"FROM PAIN TO PAINT": A SYSTEMATIC EVALUATION OF ARTMAIL FOR ALZHEIMER'S, A STRUCTURED PARTICIPATORY VISUAL ARTS PROGRAM FOR SENIORS WITH COGNITIVE SYMPTOMS

(working paper)

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Abstract

Goals: This study: a) investigated whether seniors with memory symptoms or cognitive impairment (MS/CI) who participate in ARTmail, a structured creative arts activity, improve significantly in key neuropsychiatric symptoms (apathy, agitation, and depressive symptoms) over an 8-week period compared to baseline and to a control group who participated only in their usual activities; and b) solicited input from senior care community staff, teaching artists, and ARTmail participants on benefits of participatory creative arts programs and improving program design.

Methods: The community-engaged study was conducted over 2016-2017 among seniors receiving services in 12 care communities in Greensboro, NC. We used a quasi-experimental pre-test and post-test study design, and mixed methods. Seniors were enrolled in ARTmail or assigned to a control group. A survey was administered to the usual caregivers of 179 seniors, at baseline and endline of the 8-week ARTmail program. Repeated Measures Analysis of Covariance tested whether ARTmail participants significantly improved at endline in neuropsychiatric symptoms, compared to baseline, and compared to the control group who participated in their usual activities. Standard measures were used for depressive symptoms, apathy, and agitation. We also conducted 29 qualitative interviews with staff, seniors, teaching artists, student RAs, 6 ran field observations of art sessions, and took photographs and videos to gain insights on the benefits of creative arts participation for seniors with MS/CI, and on how to improve the design and delivery of such programs.

Findings: Survey results indicate that all participants improved from baseline to endline in means for neuropsychiatric symptoms. ARTmail group seniors' improvement in depressive symptoms approached significance vs. control group. For apathy and agitation, the improvement was not significantly different between the 2 groups. Qualitative results indicate a positive impact among many participants on mood, pleasure, engagement, and social interaction. Insights on program design and delivery indicated appreciation of the program, but difficulty finding budget and staff support. Suggestions for program improvement include reducing the number of art exchanges, adding more structure to the art program, and advocating for greater support for senior programs.

Conclusions: Structured participatory arts programs are pleasant and engaging activities and non-pharmacological interventions, to alleviate symptoms and improve quality of life. Our survey results suggested few statistically significant results from the arts program participation after 8 weeks. The survey may have been "a blunt instrument" to measure the positive impacts of arts participation on seniors with MS/CI. Qualitative results indicated that most seniors enjoyed the program and engaged positively with the activity and the group during the activity periods.

Executive Summary

Goals: In light of increasing population aging and longevity, societies around the world are encountering larger proportions of seniors who experience declines in cognitive function, including symptoms of memory loss. Preventions or cures for such conditions do not exist. After diagnoses, seniors live several more years and need increasing care, placing increased demands on caregivers and society. Thus, non-pharmacological interventions that engage people in pleasant and positive pastimes, and improve quality of life, are needed. Evaluations of such programs are also needed. To further this overall goal, this study aimed to: a) investigate whether seniors with cognitive symptoms who participate in ARTmail, an 8-week-long structured creative arts activity, have significant improvement in neuropsychiatric symptoms of anxiety, agitation, and depressive symptoms, compared to baseline and to a control group who participated only in their usual activities; and b) solicit input from senior service facility staff and seniors with cognitive impairment on the design and benefits of participatory creative arts programs.

The ARTmail program: was developed and manualized by the Executive Director of the Creative Aging Network NC. Based on Abstract Expressionism, which emphasizes creativity with colors, shapes, and textures, rather than representational ability, the program is inclusive of all participants' diverse abilities. Each senior is paired with a counterpart at a different care community, with 8 to 10 participants in each site. They create art in ~ 1.5-hour sessions each week, over 8 weeks. In each session, various materials, tools, and techniques are used to create art not on the traditional canvas but on the inside surface of a cardboard box. After the first 3 sessions, the box is closed up and mailed to the partner artist, who builds on the artwork started. After 3 more classes, the boxes are exchanged again, allowing the senior who started the piece to finish it. This emphasizes community and connection along with creativity. At the end of 8 weeks, a public exhibition of the collective works of art is held.

Methods: The community-engaged study partnering UNC Greensboro with the Creative Aging Network-NC was conducted over 2016-2017 among seniors receiving services in 12 care communities in

Greensboro, NC, including residential and adult day care. We used a quasi-experimental pre-test and post-test study design, and mixed methods for data collection. We sought informed consent and HIPAA consent from the seniors' legally authorized representatives, and assent from the seniors. We administered a survey to the usual caregivers of 179 seniors in the care communities, at baseline and endline about the seniors' symptoms; 104 seniors were in the ARTmail group and 75 in the control group. We used Repeated Measures Analysis of Covariance, to test whether ARTmail participants significantly improved at endline in neuropsychiatric symptoms, compared to baseline, and compared to a control group who participated in their usual activities. We conducted 29 qualitative interviews with staff, seniors, artists, students, 6 field observations of art sessions, and photographs and videos to gain insights on the benefits of creative arts participation for seniors with diverse abilities, and how to improve the design and delivery of such programs.

Findings: Survey results indicate that all participants improved from baseline to endline in means for neuropsychiatric symptoms. ARTmail group seniors' improvement in depressive symptoms approached significance vs. control group. For apathy and agitation, the improvement was not significantly different between the 2 groups. Qualitative results indicate a positive impact among many participants on mood, pleasure, engagement, and social interaction. Insights on program design and delivery indicated appreciation of the program, but difficulty finding budget and staff support. Suggestions for program improvement include reducing the number of art exchanges, adding more structure to the art program, and advocating for greater support for senior programs.

Conclusions: Structured participatory arts programs are pleasant and engaging activities and non-pharmacological interventions to alleviate symptoms and improve quality of life. Our survey results only approached statistical significance for the beneficial effects of arts program participation over an 8-week period. The survey may have been "a blunt instrument" to measure the positive impacts of arts participation on seniors with MS/CI. Qualitative results indicated that seniors showed immediate enjoyment of the program and engaged positively with the activities and the group.

Background

Estimates suggest that 13.9% of persons aged 71 years and older in the US currently have some form of dementia, and that 12.7% of those aged 60 and above report worsening confusion and memory loss (Alzheimer's Association, 2014). People with such diagnoses live for several additional years and need increasing amounts of intensive care. Neuropsychiatric symptoms, specifically apathy, agitation, and depressive symptoms, increase with the progress of cognitive impairment, and are associated with poorer patient outcomes (Hebert et al, 2003). Apathy, defined as a loss of motivation beyond what is attributable to emotional distress, intellectual impairment, or diminished consciousness (Marin, 1991; 1996). Apathy is associated with increased impairment, reduced functioning, greater caregiver burden, increased resource use, and poorer outcome for patients (Hsieh et al, 2012). Agitation, i.e. confusion or inappropriate verbal, vocal, or motor activity not explained by needs, is the most common behavioral symptom among seniors with dementia (Kong, Evans & Guevera, 2009). It is associated with poorer quality of life (Banerjee et al, 2006). Depressive symptoms, though less linked with the progression of cognitive impairment, are often under diagnosed and are associated with lower quality of life (Kartmann et al, 2011; Wilson et al, 2010). These symptoms reduce the quality of life of persons living with dementia and their care partners, increase nursing home use, caregiver stress and depression. Neuropsychiatric symptoms are "among the most significant challenges in dementia care, yet they remain under- or mis-treated" (Kales et al, 2014: 768).

A high percentage of persons live with dementia and need care for several years. We examine whether a non-pharmacological intervention: engagement in structured creative art, can improve key neuropsychiatric symptoms: apathy, agitation, depressive symptoms of older adults with memory symptoms / cognitive impairment.

Effective prevention or cures for dementia conditions and associated neuropsychiatric symptoms are not imminent. Reviews indicate that though the US FDA has not approved pharmacological treatment for these types of symptoms, such medications are frequently used for symptom management, despite major concerns about adverse effects and limited efficacy (Kales et al, 2014; 2015). Thus, non-

pharmacologic interventions that ameliorate neuropsychiatric symptoms and improve quality of life for persons with cognitive impairment are needed (Sink, Holden, & Yaffe, 2005).

Non-pharmacological (NP) treatments are recognized as part of the spectrum of dementia care for symptom relief and reduction of caregiver stress. They have an evidence base for being effective in management of neuropsychiatric symptoms especially when they include structured sensory stimulation, but their application has been limited in clinical settings, for reasons including lack of training in non-pharmaceutical approaches and not communicating these strategies to caregivers (Livingston et al, 2015). These approaches consider the interaction of individual, environmental, and caregiver factors, where unmet needs may result in symptoms (Kales et al 2014). Further exploration is needed to examine the unmet needs that may result in neuropsychiatric symptoms, and whether non-pharmacologic interventions may ameliorate these key neuropsychiatric symptoms among seniors with cognitive impairments.

Engagement in pleasant and stimulating activities, such as participatory arts, can promote positive outcomes (Buettner et al, 2011). Studies have shown that participating in structured arts programs improves physical and mental health and social functioning of older adults including those with dementia. Chancellor et al (2013) assert that art therapy programs can be beneficial for persons with dementia, because the ability to appreciate and produce art is a skill that is relatively preserved. Producing art is a means of non-verbal expression for those whose communication abilities have declined, and art engagement produces a beneficial state of 'flow'. However, evaluating participatory arts programs for seniors of diverse abilities with emphasis on improving individuals' outcomes, is a "vastly underinvestigated area" (Noice, Noice, & Kramer, 2013). Though theories in this area are underdeveloped, relevant theoretical concepts include improved sense of control or mastery, positive pathways in mind-body connection and brain plasticity, and social engagement (Cohen et al, 2006; Cohen, 2006; Noice, Noice, & Kramer, 2013). However, research that examines whether structured creative arts participation improves apathy, agitation, and depressive symptoms among seniors with memory symptoms or cognitive impairment (MS/CI) is yet lacking. Our study delivered and evaluated a

participatory structured creative arts program which enhances the creative capacity of seniors with cognitive impairment.

Our study addresses this gap by examining a group of seniors with MS/CI receiving care in Greensboro, NC. We employed a community engaged approach, with a partnership between the Creative Aging Network-NC (CAN-NC), an organization that designs and delivers creative arts programming for seniors with diverse abilities, and researchers in the Department of Human Development and Family Studies of UNC Greensboro (UNCG-HDFS). CAN-NC designed and delivered a structured participatory arts program called ARTmail (details in a subsequent section) to seniors with MS/CI receiving day or residential care services in various care communities in Greensboro. UNCG-HDFS designed and conducted the formal evaluation. The partnership examined the following questions:

Research questions

(1) Do seniors with MS/CI who participate in ARTmail improve in apathy, agitation, depressive symptoms, vs a control group who do their usual activities?

(2) How can ARTmail design and delivery be improved?

Our first research question is: do seniors with memory symptoms or cognitive impairment who participate in ARTmail show greater improvement in apathy, agitation, and depression, from baseline to end of activity period, and compared to peers who engage in their usual activities? We hypothesized that ARTmail participants will show significant improvement at endline vs a control group who engage in usual activities. We used mixed methods to address this question.

Our second research question is: how can design and delivery of structured participatory arts programs be improved to better serve seniors with MS/CI? We used qualitative methods to address this question.

The ARTmail for Alzheimer's program

The specific participatory visual arts program evaluated here is called ARTmail for Alzheimer's. The ARTmail program was developed and manualized by Lia Miller, Executive Director of CAN-NC. The overall program is flexible and customizable for many types of interest groups and populations, such

as intergenerational, multicultural, seniors, etc. The specific customization examined here is called ‘ARTmail for Alzheimer’s’, that is accessible for seniors with MS/CI, whether or not they have a diagnosis of Alzheimer’s.

In contrast to many ‘arts and crafts’ activities typically offered at senior care communities, especially for persons with MS/CI, ARTmail for Alzheimer’s stands out as a rich and thoughtfully designed program, that is rooted in art theory and art therapeutic approaches. The art creation is based on the principles of Abstract Expressionism, which emphasizes creativity with colors, shapes, composition, and textures, rather than representational ability. It is thus inclusive of persons of diverse abilities. It emphasizes and enhances the creative capacity of seniors. It intentionally fosters choice in colors, materials, and expression. This directly promotes the agency of persons whose choices may be increasingly limited due to worsening memory or cognitive symptoms and poorer health. It encourages communication and social exchange among persons vulnerable to isolation. Therefore, evaluating the ARTmail for Alzheimer’s program will examine its potential benefits for seniors with MS/CI.

ARTmail for Alzheimer’s (henceforth called ‘ARTmail’ in this report) emphasizes personal self-expression, creative exploration, and social interaction. It is delivered in care community settings. Care communities are paired for artwork exchanges between partners. There are 8 to 10 ARTmail participants in each community. Partners are chosen by having each of these participants complete a short questionnaire about their hobbies, interests, and backgrounds. Each participating senior in a community is then paired with a counterpart at the other care community (Figure 1 below) based on commonalities (e.g. has lived in New York; is a dog-lover, etc.). Art sessions lasting about 1.5 hours are scheduled to begin the same week at each partnering community and run for 8 weeks. Care community staff from the participating sites attend orientation prior to the start of the ARTmail sessions. They learn about project goals and objectives as well as basic information about room setup, reducing interruptions, and program assessment. This is an important requirement for care community participation in the program.

Figure 1: The ARTmail for Alzheimer's program

The sessions are run by CAN-NC teaching artists specifically trained in the ARTmail program. The teaching artists in this project were practicing artists from the local area with academic and technical training in art, diverse art skills (e.g. fabric art, sculpture, painting, etc.) and bodies of work in various art techniques, and prior interest in working with seniors or other special populations.

The teaching artists begin by welcoming each participant and encouraging introductions. They explain the ARTmail program and generate discussion of art-making. However, the majority of time spent in each class is used to explore materials and make art. In the first session, participants are introduced to the cardboard box as canvas and begin by priming the inside surface to prepare it for art-making in the following sessions (Illustration 1, following page).

The second session introduces the Abstract Expressionism art technique and focuses on primary and secondary colors. This is when the participants create the foundation of the artwork (Illustration 2, following page). The third session encourages participants to explore tinting and shading to brighten or express darkness of mood and increase contrast. Participants share their artwork with the class before preparing them for the first exchange by inserting their completed 'box story' into the folded and taped box, then closing and labeling it for their partner artist.

Illustration 1: ARTmail session 1: prepping boxes by priming the inside surface

Illustration 2: Beginning to create art on the prepped boxes: choice in colors and tools encouraged

The fourth session generates excitement with the anticipation of opening the boxes received from partner artists. Each partner box is received and opened like a gift. Participants view the artwork created by their partners and read their box stories. If they choose, they may share these stories as well as the artwork with their classmates. After this, they begin building on the artwork they received by using shapes to stamp patterns on the artwork with paint.

In subsequent classes they use paper and fabric to enhance shape, color, and texture (Illustration 3). Providing choice is of utmost importance as individual choices provide insight into one's personality, beliefs, ideas and feelings. Therefore, providing this freedom of expression is encouraged which results in a variety of visual viewpoints as well as an atmosphere of acceptance and mutual respect.

Illustration 3: Continuing to build the artwork: variety in materials, colors, and textures

The second box exchange means the artist who started a box canvas will finish it. This session introduces the senior artists to using line to enhance the overall design and composition. Materials used

include ribbon, yarn, markers, paper and fabric strips and any other materials the participants choose to use at this stage. The artist who completes the work has final ownership, though both participants are credited as partner artists at the public exhibitions.

With each mailing, a written 'box story' is exchanged that asks specific prompts for participants to communicate with their partner. Seniors who cannot communicate easily in writing can speak their answers to a volunteer scribe who writes them down on the form. Prompts include questions such as *"What makes you special?", What do you want to ask your partner artist?", "What do you want to tell your partner artist"* and *"Were there any surprises in the artwork you received? If so, what?"* Some of the more notable answers emphasized how the participants enjoyed creating art, and perhaps gained a new facet of identity as an artist (even while in the midst of MS/CI): "*We are all artists - sometimes we hide because we are scared. There is nothing we can't do just have to believe in yourself. Anyone can be a artist (sic)." "I feel I need more time to make it significant." "Painting is my new skill."*. Other answers showed the pleasure of receiving a gift, which emphasizes how the activity promotes social connection and quality of life: *"I never get boxes - a surprise!"* Other responses provided insight into the caring and humorous personalities of the participants such as *"I love dogs." "When I go out of the house and get a job my wife gets a check!" "I am special because my daughters take care of me. I don't drive a car. Nothing big like that." "Working together has been a pleasure - to have a partner." "Thank you!"* Illustration 4 (next page) shows senior participant artists receiving boxes and an example of a box story.

The ARTmail program design emphasizes community and connection along with creativity. Towards this goal, at the end of the 8 weeks, a public exhibition of the collective artworks is held, to which family, friends, and others connected to the artists are invited. These exhibitions are held in public venues (e.g. Greensboro Public Library, Greensboro Cultural Center), showcase all the artworks and the box stories of those who participated (Illustration 5, following page). An opening reception with sparkling cider and hors d'oeuvres provides an opportunity for partnering artists to meet one another and celebrate their achievements. These events have been extremely well received by all who attended.

Illustration 4: Box Exchange and Box Story

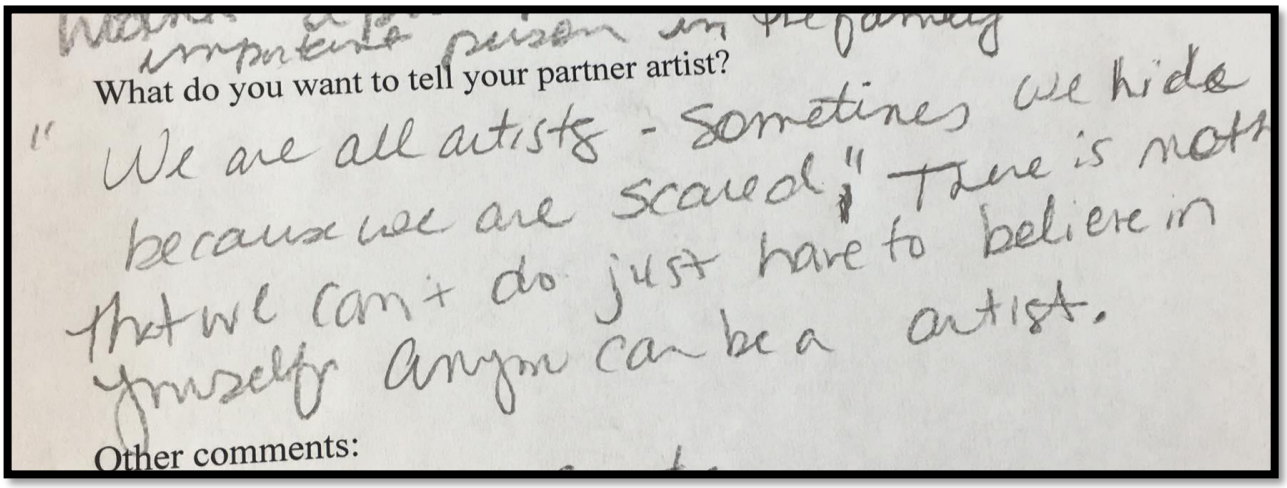


Illustration 5: Public exhibition of completed ARTmail artworks

This type of rich and thoughtfully designed program involves a higher level of costs than many simpler types of programs offered in senior care communities. The costs associated with the ARTmail program include (1) paying the Executive Director of CAN-NC for her time in program development and planning, program promotion, site recruitment and staff orientation, artist training, coordination, photography, video, (2) paying the trained professional teaching artists for program implementation, and (3) related materials and art supplies. Offering such programs therefore requires acknowledging the need to sustain and support them in financial and programmatic ways. As all societies age and people live longer with diverse conditions and abilities, there will be greater need for an array of thoughtfully designed and professionally delivered programs to enhance quality of life, and fulfill a basic human need of spending time in pleasant and productive ways. If we increase empathy towards older adults and our future senior selves, finding such support is more likely to be prioritized.

Methods

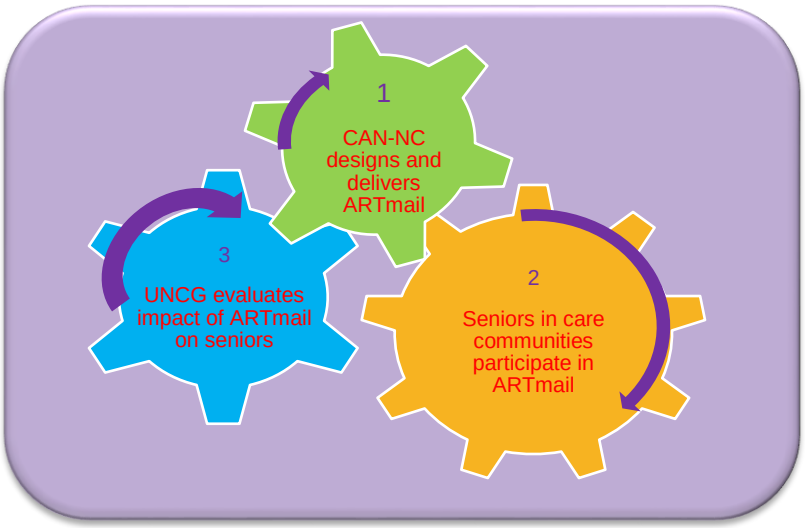
The project's first research question was to determine whether participants with cognitive impairment show greater improvement in apathy, agitation, and depression, from baseline to at the end of the ARTmail period, compared to a group of seniors with MS/CI who engage in their usual activities. The second research question was to gain insight into improvements in program design and delivery.

We addressed these questions using a community-engaged research approach, which, in contrast to conventional research, emphasizes a more equitable partnership between researchers and the community through the process of knowledge creation, from setting research priorities, framing the research questions, selecting methods, engaging with participants, collecting data, analyzing, interpreting, and disseminating results. Mutual learning and power sharing among stakeholders are key features. This approach emphasizes the equal voice of community groups and researchers in setting research priorities and determining methods. This approach is often used in health-related research, especially focusing on disparities (Cacari-Stone, Wallerstein, Garcia, & Minkler, 2014). Community engaged approaches are one strategy to promote co-creation of knowledge, which has particular potential to align the priorities of

research and service development, and move the benefits of research outside the 'ivory tower' (Greenhalgh, Jackson, Shaw, & Janamian, 2016).

In this study, the key partnership was between the community arts organization (CAN-NC) and the University (UNCG) (Figure 2). CAN-NC leadership and UNCG HDFS researchers had previously collaborated to conduct a small pilot evaluation of the ARTmail project (Sudha, Miller, Thomas, & Chia 2015). That study suggested that participating in ARTmail improved depressive symptoms of seniors with MS/CI. Senior care communities were the sites where ARTmail was delivered and evaluated. Seniors receiving care in the communities participated in ARTmail or the control group. The communities and seniors with MS/CI were also key partners in the project. However, due to logistical considerations, the communities and seniors were not full partners in planning the research design or in program design and delivery.

Figure 2: Evaluating ARTmail: a Community Based Participatory Research Project



Study design

For the first research question, we used mixed methods: a survey arm and a qualitative component. For the survey arm, we used a quasi-experimental, pre-test and post-test study design. Seniors participating in the study comprised two groups. In each study site, participants interested in ARTmail were supposed to be randomized either to ARTmail or to a control group who participated in their usual activities. The control group was to be placed on a waitlist for a future ARTmail offering at the end of the

research study period. This design allowed us to examine both within- and between-subjects effects, and their interaction over time. In practice however, study participants were entered into ARTmail on a first-come-first-served basis or on the basis of other considerations by care community staff (e.g. whether staff felt that the senior would enjoy the experience), and after ARTmail was full, the other participants were entered into the control group. This assignation of participants was outside the control of UNCG researchers and CAN-NC organization officers.

Surveys were first administered to the usual caregivers of ARTmail and control group participants, and included questions about their care recipients' characteristics and symptoms at the start of the program (baseline) and the end of the 8-week program (endline). A copy of the baseline and endline questionnaires are attached as Appendix 1 and 2.

To collect qualitative data, we employed the following techniques: (1) conducted field observations of selected ARTmail sessions, noting the numbers and characteristics of participants, time of day, and environmental conditions. Participants were specifically observed for engagement with the activity, mood, and any communication they might make. (2) Photographs were taken of various ARTmail activities and steps. (3) In-depth individual interviews were conducted with selected senior participants, site administrative staff, teaching artists and a few caregivers. (4) The endline survey questionnaire also included an open-ended question on how ARTmail or the usual activities affected the participants of the ARTmail group and control group respectively. These formed sources of qualitative information about the effect ARTmail had on the participants.

For the second research question, we used qualitative methods. We conducted in depth interviews with selected senior participants, teaching artists, and site administrative staff.

Participants and recruitment

We recruited seniors with memory symptoms or cognitive impairment (MS/CI), who were receiving residential or adult day care services in care communities in Greensboro NC. We ultimately partnered with 12 area communities including both types of care (10 residential and 2 adult day care). Our sample size goal for the analyses pertaining to the primary research question was estimated by a power

calculation using PASS11 (Hintze, 2011). Estimates of effect size were generated from data reported by Buettner et al (2011), who measured similar outcomes within a comparable population. Given an alpha level of 0.05, an expected correlation among repeated measures of 0.6, and a total sample of 148 participants, the proposed design (2-way mixed RMANCOVA with a Geisser-Greenhouse Corrected F-test) would achieve 80% power for the within-subjects factor (expected ES = 0.23), and 99% power for the between-subjects factor and the interaction term (expected ES = 0.52 and 1.68 respectively). Adjusting for a 20% rate of attrition, we aimed to recruit a minimum total sample size of 186 participants (93 in each group). We ultimately were able to enroll 179 seniors at baseline, of whom 168 also participated at endline. Of these, 104 were in the ARTmail group and 75 in the control group at baseline. At endline, these numbers were 98 and 67 respectively. This reflects an attrition rate of 6% in the ARTmail group and 11% in the control group respectively, well under the anticipated 20% rate.

Recruitment was carried out with close input and support from the administrative staff of senior care communities. The first two authors of this report made informational presentations at various community sites to solicit participation, providing descriptions of the study and a packet of paperwork including additional information and the necessary consent forms. The Institutional Review Board of UNC Greensboro approved the study. The administrative staff facilitated recruitment of seniors into the ARTmail and control groups, and to gather informed consent documentation as described below.

The first step was to gain informed consent from participants. Inclusion criteria were: seniors aged 60 and above with MS/CI. Because such seniors are a special (vulnerable) population who cannot independently consent, the consent process was very complex, comprising the four steps detailed below. We followed the principle of 'double informed consent' ie. consent from the person responsible, and assent from the senior (Beuscher & Grando, 2009). Legally Authorized Representatives (LARs) of seniors with MS/CI who could not legally consent for themselves were contacted and informed about the study. Then, consent was sought via the following steps, summarized in Figure 3:

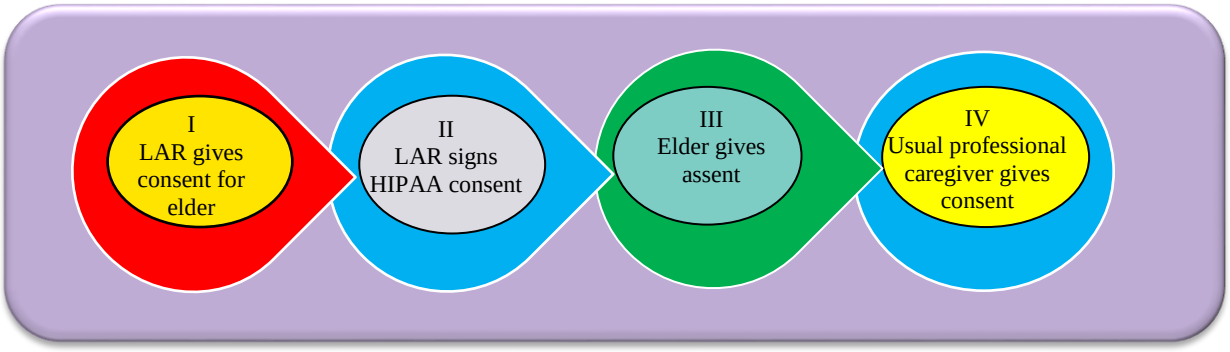
i) Informed consent was received from the LAR, which included a signed copy of the consent form or a cover email indicating consent.

ii) Informed HIPAA consent was also necessary from the LAR, since our study included Protected Health Information (PHI) about the older adult (NIH, 2004). A physical signature on the HIPAA release form was required, i.e. no emails, verbal consents, or other formats were acceptable.

iii) Assent was sought from the senior. This was gathered by reading out a very simplified description of the study. Assent could be verbal or indicated by a head nod, witnessed by a third party not connected with the study. This was typically a staff member of the senior care community.

iv) Consent from the usual caregiver of the senior was also required, since they answered the interview questions. These were directly consented, using a consent form customized for them.

Figure 3: Steps in the informed consent process



v) Consents included audiotape, photo, and video releases in addition to interview procedures and HIPAA information.

Seniors whose LARS did not consent or who did not give assent were still free to take part in the ARTmail art activity, though they would not be in the research study. Participants were free to leave the ARTmail program or the research study, at any time. There were very few cases of refusal to consent or assent, by the LARs, seniors, or usual caregivers.

Given the complexity of the consent process, the administrative staff of the participating care communities took the lead in obtaining informed consent from the LARs of the potential participants. Many LARs lived out of Greensboro or the state. Due to the paucity of time, trained personnel, and

research resources, contacting and consenting the LARs would have been an overwhelming barrier for the research team, and was more within the power of the administrative staff. Moreover, care community staff were already in frequent touch with the LARs of the seniors in their care, and would thus be more familiar to the LARs and be better able to explain the study and elicit co-operation from them compared to the research team who would be strangers to them. Outreach efforts made by care community staff to LARs to ensure consent included sending them letters describing the study, following up with phone calls, and personal interactions with LARs who visited their loved one in the care community. Despite this, many LARs did not respond to the outreach efforts (exact numbers not known) with either consent or refusal, and thus their seniors did not participate in the study, though they were free to participate in the ARTmail activity. Furthermore, the complex consent process discouraged administrative staff of 8 local area senior care communities from signing their community to participate in the study at all, despite having interest in the ARTmail program.

Other participants for the qualitative aspects of the study were consented separately. These included 4 ARTmail teaching artists, 4 site administrative staff, 2 other key informants, and 9 students. Also, 10 seniors were interviewed, but their consent was already obtained through the complex process described above. Thus a total of 29 qualitative interviews were completed for this project.

Data collection was conducted by teams of student researchers, closely supervised by the PI and the Graduate Research Assistant (GRA) who had extensive experience in human services, research, and special populations. All members of the research team had human subjects research certification. The student teams were trained in gerontology, consent processes with special populations, and survey and qualitative research methods. The research team met weekly to discuss progress, identify and troubleshoot any emerging challenges, discuss emerging qualitative results, and plan for the subsequent project activities. All members of the research team were female.

Overall, the project activities went smoothly once they started. The major effort was needed in the beginning, to enroll the various care communities and consent LARs. Many care communities were eager to have the ARTmail program offered to their seniors, but some were wary of the perceived

administrative and paperwork burden of the research arm of the study. In addition, our initial research phase identified specific challenges, such as scheduling ARTmail sessions and interviews with participants, completeness of participant records, etc., and our team developed solutions for these situations. There were no emergent concerns or unanticipated events that occurred during the project period. Following IRB protocols, the collected data were stored on password protected computers and locked file cabinets in locked University offices.

Measures

We conducted a survey at baseline and the end of the activity period using a questionnaire asked of the senior's usual caregiver, typically an employee of the care community. To examine improvements in apathy, agitation, and depressive symptoms, we measured outcomes by standard scales selected as reliable and valid measures for populations with cognitive impairment. For apathy, we used the Marin 17-item Apathy Evaluation Scale (Marin, 1991, 1996). For agitation, we used the Agitated Behavior Scale (Bogner, 2000). For depressive symptoms, we used the Cornell Scale for Depression in Dementia (Alexopoulos et al, 1998). These scales can be seen in the questionnaires attached in Appendix 1 and Appendix 2.

The questionnaire also measured a) the time of day when the interviews and the ARTmail sessions occurred; b) socio-demographic background variables: age, sex, education, race/ethnicity, marital status, living arrangements; c) functional and health status: ADL/IADL functional status, recent health status including non-routine hospital and doctor visits and proxy-rated health status; d) type of care community (i.e. residential vs adult day center); e) site ID and caregiver ID to track multiple patients in a site and per caregiver. For almost all measures, we used existing standard survey tools. However, proxy-related health status is a measure that was innovated for this study. It is measured using the same categories as self-rated health status which is an established measure of health, but in our study this question is asked of the usual caregiver of the senior. We did not directly ask seniors with MS/CI their own self-rated health status because of (1) the difficulty in communicating with some seniors with more severe symptoms and (2) the increased complexity of the consent process if we surveyed seniors rather

than caregivers. The usual caregiver is asked to assess their perception of the senior's physical health status as 'excellent', 'very good', 'good', 'fair', or 'poor'. There are no examples in the literature of health status being rated by a proxy in this way, and this measure's validity and reliability need to be established. Our original plan had been to use the MMSE to measure the senior's cognitive status at baseline, but this was not feasible due to lack of resources. Nor was this information available from the records of the care communities – who typically do not periodically monitor care recipients' cognitive status.

The endline survey also contained an open-ended question that asked what impact ARTmail activities had on participants (aiming to elicit information about impact on mood, engagement, and symptoms). For control group participants, the question asked what activities the person had participated in, and how these had affected the individual's mood and symptoms.

First, the baseline interview was administered to the usual caregiver for all participants in the intervention and the control group. At the end of the eight-week ARTmail period, the endline interview was administered.

A total of 5 detailed field observations of ARTmail sessions were conducted by different members of the research team, spread out in early, middle, and end sessions. The field observations were guided by an observation template that asked observers to fill out the date and time of the session, numbers of participants, and the viewer's observations on the atmosphere of the setting, the mood and engagement of the participants, and any other observations. The observations were conducted in different care communities.

A total of 29 qualitative individual in-depth interviews were conducted with administrative staff, artists, seniors, and students. These included 4 ARTmail teaching artists, 4 site administrative staff, 2 LARs/caregivers, 9 students, and 10 seniors. Photographs were taken of all processes and activities. Selection of these participants were based on time availability of participants, and ability to comprehend and participate in an interview (for the senior participants). The senior's ability to participate in the interview was suggested by site administrative staff and the research team member who conducted the

interview. All student team members were interviewed.

Qualitative interviews were conducted following the format outlined by Rubin and Rubin (2005) in which the conversation is guided by a combination of opening, follow-up, and probe style questions (Bernard, 2006). Opening questions asked of facility staff included: *How do you think the experience of participating in ARTmail went for the seniors? How do you think delivering the ARTmail program went for your facility?* Follow-up questions included: *Since you mentioned that the seniors enjoyed it, can you tell me more about how they showed that? Since you mentioned that the time frame was too short, how do you think that could be addressed the next time?* Probe style questions included: *Since you mentioned that seniors seemed more upbeat after the session, can you describe how you saw that? Since you mentioned that time blocks for activities tend to be 1 hour in length, is it possible to change that policy?* To interview seniors with cognitive impairment, whose voices are often lost in conventional biomedical research, we followed recommendations to be sensitive to communication challenges, kept questions less abstract or detailed, and scheduled shorter interviews at optimal times of day, avoiding late afternoons or evenings (Beuscher and Grando, 2009). Questions for seniors included: '*Did you enjoy participating in ARTmail? Can you tell us how participating made you feel? How could this program be made better for you?'* Field observations took detailed notes on the settings, participants, circumstances, and experiences of each art session observed.

Photographs and video segments were taken by teaching artists, volunteers, and students. They took photographs as the opportunity arose, to capture interesting moments. It is less likely that negative reactions or situations would have been photographed.

Our original goal had been to administer a baseline MMSE to all participating seniors to ascertain level of MS/CI severity and control for this in our analyses. However, due to lack of resources and personnel, we could not carry out this step. We then attempted to substitute this measure with diagnostic information gathered from participant records. Unfortunately, there is a lot of variability in the types of records maintained across the care communities, and we could not get information on cognitive diagnosis type or severity for most of our participants.

Analytic methods

Quantitative data were analyzed using hierarchical linear modeling of nested data (time within person) to test whether means on (1) Cornell Scale for Depression in Dementia, (2) Marin Apathy Scale, and (3) Agitated Behavior Scale differed significantly from baseline to endline, between ARTmail and control groups. Examination of the outcome distributions indicated that the Cornell and Agitation measures fit a negative binomial distribution more so than a Gaussian (normal) distribution. The Marin data was normally distributed. Age, payment method, and health ratings were included as covariates in all models.

Qualitative data were analyzed by methods that examined interview transcripts for emerging themes. These data were analyzed by the first author of this report. Photographs and video clips were also included. These were viewed and collated by the second author, who suggested notable themes.

Challenges encountered

In summary, the challenges we encountered while implementing our designed methodology included: (1) recruitment of study sites. Sites were challenging to recruit although most were interested in the ARTmail program, because of the perceived complexity of the consent process and the paperwork involved in conducting the study. (2) Some care communities enrolled fewer than the anticipated 10 ARTmail participants and 10 control group members into the study. (3) Randomization of participants into ARTmail vs control groups: in practice, staff in care communities placed participants in the different groups according to other priorities, such as on a first-come-first-served basis or whether they felt that specific participants would enjoy ARTmail. (4) Scheduling interviews with care community staff because of inconsistencies between their schedules vs that of the research team. (5) Inability to conduct MMSE screenings for participants due to lack of resources. (6) Inability to obtain cognitive diagnoses and scores, and age or education information in some instances from the care community records, because of lack of consistent records maintained by care communities. Our research team was able to find partial solutions to some of these challenges. The Director of CAN-NC made heroic outreach efforts and recruited enough care communities to participate. The research team were persistent in finding mutually convenient times

to schedule baseline and endline interviews. The other challenges however remained, and the study was conducted despite them.

Results

Research question 1

Survey results

We recruited 179 seniors to participate at baseline, and 167 of these participated at endline. The follow up rate was thus about 93%. The attrition was due to 5 deaths, 1 refusal, and 5 unable to contact. At Baseline, there were 104 participants in the ARTmail group and 75 in the Control group. At endline, there were 98 ARTmail participants and 67 Control group participants respectively, reflecting a follow-up rate of 94.2% (ARTmail group) and 89.3% (control group) respectively.

Study participants

- 178 seniors participated at baseline (104 ARTmail and 75 Control group)
- 167 were in the endline (98 ARTmail and 67 Control).
- 29 qualitative interviews included seniors, staff, artists, and research team students.
- 6 field observations of ARTmail sessions were conducted.
- Photographs and video clips were taken

Table 1 (following page), indicating participant profiles at baseline, shows that the participants were on average aged about 82 years; 77% of them were female and 23% male. Most were White, though a substantial percent: about 22%, were African American. They were evenly distributed among Medicaid, Private pay, and Don't know categories. About one-fifth had a college education, but the educational level of almost half the participants was not known, as many care communities often do not have this information on record. The vast majority of participants received help with ADLs and IADLs, as expected in this population with MS/CI. Table 1 also shows that ARTmail group and control group participants were broadly similar on most demographic covariate characteristics. ARTmail participants were more likely to be divorced and less likely to be widowed compared to the control group. The biggest difference was in the percent receiving different types of care (Memory care vs. Skilled care), source of payment for their care (Private pay vs. Don't know/missing), and whether they had gone to the ER/Urgent care in the few weeks prior to the start of the study, for reasons that are not clear.

Table 1: Sample Description at Baseline

	N=178		ARTmail grp N=103		Control grp N=75	
	Mean (SD)	**%**	**Mean (SD)**	**%**	**Mean (SD)**	**%**
Age in years (30 missing)	82.4 (9.8)		83.2 (9.9)		81.2 (9.4)	
Gender Male		22.5%		21.4%		24%
Female		77.5%		78.6%		76%
Race/Ethnicity White		73%		71.8%		74.7%
African American		22.5%		23.3%		21.3%
Other		4%		4%		3.9%
Marital status (missing 19)						
Married		16.9%		16.7%		17.3%
Widowed		52.5%		50.0%		56.0%
Single		9%		7.8%		10.7%
Divorced		10.7%		13.7%		6.7%
Payment type (missing 28)						
Private pay		33.7%		41.7%		22.7%
Medicaid		35.4%		34.0%		37.3%
Don't know/missing		30.9%		21.3%		40.0%
Education level						
Don't know		41.5%		42.7%%		38.7%
Middle school + some HS		7.1%		4.8%		5.3%
HS + trade school + some college		32.6%		32.0%		33.3%
College + graduate school		20.7%		19.4%		22.7%
Living arrangements						
Other (private home some family or senior care facility)		15.3%		12.8%		16%
Assisted living		18.1%		18.6%		17.3%
Memory care		39.5%		44.1%		33.3%
Skilled care		27.1%		24.5%		30.7%
ADL receiving help		83.1%		84.5%		81.3%
Expect to continue next 3 months		82.1%		85.4%		78.7%
IADL receiving help		92.7%		91.3%		94.7%
Expect to continue help next 3 months		94.2%		91.3%		96.0%
Health events recent (missing 18)						
ER/Urgent care: YES		18.6%		27.2%		17.3%
NO		74.2%		64.1%		70.7%
Overnight hosp stay: YES		12.2%		13.6%		14.7%
NO		80.9%		77.7%		73.3%
Non-routine doc visit: YES		19.4		29.1%		23.0%
NO		70.1		60.2%		62.2%

In Table 2, the means of some key variables are indicated, for the entire group of participants (ie ARTmail and control groups together), highlighting changes from baseline to endline. It appears that proxy-rated health declines very slightly over the 8-week period. Moreover, the mean scores on the three main dependent variables also decline, which indicates a reduction in reported symptom severity.

Table 2: Descriptive results: Comparing baseline to endline on key variables.

Measures	**Baseline Mean (SD)**	**Endline Mean (SD)**
Age	82.38 (9.74)	82.54 (9.79)
Proxy Rated Health Status	2.49 (1.02)	2.38 (0.90)
Cornell Overall	7.60 (5.67)	7.34 (5.92)
Marin Apathy	40.60 (10.19)	38.38 (9.35)
Agitated Behavior	21.91 (7.58)	21.47 (6.37)

Table 3 presents analytic results comparing the change in the Cornell Scale for Depression in Dementia, in ARTmail vs control groups, baseline to endline, adjusting for covariates. The β-coefficient for the assessment-by-condition interaction approaches significance at .08, indicating that ARTmail participation may improve depressive symptoms compared to the control group.

Table 3: Analytic Results: Comparing ARTmail vs. Control groups, baseline to endline Cornell Scale for Depression in Dementia

				Exponentiated		
Variable	β	SE	*p* -value	β	95% Conf Interval	
Intercept	2.269	0.153	<0.001	9.668	7.158	13.058
Assessment	0.032	0.131	0.808	1.032	0.797	1.337
Condition	0.247	0.139	0.076	1.280	0.974	1.682
Age	0.018	0.008	0.028	1.018	1.002	1.034
Private Pay	0.099	0.108	0.360	1.104	0.893	1.366
Health						
Excellent	-1.386	0.378	<0.001	0.250	0.119	0.526
Very Good	-1.098	0.228	<0.001	0.334	0.213	0.523
Good	-0.762	0.155	<0.001	0.467	0.344	0.633
Fair	-0.360	0.137	0.009	0.698	0.533	0.913
Poor	--	--	--	--	--	--
Assessment*						
Condition	-0.286	0.165	0.083	0.751	0.543	1.039

This is graphically illustrated In Figure 5 (next page), where the data indicate a decline in the ARTmail group participants' depressive symptoms, while the control groups' symptoms appear to remain steady. This supports the contention that participation in structured creative arts such as ARTmail can be beneficial for people with MS/CI, as compared to participation in usual activities. Participants' usual

activities, as elaborated in the qualitative results section, include TV, Bingo, arts and crafts, music, social groups, cognitive card games, etc., and vary greatly in availability and quality across settings.

Figure 5: Graphic representation of change in the Cornell Scale for Depression in Dementia: ARTmail vs Control, baseline to endline

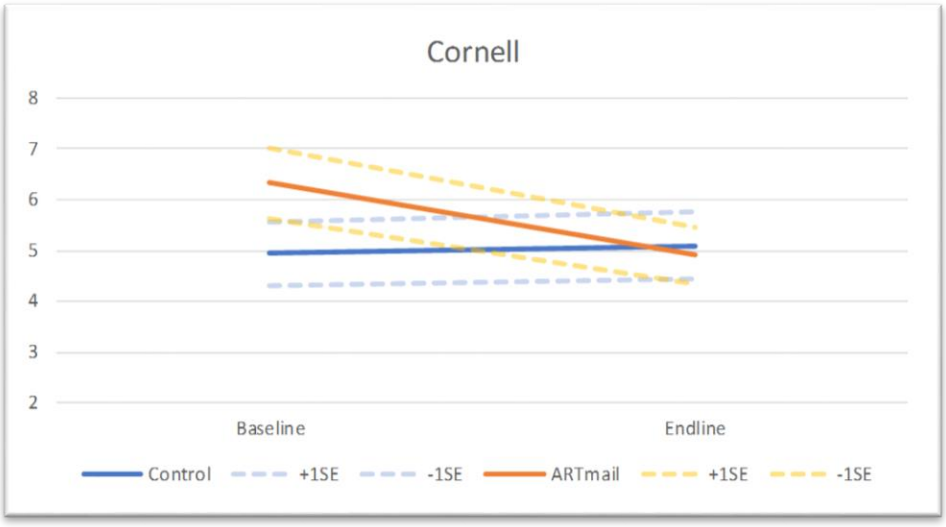


Table 4 presents results for the Marin Apathy scale. The coefficients for Assessments (baseline vs endline), Condition (ARTmail vs control), and the assessment-by-condition interaction (not shown, p = .885) all failed to reach significance, indicating that ARTmail is unlikely to have any impact on Apathy symptoms in this group of participants.

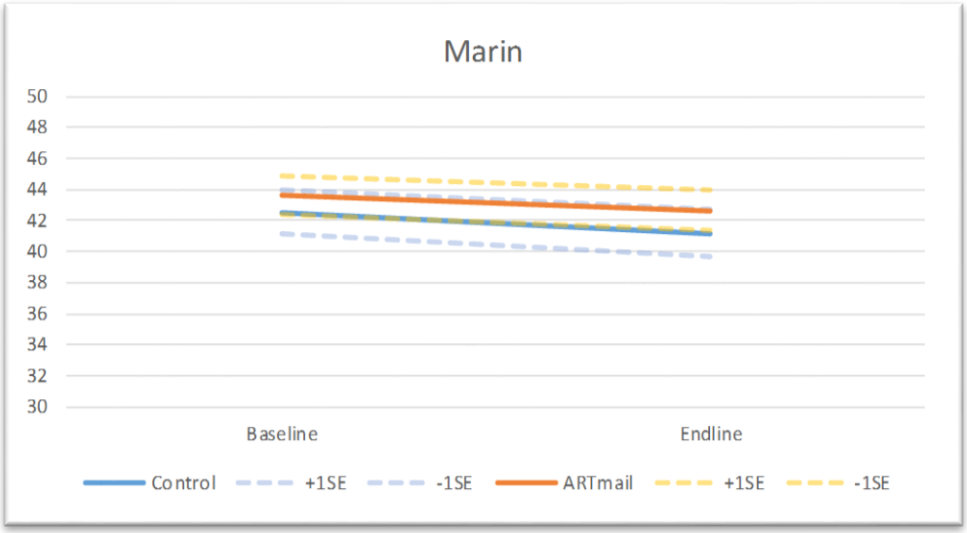
Table 4: Analytic Results: Comparing ARTmail vs. Control groups, baseline to endline. Marin Scale for Apathy

Variable	β	SE	*p* -value	LB	UB
Intercept	36.039	1.745	<0.001	32.601	39.476
Assessment	-1.141	1.049	0.278	-3.208	0.926
Condition	1.293	1.227	0.293	-1.124	3.711
Age	-0.143	0.073	0.051	-0.287	0.001
Private Pay	-1.650	1.227	0.180	-4.067	0.768
Health					
Excellent	15.032	3.806	<0.001	7.535	22.529
Very Good	13.139	2.619	<0.001	7.979	18.299
Good	5.440	1.898	0.005	1.700	9.180
Fair	2.475	1.742	0.157	-0.958	5.907
Poor	--	--	--	--	--

This is further seen in Figure 6 (next page). There graphs show that symptoms decline slightly for both the ARTmail and the control group over the study period, but the amount and steepness of the

decline remain similar between both groups. Thus, ARTmail does not appear to affect apathy symptoms in this study population.

Figure 6: Graphic representation of change in the Marin Apathy Scale: ARTmail vs Control, baseline to endline



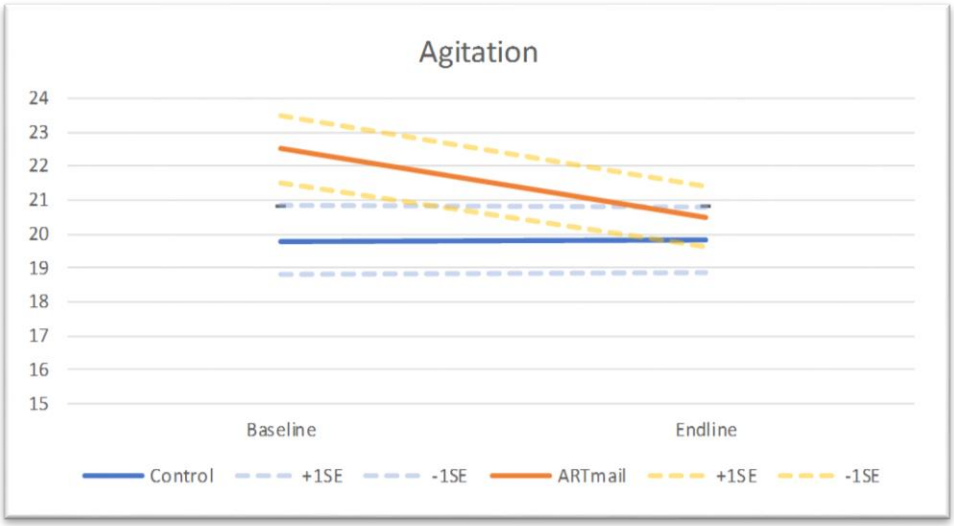
The third outcome variable we examine is the Agitation scale. In Table 5, we see that although the main effect of Condition (ARTmail vs control) was significant, that for Assessment (baseline/endline) was not, and neither was the interaction, suggesting that ARTmail did not significantly affect agitation.

Table 5: Analytic Results: Comparing ARTmail vs. Control groups, baseline to endline. Agitation Scale

				Exponentiated		
Variable	β	SE	*p* -value	β	95% Conf Interval	
Intercept	3.194	0.063	<0.001	24.380	21.531	27.607
Assessment	0.001	0.057	0.987	1.001	0.895	1.119
Condition	0.127	0.058	0.030	1.136	1.013	1.274
Age	0.002	0.003	0.454	1.002	0.997	1.007
Private Pay	0.022	0.042	0.599	1.022	0.941	1.110
Health						
Excellent	-0.479	0.142	0.001	0.619	0.468	0.820
Very Good	-0.189	0.087	0.031	0.827	0.697	0.983
Good	-0.288	0.063	<0.001	0.749	0.662	0.849
Fair	-0.135	0.057	0.017	0.873	0.781	0.976
Poor	--	--	--		--	--
Assessment*						
Condition	-0.094	0.071	0.189	0.911	0.792	1.048

In Figure 7, however, we do see a greater decline in agitation symptoms in the ARTmail group rather than the control group, suggesting that ARTmail may have a beneficial effect on agitation symptoms in the study population.

Figure 7: Graphic representation of change in Agitation Scale: ARTmail vs Control, baseline to endline



In sum, the quantitative evidence suggests that ARTmail has a near-significant beneficial effect on depressive symptoms from baseline to endline, does not appear to affect apathy, but may affect agitation (as the graph showed a steeper decline in the treatment group) though the effect did not appear significant. Another interesting finding is that the proxy-rated health variable is positively associated with feeling better on depressive symptoms, this may add evidence to the validity of this type of measure.

Quantitative findings summary

The quantitative evidence suggests that from baseline to endline, ARTmail:

1. Has a near-significant beneficial effect on depressive symptoms,
2. Does not appear to affect apathy
3. May alleviate agitation though the effect is not significant,

Qualitative evidence

Sources of qualitative evidence included 6 field observations, a total of 19 individual interviews with seniors, care community staff, ARTmail teaching artists, and open-ended answers included in the

survey questionnaire. The 10 student interviews are not reported here as they mostly concerned students' exposure to gerontology and the learning process. Other sources of evidence also included photographs and video clips that illustrated participants engagement during the ARTmail process.

The qualitative evidence indicates that participants enjoyed the ARTmail program, and observers noted a positive effect on mood, engagement, and social interaction in many cases. Mood, engagement, and social interactions are relevant to participants' neuropsychiatric symptoms of depressive symptoms and apathy. Less observation emerged regarding participants' other neuropsychiatric symptoms of agitation.

Field observations illustrated this through describing specific participants. For example, an observation of an early session described a process of engagement with the art that grew more positive. The observation noted that it took a long time to get all the participants into the session in that specific site. One participant was confused at first but was able to get some paint down after a while. Other participants were more positive. One woman was very proud of herself and the artwork she produced; one man seemed to enjoy the painting he was able to do, and another was quiet and reserved but painted his whole box and had a smile on his face.

In an observation conducted toward the middle of the 8 art sessions, the observer noted that *"Reminiscing brought smiles and laughter along with joking. Some find the art process challenging because [they were] worried about doing it right, but others encouraged them that they were doing great."* Further, *"participants who didn't engage as much with paint really enjoyed gluing textures and paper fabrics".* One unique situation was of a participant originally from Russia who did not speak English. One of her friends who spoke Russian sat with her and helped her. That was very helpful, it strengthened their relationship, improved the participant's socialization, and improved her engagement with ARTmail.

An observation towards the end of the 8-week ARTmail program described a woman who was very immersed in the ARTmail process. She had a major reminiscence episode when asked about her artwork, and recalled a fire that occurred when she was a child when lightning had struck their barn and it burned down. Her artwork reflected this event. She talked for a long time about her childhood and this

experience. Another woman really enjoyed that her partner artist was the same age, both in their 90s, and they started writing notes to each other that were incorporated into their shared artwork. The observation noted: *"the last session was sharing the art within the group … to give each piece a name … The feedback from them and to see them smile, it just gave you goosebumps."*

The individual in-depth interviews that were conducted with 10 seniors (5 male and 5 female) also revealed that their experience of ARTmail was overwhelmingly positive. In answer to the question *"how does taking part in ARTmail make you feel?"* one participant said *"I love what I am doing. I don't know what it is, but I like it."* Others' responses were similar: *"Real good … I like doing it … I would be glad to [participate again]"* or *"I enjoyed it … I am not artistic … but I like participating in it."*

Senior participants said:

"I love what I am doing. I don't know what it is, but I like it."

When I do stuff like the art … It makes me feel good … My mind goes to from pain to paint."

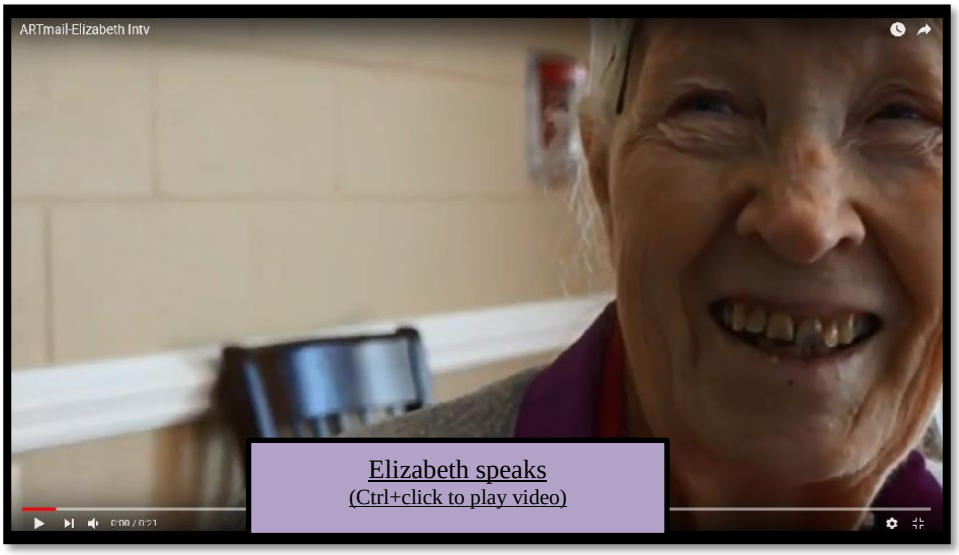
Participants responses suggested that they found ARTmail enjoyable and engaging. One man said: *"It's interesting and I like it. It gives your mind time to, um, work, and think."* Another man said: *"I kind of enjoyed it. It took my mind off other things … I was kind of nervous at first looking at it … I decided I could try to do it as well as anyone else, getting over shyness."* One woman reported that it increased her well-being by taking her mind off her arthritis pain: *"I don't feel good because of arthritis but it takes my mind off it. … and I don't feel the hurt … it hurts through the medicine sometimes. When I do stuff like the art … It makes me feel good … My mind goes to from pain to paint."*

ARTmail participation increased positive social interaction in the groups. One participant described how the group members encouraged each other: *"Some people in our group today seemed a little bit afraid … of getting started or afraid of doing it wrong … I'd tell them that they'd - if they'd just go ahead and do it, they'll learn … to love it."* Another encouraged fellow participants in the same vein, saying: *"Don't worry, don't let it make you nervous because it's a lot of fun … nothing wrong with it. You will enjoy it. … You can do any way you want with it. You can mix colors or just [use] colors that you love."* A man said: *"I just enjoy the group and the challenge and I participate as much as I can."* A 96-

year-old woman said: *"Participating makes me feel good … I can do things younger people can do … see I'm 96 years old … I'm just a person that don't like to sit still, I'm gonna want to do something, somehow, somewhere."*

ARTmail participation sparked positive reminiscing among the senior artists. A woman described how she grew up on a farm and always had to be creative *"make things out of anything … we didn't have dolls so we'd have to make a doll".* She had always enjoyed painting: *"I always liked to paint. … it made me feel like the old times … I enjoyed it."* A man who was a veteran said: *"I like the colors … and like to draw the cars and … stars … everything I was doing was World War II … it made me feel pretty good."*

Participants reported enjoying the ARTmail program structure and design. One woman said: *"One color, it don't look good … I like to do it with different colors … I painted the whole thing … Mine looks good."* Another said: *"I like you can just do what you want to".* The interviewer probed: *"So you enjoyed that freedom?"* She replied: *"I sure did … It is different, and we need something different and we love it because it is different. … It takes my mind off why we are here. I think there is an artist inside in all of us. When you ask everybody what is your favorite color, red, pink, yellow, blue, gray or black whatever … They all start with that. They can paint a picture. Everybody can do a little something."*



Two seniors described how ARTmail was different from what they had expected based on their preconceived ideas of an art program, but they enjoyed it nevertheless: A woman said: *"I do really like it*

… I didn't think I would at first. I didn't know it was gonna be like that. I thought it was gonna be like drawing and stuff." A man said: *"I didn't come to start putting, um, you know, this stuff on a piece of cardboard, that wasn't my thing, not really. … That's not what I pictured before I got here … That wasn't something I was looking forward to doing. … Uh, square boxes like this, this is all new. I hadn't ever did this stuff like this before. … But, I love it … I'm getting in to it. It's good, you know."*

Interviews with site staff and teaching artists also corroborated that they had observed positive effects of ARTmail participation on the senior artists' mood, art engagement, social engagement and reminiscence. With regard to mood, a teaching artist said that after participation, many seniors experienced an *"art high"*. With regard to engagement, a site administrator said: *"seeing people who aren't typically engaged in things … really trying to be engaged and trying to finish … you know they wanted their whole box done they didn't want to leave any part of it blank … and the interaction that some of the residents were talking even to some of our volunteers and staff that typically don't engage in things and talk it was good."* A teaching artist, describing the ARTmail program in a care community that did not provide much activity programming for its members said: *"you saw how much the participating [senior] artists craved that time, the creative outlet, the socialization, the attention, they soaked it up … you see how much these people got out of it. So that was incredibly powerful."*

A site administrative staff member's insight:

"Seeing people who aren't typically engaged in things … really trying to be engaged … and the interaction that some of the residents … that typically don't engage in things and talk it was good."

It took time over the 8-week ARTmail program to get some of the participating seniors comfortable and involved with the program and build their confidence to participate, but once they began, they were very engaged. In an illustrative example, a teaching artist described a woman who refused at first to participate in ARTmail. She had formerly been an artist who had painted realistically. She sat during the first three sessions and refused to participate. The community staff member said *"Well, she doesn't do anything, she's really pessimistic about everything all the time, so you know if she doesn't do it that's okay. I've just invited her."* In the fourth class the teaching artist described: *"I sat down and*

chatted with her about her knowledge of the arts and asked her if she had heard of abstract expressionism and she said, 'oh yeah, I know, yeah.' And I said oh good, well then, you're a pro, I don't need to explain it to you, you already know how to do it and she said 'Yeah.' … So … I put the brush down and the paint and everything beside her and walked away and … she started painting. And she continued to work on through the end of the project and … she stayed the whole time, everybody had cleaned up, everybody had left, and she was still working on her box."

This teaching artist further observed about the participants' engagement: *"it's like participants who don't engage in anything else were engaging in ARTmail … At first they may get up and leave … but by the end there were people that were sitting and engaged and doing something, where they really wouldn't do stuff before. So it was very rewarding."*

Improved mood and engagement went together. A woman participant in the beginning was unable to focus for even a very short time, and would search for her father and get weepy and agitated, but by the end of the project she was staying longer and began to engage for 10 minutes at a stretch, which was a big change for her. Another man wouldn't engage with anyone in the early sessions and behaved gruffly (he said *"this is c$@%"* and walked out of an art session), but by the end he was smiling, engaging, and trying to chat with people. This was a marked contrast to the beginning.

Another teaching artist who had led ARTmail in four communities described her observation of the effect of participation on the seniors' mood and engagement. In one community she observed: *"I saw a lot more laughter happening, socialization happening, yeah, they were just in a lighter mood, they would talk more to each other and to us. They would also start to share more about their life experiences. It was really neat. It was such a powerful and obvious change from start to finish."* In another community where the participants were all residing in the memory care unit (i.e. their MS/CI was more severe or disease more advanced), she described: *"Their willingness to participate increased, even though I don't think they really had a good memory that they had done it the week prior … it wasn't a struggle to get them interested in what we were doing. Most would participate the entire time ... stay and remain*

engaged. Did I see a difference in their mood from start to finish? Not really because their dementia was pretty advanced."

In a day program community (i.e. participants whose symptoms were less severe), she reported more social engagement among the participants: *"as the ARTmail program went on, they all started encouraging each other. Like they would pick up the art and show it to each other, … talked about what they worked on, and it was really obvious they encouraged each other 'that's nice' … or 'I like how you did that'. Their cognitive level was such that they could do that."* In fact, after ARTmail was over, this community and one other began an ongoing Art Club that meets now monthly for creative art activities. Thus, it appears that there were different types of positive effects of ARTmail participation that varied with the severity of the seniors' underlying MS/CI condition.

Teaching artist's takeaway:

"The takeaway I got from it as a person who works in the field is that the [consistent] intimate group experience … can be very therapeutic and powerful for the participants and the staff … ARTmail has shown me the importance of encouraging somebody's own creativity rather than everybody doing the same thing."

The teaching artist summarized: *"The takeaway I got from it, as a person who works in the field, is that the intimate group experience if it's consistent can be very therapeutic and powerful for the participants and the staff. In regular programming the intimacy is neglected and we forget how important it is. These folks crave the consistency and being part of something, whether or not they really know what's going on … ARTmail has shown me the importance of encouraging somebody's own creativity rather than everybody doing the same thing."*

Additional insights came from answers to the open ended endline survey questions about how ARTmail had affected participants, and what activities control group seniors had done instead and what effect those had on them. Out of the 179 interviews, 26 did not have answers to these questions, 16 of these were in the Control group, 8 of the no-answers were due to death of the participants. The answers on the impact of ARTmail were overwhelmingly positive. Predominant responses commonly included words such as *'engaged', 'enjoyed', 'happy', 'loved it'*. Typical examples of responses were: *"enjoyed*

the project and engaging with others" Or *"She loved doing it. She loved arts, the texture, strings, and usually engaged for 45 minutes. It is awesome for her"* or *"ARTmail had her engage in activities that she would not do. Given a choice, she would sit on the couch. ARTmail showed what she was capable of."* One unusually detailed response noted: *"ARTmail has a significant impact on this resident. She used to be agitated and easily distracted. During ARTmail she was very calm and focused. I took a picture and sent it to her daughter. Her daughter said she had not seen her mom smile like that for years. After ARTmail is over, she is now more calm … I am able to redirect her easier now. She used to come to the activity room and distract everyone. I had to take her out of the room. ARTmail significantly changed her mood."*

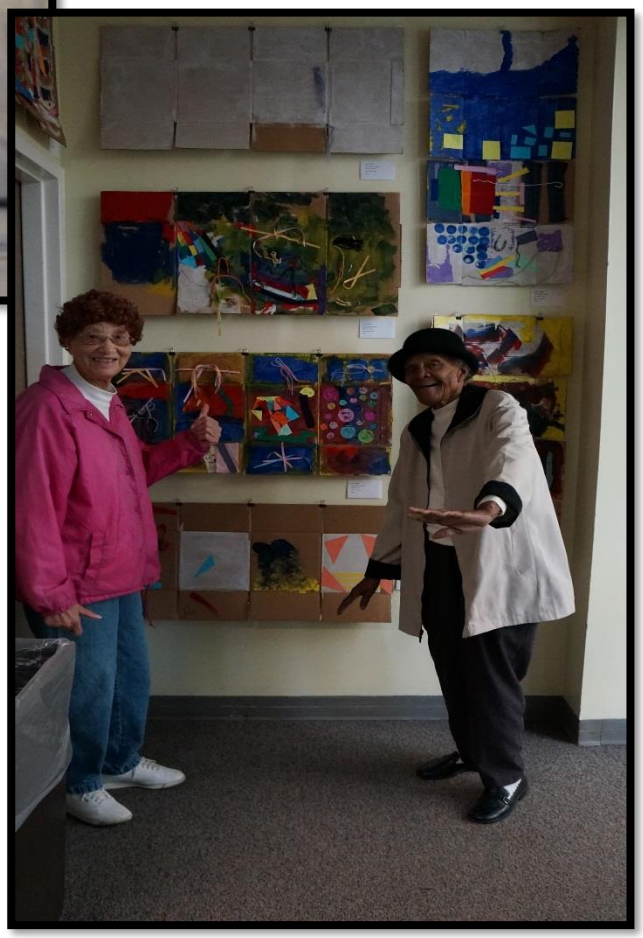
Only about 10 responses about ARTmail group participants suggested that they did not engage, or did not enjoy it, or did not participate. Such responses typically noted: *"She got agitated easily and after 20 mins said she was done"* or: *"Art did not have an effect on her because she had so many other issues going on [multiple psychiatric diagnoses]. Her anxiety was through the roof, and she was not able to participate in the ARTmail sessions. She would worry about when she was going to be picked up."*

Control group members engaged in activities such as TV, Bingo, cognitive card games, music, social groups, and arts and crafts. Responses also mentioned that they were happy and positively engaged in these activities, but less markedly so. An example states: *"Music entertainment. Sensory stimulation: she enjoys it, sings along with songs, enjoys being outside, enjoys watching TV"* or *"She just sits in one place unless the caregiver prompts her to do mainly arts and crafts"*, or *"He sits and takes a nap, or complains"* or *"Bingo, social gatherings, occasional discussion groups. Social, sometimes needs reminders to engage."* In sum, the open-ended responses gave the impression that ARTmail participants were more positively engaged and affected compared to many of the Control group participants.

Photographs also indicated enjoyment and engagement with ARTmail. Photographs were organized into themes illustrating some ARTmail goals, and a few representative pictures selected for each theme. The first theme explored was enjoyment of social connection (Theme 1, following page). The enjoyment of social connection occurred not only during the ARTmail classes, but also spilled over to the

public exhibition of works, where some partner artists enjoyed meeting each other in person for the first time and took pride in their shared creation (Theme 1, fourth picture, also relevant to Theme 4).

Theme 1: enjoying the social connection



The next theme captured in many photographs was that of uplifted and happy mood while participating. Examples are seen in Theme 2.

Theme 2: uplifted and happy mood

Another theme that clearly emerged was that the ARTmail creation process deeply engaged the participants, perhaps inducing a state of 'flow' as seen in Theme 3.

Theme 3: deeply engaged in the creative process

At the end of the program, the participant artists typically exhibited great joy and pride in their creative achievements (Theme 4, also Theme 1 picture 4). The artistic quality of their creations is evident.

Theme 4: pride in artistic creation

The next theme (Theme 5) that emerged was the close involvement of the teaching artists and volunteers with the participants. This may differ from many conventional arts and crafts programs offered in senior communities and is another hallmark of the high quality of ARTmail. This is another way of fostering social engagement which in turn affects mood.

Theme 5: close involvement of teaching artists and volunteers during sessions

Overall, qualitative findings indicated that most senior participants greatly enjoyed participating in ARTmail and it appeared to improve mood, engagement, social interaction, and reminiscence during the sessions. The qualitative data were not able to illustrate how long these benefits continued after the ARTmail sessions.

Qualitative findings summary

Most participants with MS/CI greatly enjoyed participating in ARTmail and it appeared to improve mood, engagement, social interaction, and reminiscence during the sessions.

Research Question 2

The second research question investigated ways to improve program design and delivery of structured, participatory, visual arts activities for seniors with MS/CI. This question was addressed through qualitative methods including individual interviews with administrative staff, caregivers, teaching artists, and senior participants. As described previously, the ARTmail program involves 8 weeks of weekly art sessions, lasting approximately 1 to 1 ½ hours each session. The sessions are run by a trained teaching artist, supported by a volunteer (where available) and a care community staff member. About 8 to 10 seniors are involved in ARTmail in each senior care community. Care communities are paired for the art exchange. Every senior in each community is partnered with a counterpart in the paired community, and exchanges artwork-in-progress with that partner. The art, created on the inside surface of a cardboard box, is developed over 8 sessions, and boxes are exchanged 2 times with the partner artist. The partner artists build on each other's work, and each person ends up with the art they began. At the end of the program, the artworks are exhibited publicly and family, friends, and community are invited. Program costs involve paying for materials, manual preparation, artists' time, and coordinator time.

We identified four main types of challenges for program design and delivery. First, there are structural demands on the time, material, and personnel resources of the arts organization that provides the program, and the care communities that offer the program. This leads to challenges in supporting the program and repeating it with successive groups. Second, there is lack of interest in and preconceived bias against participatory creative visual arts programs for seniors, among decision-makers in some care communities who underestimate the interests or potential for participation among those they serve. Third,

the content of ARTmail: based on Abstract Expressionism, emphasizing choice in colors and materials, and exchanging art boxes 2 times, places specific demands on participants and organizers that include advantageous and challenging elements. Fourth, some characteristics of the senior care communities influenced the potential for success of the ARTmail program. Although ARTmail has been refined over consecutive offerings, the current study offered additional insights on challenges and solutions to ongoing improvement of program design and delivery.

Regarding the first challenge, qualitative interviews indicated that the administrative staff of several of the care communities appreciated ARTmail. One said *"I would love it if I could get something ongoing for that … it's a wonderful project … since we have three different areas we could exchange boxes with people … within our same community."* Another said *"it's a free … grant funded program and to me being an activities director … it's a dream sort of program because you don't have to worry about funding, you don't have to worry about staffing."*

However, financial constraints were of major importance. When it came to paying for the program, some communities were less enthusiastic. Concerns were expressed about finding the budget and the on-site staff time for it. One activity director (AD) candidly observed: *"you know our budget is c#$%"*, and another said *"we will never be able to get approval for this"* (if it was not an externally grant funded activity). According to informants, senior care communities typically have larger budgets for marketing than for actual program activities for seniors, that is, they tend to promise more activities than they deliver. They also are often not supportive of staff time being directed away from actual caregiving activities. The better-resourced communities were supportive of ARTmail and willing to pay for the program, while other communities were not. Thus, financial issues pose a structural challenge for ongoing delivery of the program to senior care communities, despite the great enjoyment and likely benefits derived by the participants. Program improvement in this area necessitates that management of senior care communities allocate sufficient budget to provide quality programming for seniors.

Regarding the second challenge, raising awareness among care community staff, specifically ADs, about the benefits of offering participatory creative arts programming for seniors, was identified as

another systemic need. ADs in some communities decided whether or not to offer programs based on their individual interests rather than considering the wide range of interests and needs of the seniors receiving care. For example, some communities contacted for this project decided not to sign on to ARTmail because the AD did not have a personal interest in visual arts, even though many of the seniors in their care might have been interested. The Executive Director of CAN-NC described one such conversation with an AD of a community she was attempting to sign on: *"She [the AD] said "you know, I'm not a visual artist I'm a dancer and ARTmail, it just wasn't my thing" … that's what I'm dealing with, that kind of mindset of: well, "art is just not that important; visual art's not my thing; I don't know how to do it so I'm not comfortable with it" … And I reiterated that it's not about her, it's about the 48 people that she serves."*

Further even in some communities that had signed on for ARTmail, the ADs and staff needed encouragement or education to remove preconceptions or biases about the abilities of seniors. The CAN-NC Executive Director described: *"it's that kind of thing that it takes educating the staff, … then they still have to have buy in … I've heard so much like "my participants aren't going to engage for an hour, they're not going to engage for 90 minutes, that's a long time."* However, the ARTmail program experience clearly showed that seniors with MS/CI engaged successfully with the art sessions for longer than expected, even after initial reluctance. Addressing such preconceptions is essential to promote successful design and delivery of a variety of high quality programming for seniors, that aims to enhance well-being and quality of life, over and above just filling time and managing behaviors or symptoms.

Another teaching artist who had led ARTmail in four communities corroborated this observation. She described: *"I work in another facility where budget isn't an issue, but there's a lack of understanding of the benefits of art, how it can increase self-esteem and imagination, and sense of purpose … when people look at budgets they see areas that can be cut, that's really a shame. The materials we use for ARTmail aren't costly at all. So, it's a lack of understanding of the benefits of creativity in older adults. They may say that they provide programs but I didn't see any evidence of it. A lot of people sitting in one big room, TV blaring on one side. …."* In another community she described the disinterest of the ADs:

"the AD … spent all of 5 minutes with the group… she was supposed to be there the whole time … She wasn't invested in this at all … If she had prior training and understanding on how this could benefit residents, I like to think she would have been more invested … The AD over in memory care would be there but it seemed like she hated her job … I am not sure what her deal was. I feel for a program or activity, the success is measured by excitement of the staff ... The participants weren't encouraged and if they are not encouraged with enthusiasm, you lose them. This I strongly feel was the direct result of lack of empathy and enthusiasm from the staff … This was not due to shortage of funds, this place was nice."

She emphasized the contrast in another small care community that was not very wealthy: *"A key factor was that 1 or 2 of their activity staff was always present. … Even the support staff, the CNAs in memory care … were really supportive, there was a really nice atmosphere. … it was a success, and a huge part of that was the environment was set up for us and the encouragement, as the activity staff understood the purpose of what we were doing. … Their AD did a lot of arts and crafts anyway. They had music going, they had a lot of artwork displayed, very colorful, they would change things out … their environment was very personalized with pictures of the residents up. This was really homey … As far as ARTmail, because they were well cared for and there was a comfort level, it was easier to get everybody to participate, and be engaged for a long period of time … we did see some behaviors but they were easy to redirect."* This adds to the evidence that the awareness among care communities' ADs and support staff must be heightened to remove preconceptions about the creative capacities of seniors, and the benefits of supporting quality participatory arts programming for seniors.

This same key informant had prior work experience as an AD, and provided insights from that perspective: *"ADs think they have to provide an activity where they have to see a concrete outcome, rather than let participants do whatever they want and just create … let people go into the zone and experience the flow, mixing colors and paints. But a lot of times the AD and staff are too 'in the box'. … I would really hope for activity programs to help older adults engage in their creativity … get into sensory experience ... there is no pressure to have them communicate, they are more at ease, their guard is down,*

it's engaging a different part of their brain, they seem to connect better ... I want ADs to not feel that a certain activity has to produce a specific product, it has to be an experience."

The third challenge related to ongoing review and refinement of the design and delivery logistics of ARTmail. The program has already been adjusted over prior iterations, as described by the Executive Director of CAN-NC: *"the program … was 12 weeks long and the staff was like "this is just too long" ... So we cut it to 10 weeks and 4 exchanges. And that worked well but was still … just a lot of work. And so this time I cut it to 8 weeks with 2 exchanges … [but] people, while their memories are impaired, remember … to some level they're like "this isn't my box." … I guess the first couple of classes moved into their long-term memory because one person was like "I put yellow dots here, on this side, this isn't my box." I'm like, it's your partner's box … I tried to explain … I along with the teaching artists from those first 2 sites decided to go ahead and simplify it to just 2 exchanges instead of 3, ensuring the artist who started a work of art also finished it."* Thus, further simplification of the ARTmail for Alzheimer's program would make it easier for the senior participants and improve program design.

Decisions about the length and timing of ARTmail sessions had to balance optimal program design with care community schedules. The Executive Director of CAN-NC reflected that: *"I wish [ARTmail] was 10 weeks long again, and I think the participants would engage in it and enjoy it, but I'm not gonna … because the culture at these sites is so focused on monthly calendars … and they don't like something starting … or ending in the middle of the month. … I would like to be able to have longer classes … It just makes it very challenging to have the discussion at a comfortable pace in the beginning and the end because you're like quickly showing the materials and then trying to get people engaged and working on it so that they can get in that zone where the health benefits take place."*

The senior participants interviewed also shared suggestions for program improvement on the third issue. The voices of seniors with MS/CI are rarely incorporated into research, and this study provides insights from them on how program design and delivery can be improved for them. The prior section had described how the majority of them had greatly enjoyed the program. Suggestions for improvement from a few participants presented here indicate that the freedom emphasized by abstract art might be

overwhelming for some. Senior 1 said: *"I would like to do more painting"*. This was echoed by Senior 3: *"give us more things to paint … give us more ideas what to paint … I like to draw people … and faces … I'd rather have something in my mind that I want to do."* Senior 4 also expressed a wish for more concrete representation, and intergenerational engagement: *"maybe more pictures of young people playing. I'm interested in young people … in children … because you can do so much with them. They have so much to learn and if they do something like artwork, just [stay] out of trouble."* Senior 5: *"maybe we can do some other things … maybe something that's already, uh, a drawing and I could just paint it, I would like doing that, I like coloring … Something more put-together … That I can — I can decorate it, that's what I would like."* One participant did not enjoy the box exchanges. Senior 10: *"I would like a little bit more time with what we're doing here. … I would like to have somebody doing the artwork that they like. Not something you're going to push and pull somebody and trade off, nuh-uh".* In summary, the senior participants who did share suggestions for program improvement would like a few more concrete ideas for the art, more time spent on the art creation, and less emphasis on box exchanges.

This recommendation for simplification was corroborated by the Executive Director of CAN-NC. She suggested: *"Instead of having the paper and the fabric in the same class I'm going to break that down to two different classes … it was confusing for the participants. It's like they had too many choices … like piles of stuff. Here's paper, here's fabric, the paper is more of a visual component, more shape related, even though we had some sand paper for texture, and the fabric is more … really focusing on the texture. So I think that would be more understandable for the participants … there needs to be more time just with the fabric to enjoy and to really talk about the textures … There's lots of different fabrics … lots of different papers, different weighted papers, tissue paper … so with the paper we need to focus on more of the transparency, shape, and repetition, and with the fabric we need to focus more on the texture."* In sum, suggestions underscored the need to further simplify program materials and to balance the freedom of abstract expressionism with some concrete instructions for seniors with MS/CI.

The fourth pathway to improvement in program design and delivery lay in the characteristics of the senior communities. These included the physical space where the program was held. Some

communities had a designated room for the activity, which promoted its smooth and uninterrupted functioning. Others had to share a room with various other activities, which distracted participants and impeded the flow of the program. The teaching artist who had led ARTmail in four communities observed about one site: *"They didn't have a designated space … just let anybody come in and out as they wished. Another difficulty was the noise level. There was a huge activity room with a lot of residents coming and going, yelling going on, staff members were unaware of what was going on and they were a disruption too … One time they had a school group come in. Or sometimes they would play a loud game. Also, we were trying to keep the seniors involved in their work and not break their focus, and the staff would come up and give them a snack in the middle. We were like OMG please don't do that. … This is not the only place where things like that happened."* This situation was attributed to the resource shortages, the ADs being short-staffed, and the community including people with a wide range of care needs. The emphasis was more about crowd control than person-centered care. There were also budget constraints. This again reflects a systemic issue affecting senior services that needs structural solutions, outside the realm of program design and delivery.

An adult day care program presented a different challenge. They did have a designated room, but it was a boardroom, so ARTmail teachers were a little worried about spilling materials and making the room messy. The advantage however was the room's privacy. Day programs had scheduling issues with different overlapping programs: *"they don't have control over the times, sometimes the van driver would come in mid-session and they would have to leave. This really interrupted the flow. This didn't happen a lot, and we tried to get there earlier … All of their medical providers - dentist, doctor, physical therapist are there, and you have to coordinate that. … if their activity staff scheduled BINGO on a day we had ARTmail it was difficult to get them. It really didn't happen a lot, or they would come in and rush through and make it back to BINGO. ... Again, we had great support from the staff, although it was a boardroom it was private, so the group of participants really started to get to know each other."*

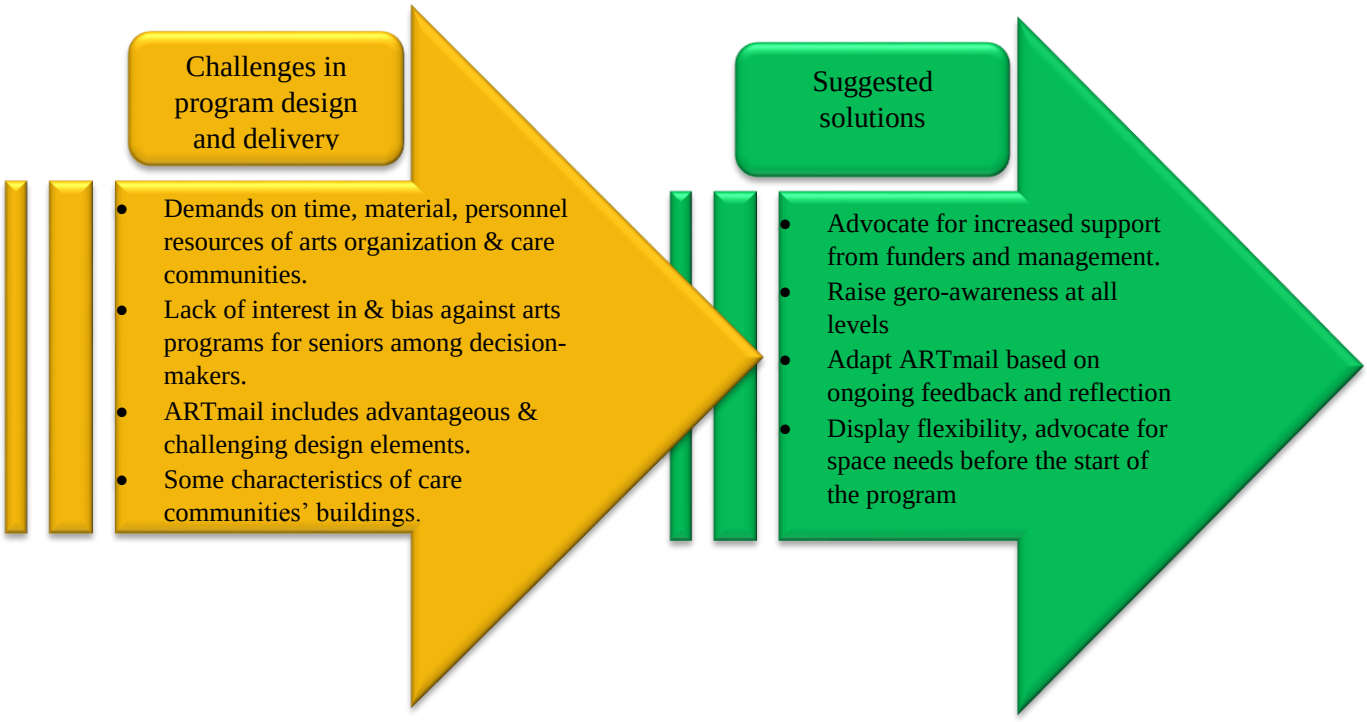
Another teaching artist shared additional logistical suggestions: to have more background information on each participant: their histories, interests, and current struggles; this would make it easier

for the teaching artists to make individual connections with them. Next, she suggested *"create groups and pairs with similar cognitive levels, so that the connections in the group would be easier, but this might be impossible to do. Have appropriate tables: rectangular, set up in a U configuration, would be the best. Some communities had round tables, that were less conducive to the class structure, since the teaching artist would be behind a person rather than in front. The round tables were also more difficult for persons using wheelchairs."*

Observers and informants noted that communities where the sessions were well-organized and smooth running, tended to remain that way over the course of the 8-week program. Other sites, where there were organizational difficulties such as lack of staff assistance, no volunteers, many residents with severe symptoms, participants brought late, CNAs or staff creating inappropriate interruptions (e.g. watching videos on their phones, carrying on loud side conversations, TVs on all the time etc.) without regard to the art participants being distracted, tended to remain that way throughout. Thus, organizational culture shaped program delivery in each site, and there were no within-site changes or trends.

To summarize (Figure 7 below), our study identified four challenges related to program design and delivery. Only one of them was rooted in the actual program characteristics. It called for further simplifications of the ARTmail program, e.g. separating specific elements (e.g. use of paper and fabric as materials) into different classes, and adding a little more concrete representation for participants who were finding abstract art difficult to grasp. The other three challenges are more rooted in societal and structural issues that affect senior-focused program design and delivery, but are beyond the individual scope of those who create programs to change. These include prioritizing sufficient financial support for quality programming for seniors, educating administrative and care staff to reduce preconceived bias about the creative capacities of seniors, and providing room and space in senior communities for various programming and activity needs. These issues are related to financial constraints and to a pervasive atmosphere of ageism in society that is found even among those who serve the senior population. This affects attitudes towards capacities of older adults and the need to allocate sufficient resources to promote quality of life among them.

Figure 7: Challenges in program design and delivery and suggested solutions



Discussion and Implications

Many prior studies of the effects of participatory structured arts on the well-being of seniors had several shortcomings, such as being conducted with limited samples or without a rigorous study design, or not including participants with cognitive declines. Our own prior pilot study indicated that ARTmail participants with cognitive symptoms could improve from baseline to endline on depressive symptoms (Sudha, Miller, Thomas & Chia, 2013). That study however did not include a control group. Our present study addressed the issue with a sufficient sample and a rigorous research design including an intervention and a control group, using mixed methods. Our statistical results were not significant at the .05 level, but approached significance regarding the beneficial effect of ARTmail on depressive symptoms and agitation, and the graphic representation of these two domains showed a greater downward trend in symptoms among ARTmail participants vs the control group over the 8-week project period. Our qualitative results on the other hand documented and supported the idea that the high-quality structured arts participation was a pleasant pastime that participants enjoyed greatly and showed evidence of improved mood, social engagement, and activity engagement during the sessions. This in turn adds

evidence for the benefits of non-pharmacological approaches to provide pleasant and engaging pastimes for seniors with MS/CI to improve mood and engagement even in the short term, and reduce sole reliance on medical approaches that focus on symptom or behavior management.

Regarding the statistical analyses, our study used CBPR methods, enrolled a robust sample size and had both intervention and control groups, and included a very thoughtfully designed and rich art program. Despite this, we faced some shortcomings in executing the planned research design, specifically our inability to measure cognitive status of the participants, and to rigorously randomly assign them into intervention vs control groups. These may have affected our results by obscuring the impact of the arts program. Further, it may be likely that our choice of dependent variables and our 8-week time frame were not sensitive enough to capture the daily positive changes resulting from structured participatory creative arts. Data collection that focuses on measurement after each art session, video coding techniques, or other measures might capture the outcomes more sensitively (e.g. Mason, 2010; Rubin & Rubin, 2005). Also, the choice of dependent variables do not capture measures of quality of life, which may of greater importance than symptom reduction. Studies should investigate subjective wellbeing and enrichment of quality of life, rather than management of deficits, in order to strengthen the evidence base to ensure that persons with cognitive symptoms get the services they want (e.g. Beard, 2011: 633) as "strictly allopathic methodologies will continue to fall short of adequately evaluating what are deeply idiosyncratic psychosocial issues". Further, as argued by De Medeiros et al (2012:352), cultural arts interventions offer "tremendous benefits" to people with dementia, their caregivers, and the communities where they live, fostering creative expression and meaningful experiences, "the essence of which are beyond measure".

Our study was conducted with a community based participatory research (CBPR) design, that aimed to balance the input, priorities, and decision-making across key partners, specifically the University of North Carolina Greensboro (research), and the Creative Aging Network NC (art program design and delivery). Though seniors in care communities were key players in this project, and assistance of care community staff was vital in securing 'double informed consent', the staff and administration could not be included as full partners in the CBPR design due to logistical considerations and lack of sufficient

resources. This led to a dilution of the 'co-creation' principle of the CBPR research enterprise (Greenhalgh et al, 2016), and the consequences were seen in the difficulties in finding mutual prioritization of aspects of research design such as randomizing participants to ARTmail vs control arms, lack of information on some participants' education, and other gaps. Care communities on the other hand felt that aspects of the research requirement were onerous and took time of the staff away from direct caregiving. Nonetheless, our study also included interviews from care community staff, teaching artists, and voices of seniors with MS/CI whose insights are rarely sought in research that is too often conducted 'on' them rather than 'with' them.

Our study also uncovered issues of ageism and age bias in the structural support for quality arts programming for seniors and in the views of some care community administrative staff regarding the creative capacity of seniors. While aging will inevitably affect each one of us, there continues to be a pervasive negative stereotype in our society resulting in a culture of ageism (Sargent-Cox, 2017). This "ism" is considered "acceptable" and even "normal" when most others have been strongly challenged or even eradicated, and has detrimental effects on older adults and on those who care for them. Hummert et al (1995) found that the older the person, the more likely it is that he or she will be seen through the lens of negative stereotypes, which have an impact on the self-confidence and health of older adults themselves. Negative self-images about aging among older people were associated with an average loss of 7.5 years from their life expectancy (Levy et al, 2002). Higher cognitive functioning is found among older people who have fewer internalized negative stereotypes of older adults (Hess et al, 2003; Levy, 1996). Negative attitudes toward aging are even found among care workers who are among the front lines of caregiving for seniors (Kagan, 2017). Care workers' ageist communication patterns with older adults may trigger withdrawal and dependent behaviors among the latter (Williams et al, 2016). These attitudes were evident in our efforts to raise financial support for the arts program and associated research study, in the responses of some care communities to the need for supporting quality programming for seniors, and in preconceived views of some staff about the creative capacity of seniors with MS/CI. We hope that our study results will help reshape some of those attitudes.

The topic of aging in a youth-worshipping society is of growing concern as our older population doubles in size over the next 20 to 30 years. “There’s a very, very deep level of dislike of aging in our whole society and philanthropy accepts some of that attitude,” says John Feather, CEO of Grantmakers in Aging. “Approximately 2 percent of American institutional philanthropy … goes to aging programs … that number has not changed substantially in at least twenty years”, which demonstrates a serious inadequacy of support (Feather, 2015: 68). He goes on to suggest that health-related funding would be a natural partner for aging-related programs. This information is hoped to generate movement toward changing attitudes about aging and encouraging funders to allocate more financial support to this population. We encountered this attitude when attempting to raise support for our study: health-related funders did not see support for an arts-based intervention as within their priority areas, and arts-related funders had little interest in supporting programs for older adults. Ultimately, changing fatalistic attitudes toward growing older, developing empathy towards older adults and our future older selves, and taking steps to improve the connection across generations, might be the most powerful ways to increase philanthropic investment and influence policy.

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APPENDIX 1: BASELINE SURVEY

Creative Aging Program

***ARTmail* Evaluation Instrument: special population**

Baseline

Participant #_____

Participant name _____ (Only for purposes of matching baseline to endline interview)

Usual caregiver name _____ (Only for purposes of matching baseline to endline interview)

Site number _____

Name of site _____

Type of site: ☐ Adult day care ☐ Residential care ☐ Other

ARTmail group ☐ Control Group ☐

Name of Interviewer _____

Date of Interview _____

Start time of interview _____

Approximate number of minutes taken for the interview_____

Any comments

_____

_____

_____

_____

To Interviewer: At the end of the interview, thank the participant for their time and participation. Offer to answer any questions they may have, or ask if they want to say anything more.

I. Demographics (one answer each): ask caregiver

1. Current Age

_____ (years)

2. Gender

- Male
- Female
- Other (describe _____)

3. Hispanic/Latino

- Yes
- No

3a. Race/Ethnicity

- White
- Black or African American
- Asian
- Native Hawaiian or Pacific Islander
- Hispanic/Latino
- Native American
- Some other race
- Two or more races
- Other
- N/A

4. Marital Status

- Single
- Married
- Separated
- Divorced
- Partnered
- Widowed

5. Is the patient:

- Private Pay
- Medicaid

6. Education Level

What level of school did this older adult complete?

- Grade school
- Middle school (incl. 6th grade)
- Some high school
- Completed High school
- Trade school
- Some college
- Junior college
- College
- Graduate school

7. Living arrangements

- In a private home by themselves
- In a private home with spouse or partner
- In a private home with children or siblings
- In a private home with other relatives or friends
- In a senior housing or an independent living facility with some support provided (e.g., meals, organized activities)
- In an assisted living facility
- In skilled or nursing facility
- In memory care facility

8: Month and Year when person received cognitive diagnosis: mm/yyyy_____

9. Date of most recent cognitive evaluation mm/dd/yyyy _____

10. Type of evaluation: _____

11. Result of evaluation: _____

II. Physical Health status: ask caregiver

7. Proxy Rated Health Status:

Compared to others their age, would you consider this person's physical health to be:

- Poor
- Fair
- Good
- Very good
- Excellent

8. ADL Functional status Circle one answer for each

a. Does this person receive help or supervision with personal care such as eating, bathing, toileting, dressing or getting around the house?

- YES
- NO

b. Do you expect this person will continue to need help or supervision with this personal care for at least three more months?

- YES
- NO

9. IADL Functional Status Circle one answer for each

a. Does this person receive help or supervision using the telephone, paying bills, taking medications, preparing light meals, doing laundry, going shopping, or managing your money?

- YES
- NO

Do you expect this person will continue to need help or supervision with these activities for at least three more months?

- YES
- NO

10. Health events Circle one answer for each

a. Has this person been to the Emergency Room or Urgent Care in the last 6 months?

- YES
- NO

b. Has this person had an overnight hospital stay in the last 6 months?

- YES
- NO

c. Has this person had one or more non-routine doctor visits in the last 6 months?

- YES
- NO

Cornell Scale for Depression in Dementia

Ratings should be based on symptoms and signs occurring during the week before interview. No score should be given if symptoms result from physical disability or illness.

SCORING SYSTEM

a = Unable to evaluate 0 = Absent 1 = Mild to Intermittent 2 = Severe

A. MOOD-RELATED SIGNS				
1. Anxiety; anxious expression, rumination, worrying	**a**	**0**	**1**	**2**
2. Sadness; sad expression, sad voice, tearfulness	**a**	**0**	**1**	**2**
3. Lack of reaction to pleasant events	**a**	**0**	**1**	**2**
4. Irritability; annoyed, short tempered	**a**	**0**	**1**	**2**
B. BEHAVIORAL DISTURBANCE				
5. Agitation; restlessness, hand wringing, hair pulling				
6. Retardation; slow movements, slow speech, slow reactions	**a**	**0**	**1**	**2**
7. Multiple physical complaints *(score 0 if gastrointestinal symptoms only)*	**a**	**0**	**1**	**2**
	a	**0**	**1**	**2**
8. Loss of interest; less involved in usual activities *(score 0 only if change occurred acutely, i.e., in less than one month)*	**a**	**0**	**1**	**2**
C. PHYSICAL SIGNS				
9. Appetite loss; eating less than usual	**a**	**0**	**1**	**2**
10. Weight loss *(score 2 if greater than 5 pounds in one month)*	**a**	**0**	**1**	**2**
	a	**0**	**1**	**2**
11. Lack of energy; fatigues easily, unable to sustain activities				
D**. CYCLIC FUNCTIONS**				
12. Diurnal variation of mood; symptoms worse in the morning	**a**	**0**	**1**	**2**
	a	**0**	**1**	**2**
13. Difficulty falling asleep; later than usual for this individual	**a**	**0**	**1**	**2**
14. Multiple awakenings during sleep	**a**	**0**	**1**	**2**
15. Early morning awakening; earlier than usual for this individual				
E**. IDEATIONAL DISTURBANCE**				
16. Suicidal; feels life is not worth living	**a**	**0**	**1**	**2**
17. Poor self-esteem; self-blame, self-depreciation, feelings of failure	**a**	**0**	**1**	**2**
18. Pessimism; anticipation of the worst	**a**	**0**	**1**	**2**
19. Mood congruent delusions; delusions of poverty, illness or loss	**a**	**0**	**1**	**2**
NOTES/CURRENT MEDICATIONS (no need for detail, a basic list is sufficient):				
TOTAL SCORE				

Instructions:

1. The same person should conduct the interviewed each time to assure consistency in the response.
2. The assessment should be based on the patient's normal weekly routine.
3. If uncertain of answers, questioning other caregivers may further define the answer.
4. Answer all questions by circling the appropriately numbered answer. (a=unable to evaluate, 0=absent, 1=mild to intermittent, 2=severe).
5. Add the total score for all numbers checked for each question.
6. Place the total score in the **"SCORE"** box and record any subjective observations in the **"Notes/Current Medications"** section.
7. Scores totaling twelve (12) points or more indicate probable depression.

Marin Apathy Evaluation Scale		
Indicators and ratings for week prior to interview: 1 = Not at all characteristic; 2 = Slightly characteristic; 3 = Somewhat characteristic; 4 = A lot characteristic		
	Indicators	**Rating**
1.	S/he is interested in things.	____
2.	S/he gets things done during the day.	____
3.	Getting things started on his/her own is important to her/him.	____
4.	S/he is interested in having new experiences.	____
5.	S/he is interested in learning new things.	____
6.	S/he puts little effort into anything.	____
7.	S/he approaches life with intensity.	____
8.	Seeing a job through to the end is important to her/him.	____
9.	He/she spends time doing things that interest her/him.	____
10.	10. Someone has to tell her/him what to do each day.	____
11.	11. S/he is less concerned about his/her problems than she/he should be.	____
12.	S/he has friends.	____
13.	Getting together with friends is important to her/him.	____
14.	When something good happens, he/she gets excited.	____
15.	S/he has an accurate understanding of her/him problems.	____
16.	Getting things done during the day is important to her/him.	____
		____

Agitated Behavior Scale

Period of Observation: _____ am/pm till _____ am/pm.

Indicators and ratings:

1 = absent: the behavior is not present.

2 = present to a slight degree: the behavior is present but does not prevent the conduct of other, contextually appropriate behavior. (The individual may redirect spontaneously, or the continuation of the agitated behavior does not disrupt appropriate behavior.)

3 = present to a moderate degree: the individual needs to be redirected from an agitated to an appropriate behavior, but benefits from such cueing.

4 = present to an extreme degree: the individual is not able to engage in appropriate behavior due to the interference of the agitated behavior, even when external cueing or redirection is provided.

	Indicators	**Rating**
1.	Short attention span, easy distractibility, inability to concentrate.	____
2.	Impulsive, impatient, low tolerance for pain or frustration.	____
3.	Uncooperative, resistant to care, demanding.	____
4.	Violent and or threatening violence toward people or property.	____
5.	Explosive and/or unpredictable anger.	____
6.	Rocking, rubbing, moaning or other self-stimulating behavior.	____
7.	Pulling at tubes, restraints, etc.	____
8.	Wandering from treatment areas.	____
9.	Restlessness, pacing, excessive movement.	____
10.	Repetitive behaviors, motor and/or verbal.	____
11.	Rapid, loud or excessive talking.	____
12.	Sudden changes of mood.	____
13.	Easily initiated or excessive crying and/or laughter.	____
14.	Self-abusiveness, physical and/or verbal.	____
	Total Score	____

APPENDIX 2: ENDLINE SURVEY

Creative Aging Program

***ARTmail* Evaluation Instrument: special population**

Endline

Participant #_____ Interview # _____

(Participant name _____) Only for purposes of matching baseline to endline interview

(Usual caregiver name _____) Only for purposes of matching baseline to endline interview

Did this participant complete all ARTmail sessions?

☐YES ☐NO → How many did they do ___ (Write number or DK if don't know)

Site number _____

Name of site _____

Type of site: ☐ Adult day care ☐ Residential care ☐ Other

ARTmail group ☐ Control Group ☐

Name of Interviewer _____

Date of Interview _____

Start time of interview _____

Approximate number of minutes taken for the interview_____

Any comments: (if this interview was not completed, note why in the space below):

_____

_____

To Interviewer: At the end of the interview, thank the participant for their time and participation. Offer to answer any questions they may have, or ask if they want to say anything more.

Demographics and Self Rated Health: Ask Caregiver

1. Has there been any change in this person's marital status since we talked last on _____ (date of first interview?

- ○ Yes, note change_____
- ○ No, go to Question 2

2. Has there been any change in where this person lives since we last talked on _____ (date of first interview)?

- ○ Yes, go to Q 3.
- ○ No, go to Question 4

3. Where does this person currently live?

- ○ In a private home by themselves
- ○ In a private home with spouse or partner
- ○ In a private home with children or siblings
- ○ In a private home with other relatives or friends
- ○ In a senior housing or an independent living facility with some support provided (e.g., meals, organized activities)
- ○ In an assisted living facility
- ○ In skilled or nursing facility
- ○ In a memory care facility

4. Proxy-Rated Health Status:

Compared to others their age, would you consider this person's physical health to be:

- ○ Poor
- ○ Fair
- ○ Good
- ○ Very good
- ○ Excellent

5. Has this person had a new cognitive evaluation since the baseline interview?

- ○ YES → Go to Question 6
- ○ NO → Go to Q 9

6. Date of most recent cognitive evaluation mm/dd/yyyy _____

7. Type of evaluation:

_____

8. Result of evaluation:

_____

9. Is the patient:

- ○ Private Pay
- ○ Medicaid

II Physical Health status

Ask Participant or Caregiver

4. ADL Functional status
Circle one answer for each

a. Does this person receive help or supervision with personal care such as eating, bathing, toileting, dressing or getting around the house?

- ○ YES
- ○ NO

b. Do you expect this person will need help or supervision with this personal care for at least three more months?

- ○ YES
- ○ NO

5. IADL Functional Status
Circle one answer for each

a. Does this person receive help or supervision using the telephone, paying bills, taking medications, preparing light meals, doing laundry, going shopping, or managing your money?

- ○ YES
- ○ NO

Do you expect this person will need help or supervision with these activities for at least three more months?

- ○ YES
- ○ NO

6. Health events
Circle one answer each

a. Has this person been to the Emergency Room or Urgent Care since we last talked on _____ (date of baseline interview)?

- ○ YES
- ○ NO

b. Has this person had an overnight hospital stay since we last talked on _____ (date of baseline interview)?

- ○ YES
- ○ NO

c. Has this person had one or more non routine doctor visits since we last talked on _____ (date of baseline interview)??

- ○ YES
- ○ NO

7. Caregiver comments:
***ARTmail group: how did ARTmail participation affect this person?**
***Control Group: What activities did this person do instead of ARtmail. How were they affected during these activities?**

_____
_____
_____
_____
_____

Cornell Scale for Depression in Dementia

Ratings should be based on symptoms and signs occurring during the week before interview. No score should be given if symptoms result from physical disability or illness.

SCORING SYSTEM

a = Unable to evaluate 0 = Absent 1 = Mild to Intermittent 2 = Severe

A. MOOD-RELATED SIGNS				
1. Anxiety; anxious expression, rumination, worrying	**a**	**0**	**1**	**2**
2. Sadness; sad expression, sad voice, tearfulness	**a**	**0**	**1**	**2**
3. Lack of reaction to pleasant events	**a**	**0**	**1**	**2**
4. Irritability; annoyed, short tempered	**a**	**0**	**1**	**2**
B. BEHAVIORAL DISTURBANCE				
5. Agitation; restlessness, hand wringing, hair pulling				
6. Retardation; slow movements, slow speech, slow reactions	**a**	**0**	**1**	**2**
7. Multiple physical complaints *(score 0 if gastrointestinal symptoms only)*	**a**	**0**	**1**	**2**
	a	**0**	**1**	**2**
8. Loss of interest; less involved in usual activities *(score 0 only if change occurred acutely, i.e., in less than one month)*	**a**	**0**	**1**	**2**
C. PHYSICAL SIGNS				
9. Appetite loss; eating less than usual	**a**	**0**	**1**	**2**
10. Weight loss *(score 2 if greater than 5 pounds in one month)*	**a**	**0**	**1**	**2**
	a	**0**	**1**	**2**
11. Lack of energy; fatigues easily, unable to sustain activities				
D**. CYCLIC FUNCTIONS**				
12. Diurnal variation of mood; symptoms worse in the morning	**a**	**0**	**1**	**2**
	a	**0**	**1**	**2**
13. Difficulty falling asleep; later than usual for this individual	**a**	**0**	**1**	**2**
14. Multiple awakenings during sleep	**a**	**0**	**1**	**2**
15. Early morning awakening; earlier than usual for this individual				
E**. IDEATIONAL DISTURBANCE**				
16. Suicidal; feels life is not worth living	**a**	**0**	**1**	**2**
17. Poor self-esteem; self-blame, self-depreciation, feelings of failure	**a**	**0**	**1**	**2**
18. Pessimism; anticipation of the worst	**a**	**0**	**1**	**2**
19. Mood congruent delusions; delusions of poverty, illness or loss	**a**	**0**	**1**	**2**
NOTES/CURRENT MEDICATIONS: Any change in medication since baseline interview?				
TOTAL SCORE				

Instructions:

1. The same CNA (certified nursing assistant) should conduct the interview each time to assure consistency in the response.
2. The assessment should be based on the patient's normal weekly routine.
3. If uncertain of answers, questioning other caregivers may further define the answer.
4. Answer all questions by circling the appropriately numbered answer. (a=unable to evaluate, 0=absent, 1=mild to intermittent, 2=severe).
5. Add the total score for all numbers checked for each question.
6. Place the total score in the **"SCORE"** box and record any subjective observation notes in the **"Notes/Current Medications"** section.
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2.	S/he gets things done during the day.	____
3.	Getting things started on his/her own is important to her/him.	____
4.	S/he is interested in having new experiences.	____
5.	S/he is interested in learning new things.	____
6.	S/he puts little effort into anything.	____
7.	S/he approaches life with intensity.	____
8.	Seeing a job through to the end is important to her/him.	____
9.	He/she spends time doing things that interest her/him.	____
10.	10. Someone has to tell her/him what to do each day.	____
11.	11. S/he is less concerned about his/her problems than she/he should be.	____
12.	S/he has friends.	____
13.	Getting together with friends is important to her/him.	____
14.	When something good happens, he/she gets excited.	____
15.	S/he has an accurate understanding of her/him problems.	____
16.	Getting things done during the day is important to her/him.	____
		____

Agitated Behavior Scale

Period of Observation: _____ am/pm till _____ am/pm.
Indicators and ratings:
1 = absent: the behavior is not present.
2 = present to a slight degree: the behavior is present but does not prevent the conduct of other, contextually appropriate behavior. (The individual may redirect spontaneously, or the continuation of the agitated behavior does not disrupt appropriate behavior.)
3 = present to a moderate degree: the individual needs to be redirected from an agitated to an appropriate behavior, but benefits from such cueing.
4 = present to an extreme degree: the individual is not able to engage in appropriate behavior due to the interference of the agitated behavior, even when external cueing or redirection is provided.

	Indicators	**Rating**
1.	Short attention span, easy distractibility, inability to concentrate.	____
2.	Impulsive, impatient, low tolerance for pain or frustration.	____
3.	Uncooperative, resistant to care, demanding.	____
4.	Violent and or threatening violence toward people or property.	____
5.	Explosive and/or unpredictable anger.	____
6.	Rocking, rubbing, moaning or other self-stimulating behavior.	____
7.	Pulling at tubes, restraints, etc.	____
8.	Wandering from treatment areas.	____
9.	Restlessness, pacing, excessive movement.	____
10.	Repetitive behaviors, motor and/or verbal.	____
11.	Rapid, loud or excessive talking.	____
12.	Sudden changes of mood.	____
13.	Easily initiated or excessive crying and/or laughter.	____
14.	Self-abusiveness, physical and/or verbal.	____
	Total Score	____