easily. By providing L the means for greater communication and equality in interaction, art making was effective in mitigating disagreements

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between the pair. Additionally, art making allowed the couple to share memories that were triggered by the sensory stimulus of making art.

In the second case caregiver N, similar to M from couple one, took on a leadership role. In case two, the intervention was successful in creating equality in interaction, however N became uncomfortable when equality was reached. When B asserted his identity, N became frustrated because it visually revealed his disease progression.

Although B's disease progression of AD was a similar level to couple one, B exhibited lower functioning due to the addition of a nerve disorder. Due to B's lower functioning, every attempt to assert his identity revealed how far his disease had progressed in the eyes of N. N was already in the beginning stages of grieving the loss of her spouse's identity. Earlier intervention may have been more effective in increasing relationship quality through art intervention.

Despite case two's difficulties in maintaining equality in interaction, the intervention was effective in increasing positive interaction for the couples. Both couples noted the artmaking as a positive experience in providing recreation and interaction. Additionally, both couples enjoyed recounting past memories as they created art. The two couples noted they enjoyed having someone visit their homes, expressing feelings of isolation due to the responsibilities of caregiving.

Intervention based on visual communication was found to be effective in increasing relationship quality in caregivers and spouses with AD. The intervention was found in both cases to increase communication, provide a source of shared experience, and gave the couples greater opportunity to interact more equally in visual interactions.

Conclusion

I developed an art therapy intervention based on visual communication in response to my grandfather's challenging caregiving relationship with my grandmother with AD. The resulting intervention was found to be effective in two case studies in improving relationship quality by increasing positive interactions of the couples. Visual communication was found to be valuable in increasing communication, providing a source of shared experience, and creating the opportunity for more equality in interactions. However, through the comparison of the case studies it was deemed possible that early intervention increased the effectiveness of the intervention in increasing relationship quality.

My grandfather experienced two waves of grief. The first was when he began to believe my grandmother was no longer connected to her prior identity, and the second was after she died. It was found in the two case studies that intervention prior to the first wave of grief is important. Once the caregiver has begun grieving the loss of their partner's identity, as in case two, it is difficult to convince the caregiver that the identity has not been lost. An art therapy intervention based on visual communication would seem to be most beneficial as a preventative tool in early stages of disease progression.

References

- American Psychiatric Association. (2000). *Diagnostic and Statistical Manual of Mental Disorders* (4th ed., text rev.). Washington, DC: Author.
- Archbold, P.G., Stewart, B.J., Greenlick, M.R. & Harvath, T. (1990). Mutuality and preparedness as predictors of caregiver role strain. *Research in Nursing & Health*, 13, 375-384.
- Bloomgarden, J., & Sezaki, S. (2000). Home-based art therapy for older adults. *Art Therapy*:

VISUAL COMMUNICATION FOR CAREGIVERS OF SPOUSES WITH AD

Journal of the American Art Therapy Association, 17(4), 283-290.

Chesla, C., Martinson, I., & Muwaswes, M. (1994). Continuities and discontinuities in family members' relationship with alzheimer's patients. *Family Relations, 43, 3-9.*

Eisdell, N. (2005). A conversational model of art therapy. *Psychology and Psychotherapy: Theory, Research and Practice, 78(1), 1-19.*

Norton, M.C., Piercy, W., Rabins, P., Green, R., Breitner, J., Ostbye, T., Corcoran, C., Welsh-Bohmer, K., Lyketsos, C., & Tschanz, T. (2009). Caregiver-recipient closeness and symptom progression in alzheimer's disease. The cache county dementia progression study. *Journal of Gerontology: Psychological Sciences, 64B(5), 560-568.*

Norton, M. C., Smith, K. R., Østbye, T., Tschanz, J. T., Corcoran, C., Schwartz, S., Piercy, K. W., Rabins, P. V., Steffens, D. C., Skoog, I., Breitner, J. C. S., Welsh-Bohmer, K. A., & The Cache County Investigators. (2010). Greater risk of dementia when spouse has dementia? The cache county study. *Journal of the American Geriatrics Society, 58(5), 895-900.*

Ott, C. H., Sanders, S., & Kelber, S. T. (2007). Grief and personal growth experience of spouses and adult-child caregivers of individuals with alzheimer's disease and related dementias. *The Gerontologist, 47(6), 798-809.*

Williamson, G.M., & Shaffer, D. (2001). Relationship quality and potentially harmful behaviors by spousal caregivers: how we were then, how we are now. *Psychology and Aging, 16(2), 217-226.*

Williamson, G. M., & Schulz, R. (1993). Coping with specific stressors in alzheimer's disease caregiving. *The Gerontologist, 33(6), 747-755.*

Winnicott, D. W. (1974). *Therapeutic Consultations in Child Psychiatry.* London: Hogarth

VISUAL COMMUNICATION FOR CAREGIVERS OF SPOUSES WITH AD

Institute of Psycho-Analysis.

Witucki, J and Twibell, R.S. (1997). The effect of sensory stimulation activities on the psychological well-being of patients with advanced alzheimer's disease. *American Journal of Alzheimer's Disease and Other Dementias*, 12(1), 10-15.