ABSTRACT

CREATIVE EXPRESSIVE ABILITIES IN NURSING HOME RESIDENTS WITH DEMENTIA: ARE CREATIVE ACTIVITIES BETTER?

by Emily M. Fox

Creative arts programming is increasingly being used in nursing homes to improve quality of life for residents with dementia. After observing residents with dementia participating in creative activities and “traditional” activities, data from the Creative Expressive Abilities Assessment (CEAA) were analyzed to determine if participants were better able to express themselves during creative activities. Seven items from the CEAA were selected to encompass dimensions of creative expression related to attention, verbal communication, nonverbal communication, self-esteem, decision making, and emotions. Paired t-tests were used in order to compare each resident’s scores on creative activities to the same resident’s scores on traditional activities. Results indicate that residents were more attentive and more able to communicate emotions during creative activities, whereas the other items showed little difference between creative and traditional activities. Future studies should explore why it is that creative activities are better able to facilitate these types of expression.
CREATIVE EXPRESSIVE ABILITIES IN NURSING HOME RESIDENTS WITH DEMENTIA: ARE CREATIVE ACTIVITIES BETTER?

A Thesis

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Chapter 1: Introduction

Statement of the Problem

According to the Alzheimer’s Association (2012), approximately 13% of Americans over the age of 65 have Alzheimer’s disease or some other form of dementia, and at least 64% of older adults who live in nursing homes are experiencing some form of dementia. As the population of the United States continues to age, these issues will affect more and more people. Nursing homes and family caregivers are searching for creative solutions to enhance quality of life for those who are living with dementia.

Some nursing homes are adding creative arts programming to their traditional activities in order to enhance the expressive opportunities for people with cognitive impairments. Cedar Village is one such facility. In January of 2012, Cedar Village received a grant from the Wolf family which allowed the facility to expand the creative arts programs offered to all residents, including those with dementia (Lokon, Kinney, Sauer, & Kunkel, 2012). This funding has allowed Cedar Village to offer visual arts activities with an experienced artist and music activities with a licensed music therapist (Lokon et al., 2012).

Background

A great deal of research has been done on the effectiveness of creative arts activities. Creative (or expressive) arts can encompass a wide variety of activities including storytelling (Fritsch, Kwak, Grant, Lang, Montgomery, & Basting, 2009), dancing (Rylatt, 2012), cooking (Basting, 2006), gardening (Basting, 2006), creating visual art (Kinney & Rentz, 2005), drama (Rylatt, 2012), and listening to or creating music (Cohen, Perlstein, Chapline, Kelly, Firth, & Simmens, 2006; Lee, Chan, & Mok, 2010). While these programs are often utilized to help people with dementia (Cooke, Moyle, Shum, Harrison, & Murfield, 2010; Rylatt, 2012; Sherratt, Thornton, & Hatton, 2004) or older adults in general (Cohen et al., 2006; Lee et al., 2010), they can also be used for other populations such as those who have pain syndromes (Siedliecki & Good, 2006), people with mental disorders (Mössler, Assmus, Heldal, Fuchs, & Gold, 2012), and those who suffer from posttraumatic stress disorder (Collie, Backos, Malchiodi, & Spiegel, 2006).
Creative arts activities may be facilitated by specially certified individuals (such as licensed art or music therapists), direct care workers (such as nurses or nursing assistants), or people with little specialized training (such as family members or volunteers). The goals and outcomes of the activities depend on the interests, abilities, and engagement level of the participants. Artistic activities (in any form) can allow people to express themselves no matter their level of skill or previous experience (Basting, 2006).

Facilitators of creative arts activities for people with dementia recognize that this type of therapy will not “cure” Alzheimer’s disease or any other kind of dementia (Basting, 2006). Instead of striving for a cure, creative arts activities for people with dementia more often focus on improving quality of life (Basting, 2006; Rusted, Sheppard, & Waller, 2006). Common goals for creative arts programs include helping people improve communication skills (Basting, 2006; Rylatt, 2012), providing opportunities for socialization (Beshwate & Kasin, 2010; McFadden, Frank, & Dysert, 2008), encouraging engagement (McFadden et al., 2008; Rylatt, 2012), and decreasing agitation and anxiety (Peisah, Lawrence, & Reutens, 2011).

In fact, facilitators of these programs may need to recognize that as people age, standards for, and measures of, success will change. It could be that these activities will lead to less decline rather than improvement (Cohen, 2006). For example, in their study of music activities for older adults, Cohen et al. (2006) found that all participants had increased doctor visits, medication, and health problems and decreased morale, but those who participated in the music program had less decline than those in the control group. However, the researchers did also find more traditional positive health impacts: the music group had better health and fewer falls at the end of the intervention, whereas the control group had worse health and more falls.

Studies have shown that creative arts activities often do make a difference in quality of life for older adults with dementia. For example, in their study on an art program for people with dementia, Kinney and Rentz (2005) found that older adults displayed more interest, attention, pleasure, and self-esteem when participating in an art program than they did when participating in other types of activities. Rylatt (2012) performed a study using multiple types of creative activities (dance, drama, music, etc.) for people with dementia and found that most participants increased their creative expression, improved their communication abilities, and showed improvements on measures of pleasure and enjoyment. Thomas and Smith (2009) found that when music was played during mealtimes, people with dementia were able to eat more. Many of
the studies reviewed by Sherratt et al. (2004) found that music activities decreased aggression, agitation, wandering, and irritability among people with dementia.

Some studies yielded results which could seem both negative and positive. For example, Cooke, et al. (2010) found that verbal aggression actually increased after their music therapy program for people with dementia. Although verbal aggression is not ideal, it does seem to indicate that participants with dementia were able to find “a voice” as they participated in the activities. As mentioned above, Thomas and Smith (2009) found that listening to music during mealtimes led to increased appetites for people with dementia. Residents tended to be more attentive and spend more time in the dining room on the days when music was played. This often meant that they ate more unhealthy foods because they stayed to eat dessert. However, due to the fact that decreased appetite and food consumption can be a major problem for people with dementia, increased food consumption can generally be seen as a positive outcome, even if the food consumed is not always healthy. Studies with mixed outcomes such as these should lead to future studies that can clarify these findings.

One reason that creative activities tend to be beneficial for people with dementia is that they often provide some connection to the person’s past. These activities can serve as a reminder of familiar pastimes or routines (Sixsmith & Gibson, 2007) and can encourage reminiscence (Beshwate & Kasin, 2010). Basting (2006) says that the arts can connect to people “on an emotional level” (p. 17) and can be even more effective when tailored specifically to an individual’s past interests.

Researchers have employed a variety of methodologies to study the effects of creative programming for older adults. Many studies compare the effects of art or music to the absence of such activities. For example, in their study on music and caloric intake, Thomas and Smith (2009) examined the same group of 12 participants while they ate either with music or without music. Out of the 21 studies reviewed by Sherratt et al. (2004), 15 of them compared music activities to alternate periods of no music or to the participants’ characteristics prior to the introduction of the music program. Lee et al., (2010) conducted a study with one group of older adults receiving a music intervention and a control group receiving no music or other substitute activity.

Other studies have used an intervention group and a control group to compare a group of older adults participating in creative activities to a different group participating in more
traditional activities. Rusted et al., (2006) compared participants in art groups to participants in non-art activities conducted by an occupational therapist. One of the studies reviewed by Sherratt et al. (2004) compared a music therapy group to another group that participated in a puzzle solving activity.

Some researchers have used a within-participants design, allowing individual participants to also serve as their own control. A few of the studies reviewed by Sherratt et al. (2004) compared individuals’ responses to creative activities to their responses to other activities such as being read to, exercise, hand massages, and discussion groups. Kinney and Rentz (2005) also employed this methodology by observing participants in an art activity and the activity that directly followed it (discussion, games, etc.). However, these types of studies were not as commonly reported as the studies simply comparing creative activities to the absence of creative activities.

Studies also vary in the measurement of outcomes. Most studies use some type of observation measure. All but one of the studies evaluated by Sherratt et al. (2004) involved either in-person observations or coding of observations that had been videotaped. A variety of tools were used to guide these observations. Rylatt (2012) measured outcomes such as communication, pleasure, and engagement by having staff members rate “degree of improvement” during each session (p. 43). Kinney and Rentz (2005) developed an observational tool (the Greater Cincinnati Chapter Well-Being Observation Tool) to assess the frequency of outcomes such as interest, attention, pleasure, and self-esteem. These observations were conducted by trained researchers, not the staff members who were providing the activities. At least five of the studies reviewed by Sherratt et al. (2004) utilized a modified version of the Cohen-Mansfield Agitation Inventory (CMAI) in order to record various behaviors generally associated with agitation such as shouting, hoarding, or being physically aggressive. Other studies in that review used observational measures developed by the researchers to detect behaviors such as disruptiveness and wandering or outcomes such as sociability and engagement (p. 7).

Whereas many studies focus on using creative activities to improve quality of life for older adults or reduce negative symptoms such as aggression or agitation, some studies have also included measures of creative expression. Creative self-expression can include abilities such as verbal and nonverbal communication, social interaction, and emotional expression. Rylatt (2012)
included “creative self-expression” as one of her observed outcomes. However, this was simply included as one of the outcomes on the list and did not measure any dimensions of self-expression. Also, this study involved very little consistency since it involved different activities delivered by different staff members on different units. Baines (2007) and McFadden et al. (2008) write anecdotally about increased creative expression resulting from creative activities, but neither of these articles includes a specific observational tool or any sort of detailed description of expression.

There is a great need for further research on this topic, particularly as nursing homes and other organizations continue to seek non-pharmacological options for improving quality of life for people with dementia. Creative activities seem to have great potential to help people with dementia maintain personhood and experience positive interaction (Sherratt et al., 2004). However, more evidence about what types of programs are most effective and what sort of benefits can be expected is necessary. This study can fill gaps in the literature about the differing effects of creative and traditional activities on the same group of people. There is also a need for more research on the specific types of creative expression that can be fostered by different kinds of activities. This study will provide evidence about various dimensions of creative self-expression related to attention, verbal communication, nonverbal communication, self-esteem, decision making, and emotions.

Focus of this study

Facility. All data for this study were collected at Cedar Village, a large non-profit retirement community in southwestern Ohio. The mission statement of this 162-bed nursing facility is “To make aging an enriching and fulfilling experience” (Cedar Village, 2011). Staff members at this facility provide a wide variety of activities for residents.

In 2012, Cedar Village received a grant from the Wolf family to expand the creative arts programs offered to all residents, including those with dementia (Lokon et al., 2012). Previously a licensed music therapist had been employed by the facility on a very part-time basis. Funding from the Wolf family allowed her hours to be significantly expanded and also allowed for the hiring of a part-time artist to facilitate art activities.

Previous Research. Over the past year, Scripps Gerontology Center has been conducting research on the effects of these programs. Observational data has been collected using the
Creative Expressive Abilities Assessment (CEAA) (Appendix A), a tool designed to measure individuals’ abilities in the areas of memory, attention, language, psychosocial skills, reasoning/problem solving, emotions, and culture (Lokon et al., 2012). Preliminary results have shown that the creative arts programs do allow for greater creative expression than the regular activities at the facility (i.e. Bingo, discussion groups, etc.) (Lokon et al., 2012; Lokon, Kinney, Fox, Kunkel, & Sauer, 2013).

However, these analyses were conducted only in the aggregate, comparing groups of people who participated in arts programs to groups who participated in traditional activities. The two groups were not identical. Also, the participants did not have a consistent number of observations (allowing those who had been observed more often to have more influence on the results).

**Purpose of this study.** The purpose of this research is to expand on the work that Scripps Gerontology Center has already begun to evaluate the Wolf Project at Cedar Village. This study will analyze the data on an individual level by comparing a participant’s scores on traditional activities to his or her scores on creative activities.

**Research Questions.**

- How do an individual resident’s responses to creative activities compare to the same individual’s responses to more traditional activities?
- How is activity type related to residents’ ability to exhibit various dimensions of creative expression?

**Hypothesis.**

- Nursing home residents with dementia will exhibit more creative expression when participating in creative activities than when participating in traditional activities.
Chapter 2: Methodology

Introduction to the Wolf Study

Participants. All of the participants in this study were residents of Cedar Village. The majority of them live in one of the facility’s nursing care units, but some reside in the assisted or independent living apartments. Over the course of two semesters, 110 people were observed for a total of 424 observations.

Cognitive status for residents at Cedar Village is defined using “gem sets.” Each resident is assigned to a gem category to note his or her cognitive status. Those without any signs of dementia or other cognitive disabilities are known as Sapphires. These are followed by Diamonds, Emeralds, Ambers, Rubies, and Pearls. Pearls represent the residents with the most severe cognitive impairment. (See Appendix B for a more detailed description of the gem levels.) Residents are reevaluated periodically, and some of the participants in this study changed gem categories over the course of the project.

Observers. All of the observers in this project were faculty, staff, or students of Miami University. There were nine observers during both semesters, but it was not the same group of nine in each semester (Lokon et al., 2012; Lokon et al., 2013). Before starting data collection each semester, observers received several hours of training on the use of the observation tool. Training involved detailed discussions of the observation instrument and the opportunity to practice coding using videotaped data. Some Cedar Village staff members also participated in the training sessions, but due to time constraints, they did not participate in the data collection (Lokon et al., 2012).

The researchers on this project achieved high inter-rater reliability. At the beginning of each semester, observers worked in pairs to code activities so that they could compare their scores. After the first two weeks of the first semester, observers reached 74%-85% (average of 81%) agreement (Lokon et al., 2012, p. 3). After the first two weeks of the second semester, observers had reached 81%-96% (average of 88%) agreement (Lokon et al., 2013, p. 4).

Data Collection Process. Data collection took place over two semesters (Spring 2012 and Fall 2012). Researchers from Miami University visited Cedar Village several times per week to observe various activities. Each observer selected an unobtrusive spot in the room from which to watch the activity. Observers typically observed two different residents at a time.
Observations generally lasted between 15 and 60 minutes and occurred during a wide variety of activities in the facility including art therapy (one-on-one or group), music therapy (one-on-one or group), other art activities, Bingo, trivia games, social gatherings, religious programs and services, and many others.

Activities were coded into nine different categories: Art Therapy, Music Therapy, (other) Creative Activities, Religious, Physical Activity, Games, Social food-related, Passive leisure, and Opening Minds through Art (OMA).

For each observation, researchers collected the resident’s name, gender, date of the observation, time of observation, duration of observation, duration of the activity, name of activity, and the facilitator’s position (i.e. music therapist, art therapist, member of the activity staff, volunteer, etc.). During the second semester of data collection, observers also recorded the number of residents and non-residents present during the activity. After recording this demographic information, the observers scored the residents’ responses to the activity using three scales: the Creative Expressive Abilities Assessment (CEAA), the Oshkosh Social Behavior Checklist (OSBC), and the Measurable Assessment in Recreation for Resident-Centered Care (MARRCC). The latter two tools were included primarily to assist in the comparison and validation of the CEAA. Only results from the CEAA scale will be included in this study.

**Observation Tool: CEAA.** The Creative Expressive Abilities Assessment (CEAA) was developed by Dalia Gottlieb-Tanaka, Hilary Lee, and Peter Graf to address the need for tools to properly assess the effects of creative programs on older adults (particularly those with dementia) (Gottlieb-Tanaka, Lee, & Graf, 2008). These authors developed and tested several drafts of the instrument as they worked toward the tool in its current form. The first version of the CEAA had 45 items and eight different domains (Gottlieb-Tanaka et al., 2008). Testing of this draft led to the development of two more versions. The version used for this project is the third version of the scale.

The CEAA now consists of 27 items and encompasses seven different “ability domains” (Gottlieb-Tanaka et al., 2008, p. 6) (See Appendix A). The seven domains are memory, attention, language, psychosocial skills, reasoning/problem solving, emotions, and culture. Each domain includes between one and eight items. Two of the items are not generally used in analysis because they deal with writing, which does not occur during most activity programs. The 25-item
scale has a Cronbach’s alpha of .86, revealing good internal consistency (Gottlieb-Tanaka et al., 2008).

For each item on the CEAA, an individual can receive a score between 0 and 4. These scores represent how frequently each item occurred (0 = No observation or No opportunity, 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = (nearly) Always). The distinction between 0 and 1 can sometimes be a bit nebulous because it can be difficult to judge when exactly a person has an “opportunity” to partake in a certain activity. In general, “opportunity” was judged by the behavior of the other participants in the activity. For example, one item on the CEAA says “Uses humor (wit, joking, irony & sarcasm) when speaking.” If a person made humorous comments throughout the duration of the activity, he would receive a 4. If he made them occasionally, he would receive a 2 or a 3. If he never made a joke or humorous comment even though other participants did, he would receive a 1. However, if nobody was making jokes or if the activity were a passive one (i.e. watching a movie), the participant would receive a 0. If there was a question about whether an item should be scored 0 or 1, observers in this study were instructed to enter 1. With the 25-item CEAA, the total possible score is 100.

Details of this study

Selected Participants. Although the observers attempted to plan observations by activity and day in order to see the same residents in different types of activities, this was not always possible. Since this study looks specifically at individual differences in creative expression in creative activities and traditional activities, only those subjects who had at least one observation in each category are included in this analysis. There were 59 residents who met these criteria. Each of them had been observed between 2 and 17 times for a total of 341 observations for the whole group. The table below describes the average number of observations of each type for the 59 residents included in the subsample. Of these 59 residents, 46 (78%) were female. One participant was a Ruby, and the rest were Diamonds, Emeralds, and Ambers.
Table 1

*Number of Observations for Subsample*

<table>
<thead>
<tr>
<th></th>
<th>Total Observations</th>
<th>Creative Observations</th>
<th>Traditional Observations</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Mean</strong></td>
<td>5.78</td>
<td>2.73</td>
<td>3.05</td>
</tr>
<tr>
<td><strong>Std. Deviation</strong></td>
<td>4.03</td>
<td>2.16</td>
<td>2.3</td>
</tr>
<tr>
<td><strong>Minimum</strong></td>
<td>2</td>
<td>1</td>
<td>1</td>
</tr>
<tr>
<td><strong>Maximum</strong></td>
<td>17</td>
<td>11</td>
<td>10</td>
</tr>
</tbody>
</table>

N = 59

**Activity Definitions.** Although there are many different types of programs which could be considered “creative” activities, this study only counted art therapy, music therapy, and OMA as “creative.” “Art therapy” included *any* activities conducted by the facility artist, “music therapy” included *any* activities conducted by the music therapist, and OMA is an intergenerational art program for people with dementia. The first two are included because they are the main components of Cedar Village’s newly funded focus on arts programming. OMA is included because it is an evidence-based program that has been designed specifically to allow creative expression for people with dementia. The activities in all other categories are counted as “traditional” activities.

**Selected CEAA Items.** This study will focus on only a few items from the full CEAA. Items were excluded based on a high occurrence of missing data. Observations with a score of 0 were counted as missing because the activity provided no opportunity for that particular behavior to be observed. For this project, any item with missing data for more than 10% of the observations will be excluded.

In addition to issues with missing data, there are several other justifications for removing items from this analysis. Some of the items on the CEAA only apply to creative activities and have very little relevance to more “traditional” activities that do not involve art or music. For example, Psychosocial 15 says, “Attracts/holds attention of other(s) when dancing, performing or playing an instrument.” These actions apply to very few of the activities. Another example is item Emotions 22 which states, “Expresses moods and emotions in visual displays.” This item only applies to activities during which participants are creating some sort of art.
The entire Culture domain was removed from analysis for a similar reason. Very few activities provided an opportunity for participants to “speak from the heart,” “share wisdom,” or do the other things mentioned in this domain. These items were some of the hardest to measure, and in most observations within the larger study, and within this research, participants received a score of 0. The literature that was reviewed for this study does not necessarily support the idea that creative activities will affect an individual’s ability to engage in these sorts of discussions.

The remaining seven items include the one item that measures Attention, three items from the Language domain, one item from the Psychosocial domain, one item from the Reasoning domain, and one item from the Emotions domain (see Table 2). Together, these items have a Cronbach’s alpha of .84 (compared with a Cronbach’s alpha of .88 for the entire CEAA). These items are still able to provide a broad overview of creative expression and can be clearly related to outcomes predicted by the literature such as engagement (Fritsch, et al., 2009; Rylatt, 2012), attention (Kinney & Rentz, 2005), self-esteem (Beshwate & Kasin, 2010; Kinney & Rentz, 2005), communication (Baines, 2007; McFadden et al., 2008; Rylatt, 2012), pride (Baines, 2007; McFadden et al., 2008), and socialization (Beshwate & Kasin, 2010; McFadden et al., 2008; Rusted et al., 2006).
Table 2
*CEAA Items Retained for this Study*

<table>
<thead>
<tr>
<th>CEAA Item</th>
<th>Related Outcome</th>
<th>% Missing</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Attention 4:</strong> Stays engaged for: 1= &lt;5 min; 2= between 5 &amp; &lt;10 min; 3= between 10 &amp; &lt;30 min; 4= 30 min or more</td>
<td>Engagement, Attention</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Language 6:</strong> Produces complete grammatical sentences when speaking</td>
<td>Communication, Socialization</td>
<td>9%</td>
</tr>
<tr>
<td><strong>Language 7:</strong> Uses key words and/or simple sentences with appropriate body language</td>
<td>Communication, Socialization</td>
<td>8%</td>
</tr>
<tr>
<td><strong>Language 11:</strong> Uses facial expressions and body language to communicate/indicate understanding</td>
<td>Communication, Socialization</td>
<td>2%</td>
</tr>
<tr>
<td><strong>Psychosocial 17:</strong> Shows self-esteem/confidence or pride</td>
<td>Self-esteem, Pride</td>
<td>10%</td>
</tr>
<tr>
<td><strong>Reasoning 20:</strong> Makes clear choices and decisions</td>
<td>Self-esteem, Pride</td>
<td>9%</td>
</tr>
<tr>
<td><strong>Emotions 21:</strong> Uses facial expressions to communicate moods and emotions</td>
<td>Communication, Socialization</td>
<td>4%</td>
</tr>
</tbody>
</table>
**Dataset Construction.** The dataset was initially arranged by individual observation, not by individual participant. It was necessary to create a rectangular file organized by participant so that each person could be compared to him or herself instead of using group means as had been done in previous analysis. The first step was to give each participant a unique identification number. Then, the observations for each person had to be numbered as well. Since each participant had at least two observations, each person had at least an Observation 1 and an Observation 2. The average number of observations was 5.78, and one person had been observed 17 times (See Table 1). Participants received zeroes for the empty observations. For example, if a resident had only been observed 12 times, he would have zeroes for Observation 13, 14, 15, 16, and 17. Each observation was coded as traditional or creative.

Since participants had different numbers of observations, it was necessary to calculate mean scores on each of the expressive ability items for each individual for traditional and for creative activities. Two averages were created for each of the seven CEAA items, one for creative activities and one for traditional. This was accomplished by adding up all of the traditional or creative scores on each item and then dividing by the individual’s count for traditional or creative activities. For example, to calculate the average score on the Attention item for traditional activities, the Attention scores for each traditional observation were added together and then divided by the total number of traditional observations. In the end, each participant had a creative average and a traditional average for each expression item.

**Analysis Plan.** After data cleaning, the primary method of analysis was paired t-tests. This allows residents’ scores on creative activities to be compared to their scores on traditional activities in order to determine whether there is truly a difference of creative expression between the two types of activities. This analysis strategy is very similar to the strategy employed by Kinney and Rentz (2005) in their study on individuals’ responses to an art program and more traditional activities.
Chapter 3: Results

This study compared the expressive abilities of 59 nursing homes residents across traditional and creative activities. Comparisons were made using seven items from the CEAA observational tool. Possible scores on each item ranged from 0 to 4, with 4 representing a behavior that occurred (nearly) always and 1 representing a behavior that never occurred. A score of 0 indicated that the activity did not provide an opportunity for that behavior to occur. All participants were observed in at least one creative activity and one traditional activity. For those who were observed more than once, expressive ability scores were averaged across all of their observations.

Overall Scores

Overall, scores on the CEAA items were fairly high. Table 3 shows the average of the average scores for each of the seven expressive ability items for both creative and traditional activities. The relatively high mean scores in both categories seem to suggest that most activities at Cedar Village allow for fairly high levels of creative expression. Even though scores are generally high, there appear to be some differences in some dimensions of creative expression observed during traditional and creative activities.

Table 3
*Averages of Average Scores for Traditional and Creative Activities*

<table>
<thead>
<tr>
<th>Item</th>
<th>Traditional Mean</th>
<th>Standard Deviation</th>
<th>Creative Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>3.28</td>
<td>.89</td>
<td>3.59</td>
<td>.56</td>
</tr>
<tr>
<td>Language 6</td>
<td>3.11</td>
<td>1.31</td>
<td>3.39</td>
<td>.98</td>
</tr>
<tr>
<td>Language 7</td>
<td>3.11</td>
<td>1.26</td>
<td>3.54</td>
<td>.77</td>
</tr>
<tr>
<td>Language 11</td>
<td>3.17</td>
<td>1.04</td>
<td>3.49</td>
<td>.70</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>2.85</td>
<td>1.29</td>
<td>2.90</td>
<td>1.13</td>
</tr>
<tr>
<td>Reasoning</td>
<td>3.17</td>
<td>1.14</td>
<td>3.19</td>
<td>.94</td>
</tr>
<tr>
<td>Emotions</td>
<td>2.91</td>
<td>1.10</td>
<td>3.31</td>
<td>.97</td>
</tr>
</tbody>
</table>
**Paired t-tests**

In order to determine if the differences between the traditional and creative scores were statistically significant, paired t-tests were used, comparing the traditional average for each item with its corresponding creative average for each individual. Participants who had missing data on a particular item were excluded from the calculations for that item.

This initial analysis indicates that there is a significant difference between creative and traditional scores for four out of the seven items (Attention, Language 7, Language 11, and Emotion). In each of these cases, the creative activities have the higher score (See Table 4).

Three of these significant items (Language 7, Language 11, and Emotion) seem to be related as they all deal with communication through facial expressions or body language. This seems to suggest that creative activities provide more opportunity for nonverbal expression and attention, whereas there is no difference in opportunities for verbal expression, self-esteem, or decision making (Language 6, Psychosocial, and Reasoning).

Table 4

*Results of Paired t-test*

<table>
<thead>
<tr>
<th>Item</th>
<th>N</th>
<th>Traditional Mean</th>
<th>Creative Mean</th>
<th>Mean Difference</th>
<th>T Value</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>56</td>
<td>3.27</td>
<td>3.58</td>
<td>-.31</td>
<td>-2.76</td>
<td>.008**</td>
</tr>
<tr>
<td>Language 6</td>
<td>46</td>
<td>3.10</td>
<td>3.37</td>
<td>-.27</td>
<td>-1.56</td>
<td>.126</td>
</tr>
<tr>
<td>Language 7</td>
<td>50</td>
<td>3.11</td>
<td>3.51</td>
<td>-.40</td>
<td>-2.68</td>
<td>.010**</td>
</tr>
<tr>
<td>Language 11</td>
<td>58</td>
<td>3.17</td>
<td>3.48</td>
<td>-.31</td>
<td>-2.23</td>
<td>.029*</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>57</td>
<td>2.85</td>
<td>2.90</td>
<td>-.05</td>
<td>-.26</td>
<td>.794</td>
</tr>
<tr>
<td>Reasoning</td>
<td>54</td>
<td>3.18</td>
<td>3.19</td>
<td>-.01</td>
<td>-.08</td>
<td>.938</td>
</tr>
<tr>
<td>Emotions</td>
<td>58</td>
<td>2.91</td>
<td>3.31</td>
<td>-.40</td>
<td>-2.46</td>
<td>.017*</td>
</tr>
</tbody>
</table>

* p < .05, **p < .01

These data are skewed by the fact that some of the activities do not provide opportunity for various types of expression. For example, it is possible that an activity such as watching a movie would not provide opportunity for a participant to speak. When an activity does not provide an opportunity for a particular type of expression, the participant receives a score of “0”
for that item. Since a “0” is conceptually distinct from the other numerical scores assigned to the expressive abilities, this issue required further analysis. Some participants even had an average score of zero on a particular item because none of the activities they participated in provided an opportunity for that form of expression. Greater numbers of participants had scores of zero on the psychosocial and emotion items, suggesting that these opportunities for expression are less common in both traditional and creative activities (See Table 5). The zeroes also help to explain why the averages including zeros (shown in Table 3) were lower on these two items. The psychosocial item measures self-esteem, confidence, and pride so it may be that this item had the most zeroes because these were difficult items to objectively define and rate. The same may be true of the emotion item which measured the use of facial expressions to communicate emotions. However, across all seven items, it was more common for participants to have a score of zero on the traditional activities than on the creative activities.

Table 5

*Percentage of Observations with a Score of Zero*

<table>
<thead>
<tr>
<th></th>
<th>Traditional</th>
<th>Creative</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>1.7%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Language 6</td>
<td>7.2%</td>
<td>3.1%</td>
</tr>
<tr>
<td>Language 7</td>
<td>8.3%</td>
<td>1.9%</td>
</tr>
<tr>
<td>Language 11</td>
<td>3.4%</td>
<td>0.6%</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>9.6%</td>
<td>9.3%</td>
</tr>
<tr>
<td>Reasoning</td>
<td>9.7%</td>
<td>5.6%</td>
</tr>
<tr>
<td>Emotion</td>
<td>3.9%</td>
<td>2.5%</td>
</tr>
</tbody>
</table>
Table 6

Averages of Average Scores for Traditional and Creative Activities (Without Zeroes)

<table>
<thead>
<tr>
<th></th>
<th>Traditional Mean</th>
<th>Traditional Standard Deviation</th>
<th>Creative Mean</th>
<th>Creative Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>3.36</td>
<td>.77</td>
<td>3.59</td>
<td>.57</td>
</tr>
<tr>
<td>Language 6</td>
<td>3.46</td>
<td>.96</td>
<td>3.53</td>
<td>.90</td>
</tr>
<tr>
<td>Language 7</td>
<td>3.53</td>
<td>.79</td>
<td>3.60</td>
<td>.73</td>
</tr>
<tr>
<td>Language 11</td>
<td>3.38</td>
<td>.71</td>
<td>3.52</td>
<td>.73</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>3.37</td>
<td>.71</td>
<td>3.29</td>
<td>.80</td>
</tr>
<tr>
<td>Reasoning</td>
<td>3.57</td>
<td>.77</td>
<td>3.46</td>
<td>.77</td>
</tr>
<tr>
<td>Emotions</td>
<td>3.10</td>
<td>.87</td>
<td>3.46</td>
<td>.75</td>
</tr>
</tbody>
</table>

The problem with including these zeroes in the analysis is that they provide more information about the activities than about the individuals’ responses to the activities. Removing all of the zeroes on a particular item makes the activities more comparable by eliminating activities that did not provide opportunities to respond. There are a variety of activities that may not have provided opportunities for certain types of expression. For example, watching a concert probably would not provide many opportunities for verbal communication, self-esteem, or decision making. An activity like Bingo may not provide much opportunity for emotional expression. One creative activity that may not always provide opportunities for self-expression is bell choir rehearsal. Since this is a fairly structured activity, there may not be much opportunity for decision making or emotional expression. Since a greater percentage of traditional activities than creative activities had scores of zero, this change improves the averages on most of the traditional items and consequently reduces the number of significant differences between traditional and creative activities. In the second round of t-tests (See Table 6), only two items are significant (Attention and Emotion) (p < 0.05). In these two pairs, the creative activities still have the higher scores.
Table 7

*Results of Paired t-test (Without Zeros)*

<table>
<thead>
<tr>
<th></th>
<th>N</th>
<th>Traditional Mean</th>
<th>Creative Mean</th>
<th>Mean Difference</th>
<th>T Value</th>
<th>Significance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Attention</td>
<td>55</td>
<td>3.36</td>
<td>3.59</td>
<td>-.24</td>
<td>-2.42</td>
<td>.019*</td>
</tr>
<tr>
<td>Language 6</td>
<td>43</td>
<td>3.46</td>
<td>3.53</td>
<td>-.07</td>
<td>-.54</td>
<td>.595</td>
</tr>
<tr>
<td>Language 7</td>
<td>46</td>
<td>3.53</td>
<td>3.60</td>
<td>-.07</td>
<td>-.64</td>
<td>.525</td>
</tr>
<tr>
<td>Language 11</td>
<td>55</td>
<td>3.38</td>
<td>3.52</td>
<td>-.13</td>
<td>-1.25</td>
<td>.216</td>
</tr>
<tr>
<td>Psychosocial</td>
<td>50</td>
<td>3.37</td>
<td>3.29</td>
<td>.08</td>
<td>.55</td>
<td>.585</td>
</tr>
<tr>
<td>Reasoning</td>
<td>50</td>
<td>3.57</td>
<td>3.46</td>
<td>.11</td>
<td>.80</td>
<td>.426</td>
</tr>
<tr>
<td>Emotions</td>
<td>54</td>
<td>3.10</td>
<td>3.46</td>
<td>-.36</td>
<td>-2.57</td>
<td>.013*</td>
</tr>
</tbody>
</table>

* p < .05
Chapter 4: Discussion

Overview

Many studies have focused on the ways that creative arts activities can affect people with dementia. Researchers have used a variety of strategies to examine this topic, including descriptions of the implementation of an assortment of different creative programs and comparing intervention groups and control groups on a variety of different outcomes. Studies related to creative arts and people with dementia have yielded outcomes such as engagement (Fritsch, et al., 2009; Rylatt, 2012), attention (Kinney & Rentz, 2005), self-esteem (Beshwate & Kasin, 2010; Kinney & Rentz, 2005), communication (Baines, 2007; McFadden et al., 2008; Rylatt, 2012), pride (Baines, 2007; McFadden et al., 2008), and socialization (Beshwate & Kasin, 2010; McFadden et al., 2008; Rusted et al., 2006). However, there were not many studies that compared the same participants’ responses to both creative activities and more traditional programs. One of the goals of this study was to make a contribution to this gap in the literature.

This study focused specifically on the ways that various types of activity programming can facilitate expressive abilities among people with dementia. The concept of expressive abilities refers to forms of verbal and nonverbal communication, social interaction, attention, emotional expression, and other abilities. It is important to measure and understand these abilities because they can help maintain personhood and quality of life for people with dementia (Basting, 2006; Gottlieb-Tanaka et al., 2008). Seven items from the Creative Expressive Abilities Assessment (CEAA) were selected based on data limitations and outcomes suggested by the literature.

The initial hypothesis proposed that residents would exhibit more creative expression during creative activities than during traditional activities. This hypothesis received support for some of the seven expression items. The first set of paired t-tests showed significant differences for four of the items (Attention, Language 7, Language 11, and Emotion). However, after the observations scored as zero were eliminated, the second paired t-tests showed significant differences only for Attention and Emotion. By removing the zeroes, the second set of t-tests adjusted for the fact that the traditional activities were more likely to provide no opportunity for creative expression, thus providing a more stringent comparison of the impact of creative arts activities.
Types of expression showing no significant differences

Three of the expression items (Language 6, Psychosocial, and Reasoning) did not reveal significant differences between creative and traditional activities in either of the analyses. There are several possible explanations for these outcomes.

**Language 6.** This item measures how frequently respondents produce complete sentences when speaking. The description of the item in the CEAA scale does not offer any more details about the nature of these sentences. Residents could receive a high score on this item by speaking to anyone about anything. Thus, it is not hard to imagine that participants could receive similar scores on this item during any type of activity. It seems reasonable to suppose that residents who are able to speak would engage in conversation during any activity that provided the opportunity to do so.

**Psychosocial.** This item measures self-esteem, confidence, and pride. These concepts can be difficult to operationalize and measure. In the scoring guide that accompanies the CEAA, the authors say that expressions of self-reliance and future plans are included in the measurement of this item. Self-esteem is also demonstrated when a person displays enough confidence to leave the activity (Gottlieb-Tanaka, Lee, & Graff, 2011). Other studies (Beshwate & Kasin, 2010; Kinney & Rentz, 2005) have found that creative arts programming can lead to increased self-esteem for people with dementia. Kinney and Rentz (2005) utilized three different observation items to measure self-esteem including items about nonverbal expressions of pride, verbal expressions of satisfaction, and verbal expressions of pride through reminiscence (p.224). Perhaps a more clearly defined and multi-dimensional measure of self-esteem would have yielded results more similar to those other studies, but in this study, self-esteem did not prove to be significantly different in creative activities compared to traditional.

**Reasoning.** This item measures how often residents make clear choices and decisions. It would seem that creative activities would naturally lend themselves to more decision-making opportunities since residents may have the chance to choose things such as what color of paint they would like to use or what song they would like to sing. However, in this study, there were no significant differences between creative and traditional scores on this item. One reason for this could be the wide array of decisions that could be included as this item was scored. Decision making could include deciding to move to a different part of the room, deciding not to actively participate in the activity, or even deciding to leave the area entirely. Thus, residents could
receive high scores on this item without even participating in the program that was being conducted at the time. Most activities provide equal opportunity to make those sorts of decisions so this could be part of the reason why there were no significant differences in this analysis.

Types of expression that vary significantly across activities (before controls)

The first set of paired t-tests revealed significant differences on four of the CEAA items (Attention, Language 7, Language 11, and Emotion).

Language 7. This item measures the use of key words and appropriate body language. In the first set of paired t-tests, there are significant differences between creative and traditional activities on this item, but after the zeroes are removed, the difference is no longer significant. McFadden et al. (2008) noted that people with dementia who participated in creative arts programming often demonstrated greater degrees of “social normalcy” whereby they communicated with other participants both verbally and nonverbally (p. 142). Kinney and Rentz (2005) made this same observation in their research. McFadden et al. (2008) are unclear about whether this increase in sociability and communication is specifically connected to the creative activities or is more related to the social opportunities inherent in any group activity. It is possible that this item is related to opportunities for socialization more than opportunities for creative expression.

Language 11. This item measures the frequency of using facial expressions and body language to communicate understanding. Like Language 7, this item showed significant differences in the first set of t-tests, but after the zeroes were removed, the differences were no longer significant. This difference could be due to the difficulty of measuring “understanding.” Whereas Language 7 simply measures the use of key words and body language in any context, this item focuses specifically on nonverbal expressions of “understanding.” Judging a person’s expressions of understanding could have been difficult regardless of the activity context.

Types of expression that vary significantly across activities (after controls)

After the second set of t-tests (which controlled for the opportunity to exhibit creative expression), Attention, and Emotion remained significant, but Language 7 and Language 11 were no longer significant.
**Attention.** This item measured how long the resident was able to pay attention to the activity. Results indicate that residents were able to pay attention longer when participating in creative arts programming. Thomas and Smith (2009) came to a similar conclusion when they found that their participants spent more time at the lunch table when music was being played. Fritsch et al. (2009) propose that people with dementia are able to be more engaged in creative activities because they are “failure-free” (p.118). If there is no wrong way to participate, residents will likely pay more attention, whereas activities such as Bingo or trivia games have more rules and “wrong” ways to play which could discourage people with dementia from engaging.

**Emotion.** This item measures the expression of emotions through facial expressions. Residents were able to engage in this type of expression more frequently during the creative activities than the traditional activities. In the second t-test, there was a greater difference between creative and traditional activities on this item than on any of the other items. This item is similar to Language 7 in that it measures sociability of people with dementia. However, it seems that creative activities have some unique connection to the ability to express moods and emotions. Basting (2006) says that arts based programs are important because they “operate on an emotional level” (p.17). She suggests that these activities can help people with dementia connect with deeper parts of themselves that have been forgotten. She also notes that the arts can encourage expression even when language is lost, which is very much related to this item which measures nonverbal communication rather than verbal communication.

Although it meant that fewer of the items had significant differences, it was still conceptually important to remove the observations scored as zero and run the second set of t-tests. Both sets of t-tests are useful. The first shows that creative activities really seem to provide more opportunities for creative expression. The second shows how residents respond when all of the activities are equal. Generally it seems that regardless of the opportunity for creative expression, residents pay more attention and display more emotional expression during creative activities than they do during traditional activities.
Limitations of study design and implementation

This project had several limitations. Some were related to the data collection process, and others were related to this particular study.

**Limitations related to data collection.** One issue with the data collection was the somewhat disordered nature of the process. The original plan involved a very structured schedule for conducting observations (i.e. certain residents would be observed in certain activities on certain days). However, due to the unpredictability of activities in a nursing home it was difficult to maintain this schedule. For example, it was common for any given resident to be sick or at a doctor’s appointment or simply uninterested in participating on the days that he or she was supposed to be observed. Also, some residents consistently participate in more activities than others so they were observed more often.

The data collection took place over two semesters with a four month break in between. It is quite possible that residents could have undergone any number of traumatic life events in the intervening time (i.e. death of a spouse or other loved one, significant health issue, moving to a new room or unit, etc.) which could affect their ability to respond to activities. With a larger sample it would have been interesting to look at residents’ scores over time to see how they changed.

Another issue related to having two distinct data collection periods is that the same group of observers did not participate each semester. This is not a major issue since during both semesters the groups established high rates of inter-rater reliability. However, there could be some discrepancies between the two semesters.

Finally, the relatively small sample size made it impossible to conduct more detailed and specific analysis. If there had been more people in the sample, it would have been easier to create subgroups of participants (i.e. by cognitive status) or subgroups of activities (i.e. large group activities compared to small group activities or art activities compared to music activities).

**Limitations of this study.** As mentioned above, it was beyond the scope of this study to conduct any sort of time-based analysis of the data. Had this type of analysis been conducted, it could have eliminated some of the problems related to the two different data collection periods. Also, the CEAA items that were included in this study were kept for specific methodological and conceptual reasons, but the study could have been more descriptive had all of the CEAA items been included.
Limitations of the CEAA

There are very few instruments to measure creative expression in people with dementia. The CEAA undoubtedly contributes to the effort to find effective ways to measure these abilities. However, this study revealed several major limitations of the CEAA.

Limitations related to operationalization. One issue is that some of the items on the scale were difficult to observe and measure. For example, it was not easy to understand exactly what was meant by “self-esteem” or “understanding.” In fact, some of the items from the CEAA (such as the entire Culture domain) were not used in this particularly study partially because of this difficulty. Although this lack of clarity did not prevent the observers from reaching high inter-rater reliability, understanding and analysis of these concepts could be clarified by breaking them down into specifically observable elements.

Also, the wording of some of the CEAA items was changed slightly at the beginning of the second semester after consultation with the authors of the instrument. In general, this has improved the clarity and quality of the scale, particularly in some of the more difficult items including those in the culture domain. However, since the changes were made after the first data collection period, they could have some effect on the results as well.

Limitations related to scoring. The most concerning issue with the CEAA is the scoring system. The current system attempts to evaluate both the activity and the participant. This leads to great confusion about the unit of analysis. A score of zero indicates that the activity did not provide an opportunity for that particular form of expression. Any other score is related to a participant’s ability to express him or herself in a certain way during the activity. Consequently, the zeroes are not comparable to any other score and should not be included in any analysis that is meant to understand the behavior of the participants.

This study shows that this instrument may not be the best way to assess the abilities of older adults with dementia. Perhaps it would be better to use two separate scales: one to assess the opportunities provided by the activities and another to assess the actual abilities of the participants.

Implications and ideas for future research

The literature (including this study) suggests that there truly is something about creative arts activities that encourage and facilitate increased creative expression. When the “opportunity”
for expression is controlled for, there are fewer differences between creative and traditional activities. Still, this study shows greater levels of engagement and emotional expression when participating in creative programs even when the potential for expression is equal. It is not explicitly clear why these types of activities have this effect.

A first step toward answering this question could involve research that breaks activities into more discrete categories. For example, art activities and music activities could be separated from each other. Activities could also be separated into groups based on the number of staff members and residents present. Another grouping mechanism could involve separating passive activities from more active ones (i.e. watching a movie or a concert as opposed to doing exercise or making an art project). Other information including time of day and duration of the activity could be taken into account. All of these items could provide some more clues as to exactly what elements are necessary to encourage increased expression.

It would also be interesting to study the effects of dosage. Does the amount of creative arts programming that a person participates in influence the effect? Again, a time-based study would be efficacious in answering this question. It would be interesting to see how creative programming affects people over time, particularly as the effects of dementia are presumably progressing as well. In addition to effects of dementia, a time-based study could also examine the effects of traumatic events such as major illness, hospitalization, or death of a loved one.

It will also be important for future studies to address the unit of analysis issue. It is important to assess the potential for expression provided by the activities, and it is important to assess the actual expressive abilities of the older adults. It may not be possible to assess both using the same scale.

Conclusion

This study shows that there are some types of creative expression (including sustained attention and emotional expression) that are better facilitated by creative activities than by traditional activities for people with dementia. As this segment of the population continues to increase it will be important to come to a greater understanding of exactly why that occurs so that quality of life for people with dementia may be continually improved. It would be beneficial for future studies to examine how various types of expression can benefit people with dementia and how exactly creative activities facilitate this expression. It will also be helpful to come up
with even more effective means of measuring creative expressive abilities. Answers to these questions will lead to improved programming for people with dementia and further recognition of their personhood and value.
References


Baines, P. (2007). Nurturing the heart: Creativity, art therapy and dementia. *Quality Dementia Care Series, Alzheimer’s Australia, 3*, 1-45.

Basting, A.D. (2006). Arts in dementia care: ‘This is not the end…it’s the end of this chapter.’ *Generations, 30*(1), 16-20.


Appendix A: Creative Expressive Abilities Assessment (CEAA)

CEAA Ability Domains and Items
(0 = No Opportunity, 1 = Never, 2 = Rarely, 3 = Sometimes, 4 = (nearly) Always, 9 = missing data)

Memory
1. Reminisces about people, events and personal experiences
2. Recites poems, songs or jokes
3. Invents (fabricates) realities about the past, present or future

Attention
4. Stays engaged (1 = less than 5 minutes; 2 = 5-10 minutes; 3 = between 10-30 minutes; 4 = more than 30 minutes

Language (spoken and body)
5. Produces complete grammatical sentences when writing
6. Produces complete grammatical sentences when speaking
7. Uses key words and simple sentences with appropriate body language
8. Uses humor (wit, joking, irony & sarcasm) when writing
9. Uses humor (wit, joking, irony & sarcasm) when speaking
10. Provides elaborate/informative descriptions of objects, actions or events
11. Uses facial expressions and body language to communicate/indicate understanding
12. Makes vocal and body responses to music

Psychosocial
13. Attracts/holds attention of other(s) when telling a story, joke or anecdote
14. Attracts/holds attention of other(s) when singing a song
15. Attracts/holds attention of other(s) when dancing, performing or playing an instrument
16. Responds to (comments, shows compassion for, reflects or elaborates on) productions of others
17. Shows self-esteem/confidence
18. Shows interest in/concern for grooming and clothing

Reasoning/Problem Solving
19. Shows insight into problems (puzzles or compositions in visual & performing arts) by commenting on plans, designs, spaces & objects, by analyzing music, suggesting solutions, reasons & explanations
20. Makes clear choices and decisions

Emotions
21. Uses facial expressions to communicate moods and emotions
22. Expresses moods and emotions in visual displays
23. Expresses moods and emotions in music
24. Expresses moods and emotions in anecdotes and stories

Culture (spirituality, religion, traditions, customs)
25. Shares deep thoughts and speaks from the heart through words, the arts or through movement
26. Shares wisdom and life experiences, teaches lessons about life
27. Engages in discussions on the meanings of culture, spirituality, religion, traditions and customs

Items 5 and 8 were omitted from the analyses because they deal with written communication, which is not a component of the programs that were evaluated. The CEAA is copyrighted by ArtsScience Press (2008, 2011).
Appendix B: Cedar Village Gem Levels

**Appendix B: Cedar Village Gem Levels**

**Gem Levels**
Understanding What Each Level Means

*Imagine Driving a Car... At Each Gem Level*

<table>
<thead>
<tr>
<th>Gem Level</th>
<th>Basic Meaning</th>
<th>So If They Were Driving a Car... They would</th>
</tr>
</thead>
</table>
| **Sapphire** | Normal Aging Changes – NO Dementia Slowing Down | - Goes slower & stops sooner  
- Reacts slower  
- Takes longer to learn how to operate a ‘new’ car  
- May want to ‘rehearse’ a trip  
- Likes to allow PLENTY of time to make a trip  
- May worry about trips/travel  
- Doesn’t like to be pushed or followed too closely  
- May give up some driving responsibilities due to ‘fear’ of failure or vision or mobility changes  
- May blame others for causing risky situations |
| **Diamond** | Early Dementia Or Mild Depression  
Mild Cognitive Impairment  
Using old habits & routines to Get By  
Covers up mistakes  
Gets angry at others  
Fears getting caught  
Likes being valued as smart, pretty, thrifty, clever, experienced...  
Wants to tell their old stories  
Wants to let you know who they have been  
Wants to give something to others | - Can drive their OLD, FAMILIAR CAR on their routine trips, along well-known routes, during the usual times, with the regular people in the car, as long as there are NO problems with the weather, equipment, light levels, detours, heavy traffic, distracting conversations of sights, their health, and their family!  
- If there are any changes they may:  
  - Get lost  
  - Get upset or angry  
  - Get scared or panic  
  - Make mistakes that are dangerous  
  - Accuse others of misbehaving, breaking the law  
  - Make things up to explain what happened  
  - Demand to do it ‘their way’  
  - Refuse to let someone step in and tell them what to do  
  - Get so involved with talking to a passenger, they forget to watch the road |
| **Emerald** | Moderate Dementia Or Significant Depression  
Repeats some steps  
Skips some steps  
Thinks it’s OK  
Fears being disrespected  
Gets lost in time & place  
Goes back in time  
Mis-remembers & makes stuff up to fill in  
Wants to be ‘normal’  
Wants to be in the ‘action’  
Wants to be helpful and involved OR left alone to do what they want to do  
Do things or supervise others doing things | - Can do many of the mechanics of driving BUT can’t hook it all together to drive safely  
- Can get in and turn on the car, can put it in gear, but may be looking out the front while it is going in reverse  
- Can ‘know’ how to ‘change the oil’ BUT will make mistakes doing it – empty out the oil, put in a new filter, then fill up the crank case with anti-freeze  
- May turn on the windshield wipers when trying to change the radio station  
- Try to get in a car at the mall that looks like one they owned several years ago – may even try to break in  
- Become upset when they can’t find a car that they had when they were a teenager – accuse a family member of stealing it  
- Try to manually shift an automatic transmission  
- Stop to fill up with gas at every station  
- Forget to pay one time, then overshpay the next  
- Sit at the entrance ramp and wave at the passing cars, then get out to flag help down on a busy highway |

Alzheimer’s North Carolina, Inc. 2010 Teepa Snow & Melanie Bunn
<table>
<thead>
<tr>
<th>Amber</th>
<th>Mid Dementia</th>
<th>Severe Dementia</th>
<th>Profound Dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td>• In the moment</td>
<td>• Wants to mess with the radio — pushing all the buttons and switches on the dashboard and console</td>
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<tr>
<td>• All about sensation</td>
<td>• Gets in the glove compartment and takes everything apart</td>
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<tr>
<td>• All about exploration</td>
<td>• Rolls the windows up and down and throws things out, then tries to open the door to go get them</td>
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<tr>
<td>• No safety awareness</td>
<td>• May suddenly shift gears or even put the car in reverse, with little or no warning</td>
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<tr>
<td>• No ability to understand another person’s point of view</td>
<td>• May start off wanting to drive the car, but then may just let go of the wheel and start to fasten and unfasten their seatbelt over and over</td>
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<tr>
<td>• Do what is liked — avoid what is disliked</td>
<td>• Pulls all the knobs off the controls and puts them in their pocket</td>
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<td></td>
<td>• Says they want to “Let’s go!” but won’t get in the car</td>
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<tr>
<td></td>
<td>• Will not get in the car for over 2 hours, but then suddenly gets into the car and says, “come on, let’s go!”</td>
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<td></td>
<td></td>
<td>• Car copy you for simple actions — hands on the steering wheel, waving to others</td>
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<td></td>
<td></td>
<td>• Singing along with a favorite station, may clap or hum along</td>
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<td></td>
<td></td>
<td>• Falling asleep on long road trips</td>
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<tr>
<td>Ruby</td>
<td></td>
<td>• Wanting to get out as soon as they get in...</td>
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<tr>
<td>• No fine motor only big movements — over and over</td>
<td>• “Are we there yet...are we there yet?... Are we there yet?...” over and over — not waiting for an answer</td>
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<tr>
<td>• Limited words, repetitive actions or motions</td>
<td>• If you get the car in gear, they may be able to steer for a while, but they can’t shift gears, and they can’t do it again, unless you show them how</td>
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<tr>
<td>• Moves forward, not backing up</td>
<td>• May repeat something they see or hear, over and over — “The Wheels on the Bus Go Round and Round”...</td>
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<tr>
<td>• Loses all depth perception</td>
<td>• May crawl into the car, across the seat, and out the other side — crawl out and do it again and again</td>
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<td>• Startles easily</td>
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<td></td>
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<tr>
<td>Pearl</td>
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<tr>
<td>• Unable to actively move</td>
<td>• Unable to sit up in the car, leans into the door or onto a partner</td>
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<tr>
<td>• Limited awareness of the world around them</td>
<td>• Generally not aware they are even in a car, but once in a great while will look out and say something like ‘It’s that beautiful’, or ‘Pretty, pretty, pretty’</td>
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<tr>
<td>• Moments of alertness</td>
<td>• May like the feel of riding in the car, especially on a long highway trip — the hum of the engine, the rhythm of the tires, drumming of rain on the roof</td>
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<tr>
<td>• Aware of sensations at times</td>
<td>• May like to feel the wind and sun on their face as you slowly cruise</td>
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<tr>
<td>• Slow to respond</td>
<td>• May like to sit and cuddle in the backseat, with a blanket over them, like you used to do when you went to a drive in movie</td>
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<td>• Ruled by reflexes</td>
<td>• May hum to old tunes on the radio</td>
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<tr>
<td>• Can over-react</td>
<td>• May yell out with bumps or direction changes</td>
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<td></td>
<td>• May suck down some of a milkshake you get at a drive thru</td>
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<td></td>
<td>• May sniff and get alert when passing by some fresh cut grass, newly mown hay, cinnamon scented bakery, or wood smoke</td>
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</tbody>
</table>

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