White Paper Exploring the Potential for Online, Small-Group Cognitive Stimulation Therapy to Improve Quality of Life for Dementia Patients and Their Caregivers

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Abstract:

Background:

As medical science strives to provide definitive cures for dementia, with its numerous subtypes that all progress into profound dysfunction, clinical social workers and occupational therapists labor to improve quality of life (QoL) for patients and their loved ones. Though effective pharmacotherapies options remain limited, the lineup of psychotherapeutic, cognitive stimulation, Montessori-type, and reminiscence-based therapies continues to expand. These multifaceted and multifactorial therapies strive not only to maintain cognitive function, but also improve mood, social engagement, physical mobility, and activities of daily living (ADL) function and participation of the person with dementia (PWD). Cognitive stimulation therapy (CST) is a medicare-approved dementia intervention that aims to improve QOL for PWD and their caregivers directly, by decreasing dementia symptom severity, and indirectly, by meeting the social needs for PWD and providing community and resources for caregivers. How to effectively carry out CST safely in the context of an ongoing global pandemic and increasing dementia morbidity, which limits PWD mobility, is a question that has not been well explored.

Aim:

To explore the effectiveness of a small-group CST program administered weekly via an online meeting platform.

Methods:

A prospective, non-blinded, non-randomized, exploratory study wherein 11 PWD and their primary caregivers acted as their own controls. The exposure was a highly structured program of cognitive stimulation based on the extant dementia-care literature, which contained orientation exercises, movement, music, and guided, topic-driven conversation between PWD. The exposure, hereafter called the Memory Keepers (MK) program, was administered to each PWD via the online platform Zoom in groups of 7-10 persons weekly for 14 weeks. Between November 2020 and March 2022, all 11 PWD completed between one and three 14-week MK programs. A standard battery of neuropsychological screening tests and tools measuring cognition, memory, mood, quality of life, and caregiver burden were administered before the first MK exposure and at the end of each 14-week exposure.

The standardized survey tools utilized at the beginning of the pilot study in 2020 and after each MK session consisted of one measure of cognitive function and mental status (SLUMS); one measure of self-reported mood and depression (GDS); one measure of caregiver-reported mood and depression (hereafter Cornell); one measure of Quality of Life as reported by the PWD (QoL-AD patient); one measure of Quality of Life as reported by PWD's caregiver (QoL-AD family); and one measure of the burden of caring for the PWD on the primary caregiver (FTLDA).

Results:

The major results of this prospective, exploratory, pilot study are summarized in Chart 1. Though cognitive function declined by more than 40%, quality of life on average rose for PWD both by self-report and by caregiver report. Depression symptoms, likewise, decreased by both self report and caregiver report. Caregivers reported that, in spite of their loved one's increasing cognitive impairment secondary to dementia, the burden of care over the period of receiving MK interventions decreased from mild-moderate burden to little-to-no burden.

Scale	Overall (N=31)				After 3 MK Sessions	Changes After 1 MK Session	Changes After 2 MK Sessions	Changes After 3 MK Sessions
Cornell.Depression.Scale	(N=01)	Medouremento			000010110			
Mean (SD)	6.29 (3.73)	7.3	6.1	6	4.3	-1.2	-3	-3
Median [Min, Max]	6.00 [0, 14.0]	7.5	6	5	5	-1.5	-8	-21
Caregiver.Burden.ScaleFTLDA.								
Mean (SD)	24.6 (16.5)	28	27	22	12	-1	-6	-16
Median [Min, Max]	22.0 [5.00, 57.0]	30	22.2	22	9	-7.8	-8	-21
QOL.AD.patient								
Mean (SD)	41.3 (5.82)	40.3	42	41.5	42	1.7	1.2	1.7
Median [Min, Max]	43.0 [29.0, 50.0]	41	43	42	45	2	1	4
QOL.AD.family.member								
Mean (SD)	39.1 (5.74)	39.2	38.2	38.7	42.5	-1	-0.5	3.3
Median [Min, Max]	41.0 [22.0, 46.0]	41.5	37.8	39.2	42.5	-3.7	-2.3	1
GDS.SF								
Mean (SD)	2.34 (2.31)	3.1	2.9	1.44	0.333	-0.2	-1.66	-2.767
Median [Min, Max]	2.00 [0, 10.0]	3	2.5	1	0	-0.5	-2	-3
SLUMS								
Mean (SD)	12.5 (7.86)	13.6	13.6	11.2	8	0	-2.4	-5.6
Median [Min, Max]	11.0 [2.00, 30.0]	11.5	10.5	10.5	6	-1	-1	-5.5

Chart 1: Summary of Changes in MK Participant Neurocognitive Scales Between March 2020 and March 2022

Conclusion

Though the medical community's understanding of dementia as a disease state continues to evolve, the burden of caring for this population is growing as the over-65 population grows. The demand for low-cost, medicare-covered, home-based services that improve mood and quality of life and decrease burden of care is also expanding. Though much more study is required, these preliminary data suggest that small-group, online cognitive stimulation therapy may be a useful tool to help decrease depression and improve quality for life for PWD and their caregivers when administered on at least a weekly basis for at least 14 weeks.

Key Words: Dementia, Alzheimer's, Quality of Life, Depression, Care, Cognitive Stimulation Therapy

Introduction:

The compromised cognitive state that we refer to broadly as dementia is not a single disease, but rather a constellation of symptoms that arise from pathologic processes taking place within neurologic and vascular tissues of the mammalian brain. Many clinical subtypes of dementia exist. Vascular, frontotemporal, and Alzheimer's dementia are three of these clinical subtypes. All subtypes are typified by increasingly compromised cognition, progressive loss of orientation to time and place and, eventually, self. As dementia progresses, the PWD loses their link to the narrative of their lives: first to recent events and people they have known the least amount of time, and, later, to basic life skills including self-care and to their knowledge of friends, family, and all personal history.

True dementia type can only be determined by directly visualizing brain material. Direct visualization is achieved either by brain biopsy during a patient's lifetime or, more commonly, during autopsy. Decades of autopsy data have demonstrated that Alzheimer's dementia is far and away the most common type of dementia, representing 60-80% of dementia diagnoses in the United States (Alzheimer's Association, 2022). In 2022, the Alzheimer's Association reported that 13 percent of people over age 65 have Alzheimer's dementia. In other words, the current population of people age 65 and older who require dementia-related care is greater than 3.5 million and rising rapidly (Roberts, 2018). These PWD will survive an average of four to eight years after a diagnosis of Alzheimer's dementia (Alzheimer's Association, 2022).

As our understanding of dementia and its causes evolves, so too evolve best-practices driving care for persons living with this complex disease state. Over the decades since dementia was classified as a disease, many approaches to improving Quality of Life (QOL) have been attempted. The Alzheimer's Association of America has driven much of the research to make interventions accessible, affordable, and acceptable as possible. Due to their leadership and the continuous labor of doctors, nurses, therapists, social workers, caregivers, and PWD, current best-practices have grown to include (Meeks 2018):

- Provide disease education including what to expect and strategies to manage symptoms
- Establish a care team
- Plan for the future (put legal and financial matters in order)
- Talk to others going through a similar situation
- Online forums and message boards

- Support groups
- 1:1 discussions
- Therapy
- Those who respond best to therapy include those who -
- Accept their diagnosis
- Can communicate their needs and concerns
- Can hear well enough to receive information
- Are able to collaborate in the therapy process
- Stay socially connected and cognitively stimulated
- Informal support
- Games, reading, discussions, classes, volunteering
- Cognitive stimulation therapy, reminiscence, Montessori for dementia

As can be appreciated from Figure 1, many of the PWD requiring the above-listed services live in highly rural and rural areas where access to dementia care and communities that provide dementia resources is limited.

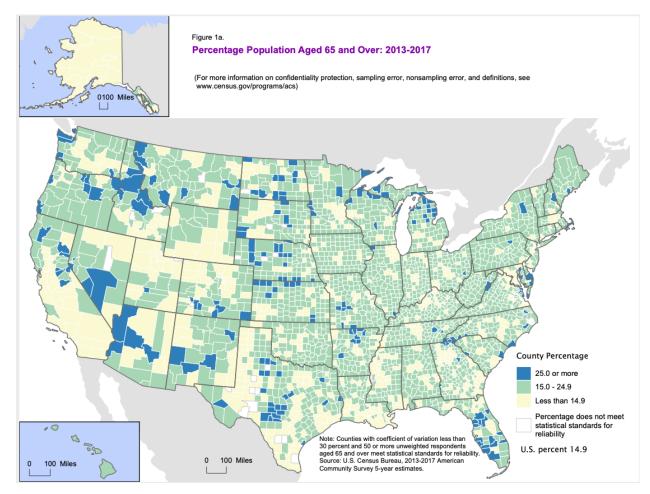


Figure 1: Concentration of US population age 65 and over (US Census Bureau, 2016)

Cognitive Stimulation Therapy (CST) is an evidence-based, Medicare-approved method utilized by dementia-care practitioners worldwide for meeting a broad set of the

therapeutic goals for PWD. The key principles of CST, as described by the Division of Psychiatry, University College London (2019) include:

"1. Mental stimulation; 2. Developing new ideas, thoughts and associations; 3. Using orientation in a sensitive manner; 4. Focusing on opinions, rather than facts; 5. Using reminiscence as an aid to the here and now; 6. Providing triggers to support memory; 7. Stimulate language and communication; 8. Stimulate every day planning ability; 9. Using a 'person-centred' approach; 10. Offering a choice of activities; 11. Enjoyment and Fun; 12. Maximising potential; 13. Strengthening the relationship by spending quality time together."

When the COVID pandemic struck in March 2020, a team of social workers and researchers from the Alzheimer's Association and Washington University St. Louis' Brown Schools of Social Work and Public Health resolved to create a CST-based intervention that could be deployed in an online format: one that would allow PWD to continue receiving the care they needed to have an improved QOL; have access to and interact with a supportive community; and continue to be seen by social workers.

To examine the effectiveness of such an intervention, between November 2020 and March 2022, a total of 11 PWD between the ages of 50 and 80 underwent multiple sessions of an online, small-group-based CST program (osCST) called Memory Keepers (MK). The MK participant group consisted of 9 men and 2 women, all Caucasian, with educations of at least high school graduate level or more, who carried a diagnosis of Alzheimer's, frontotemporal, or undifferentiated dementia.

Each MK session consisted of fourteen concatenate weekly Zoom meetings in groups of 8-10. During each MK meeting, participants spent 1 hour engaged in a choreographed series of CST activities that included repeated orientation to day, month, year, and season; gentle physical movement; patterned reminiscing of recent events as well as remote events of historic significance and cultural salience; episodes of music and/or singing; and opportunities for each PWD to engage in conversation with his or her fellow participants.

Every MK meeting and session presented distinct content, but preserved this general pattern of CST activities. Each PWD participated in between two and four 14-week sessions, for a total of 28-56 hours of exposure per participant. Every meeting was led by a social worker trained in use of CST for this population using a slide deck designed by the MK staff. Caregivers were permitted to be present during meetings, but could, and often did, elect to leave the area while the PWD participated in the MK program.

Methods

All interactions with MK participants and their caregivers occurred via the online platform Zoom. Before a PWD's first MK session and after each subsequent session, MK participants and their caregivers were administered a standard battery of neuropsychological screening tests and tools considered clinically appropriate to measure cognition and memory; depression and mood; quality of life; and burden of caring for the PWD. These were:

- 1. St. Louis University Mental Status Exam (SLUMS);
- 2. Geriatric Depression Scale (GDS);
- 3. The Cornell Scale for Depression in Dementia (Cornell);
- 4. Quality of Life in Advanced Dementia as reported by the PWD (QoL-AD patient);
- 5. Quality of Life in Advanced Dementia as reported by PWD's caregiver (QoL-AD family; and
- 6. The burden of caring for the PWD as reported by the primary caregiver (Caregiver Burden Scale/FTLDA).

Scores from the GDS, the Cornell, the QoL-AD patient, QoL-AD family, and FTLDA is explained and summarized here:

Survey Tool	What It Measures	Score Interpretation	Best Possible Score
St. Louis University Mental Status exam (SLUMS)	Mental Status and cognitive function in persons with suspected or diagnosed dementia	Assuming level of education >= high school, Normal cognition is in the 27-30 range; Mild neurocognitive disorder 21-26; dementia 20 or less	30
Geriatric Depression Scale (GDS)	Self-Reported Depression Symptoms	A score of > 5 suggests depression	0
Cornell Scale for Depression in Dementia (Cornell)	Depression Symptoms in Dementia	A score >10 probably major depressive episode A score >18 definite major depressive episode	0

Chart 2: Details of the Standard Survey	Tools Utilized in the MK CST Pilot Study
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Quality of Life in Alzheimer's disease as reported by the patient (QoL-AD patient)	A PWD's self-reported Quality of Life	Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4. The total score is the sum of all 13 items.	52 (a score of 4 on every item of 13 items)
Quality of Life in Alzheimer's disease as reported by the family (QoL-AD family)	PWD's Quality of Life as reported by their primary caregiver	Points are assigned to each item as follows: poor = 1, fair = 2, good = 3, excellent = 4. The total score is the sum of all 13 items.	52 (a score of 4 on every item of 13 items)
Caregiver Burden Scale (FTLDA)	Burden of care for PWD self-reported by caregiver	0 to 20 = little or no burden; 21 to 40 = mild to moderate burden; 41 to 60 = moderate to severe burden; 61 to 88 = severe burden	0

Data Details

The analysis of this exploratory study consisted of two parts. The first was a descriptive statistics analysis. The total observations recorded during this study, as well as overall mean and median values for each survey instrument, is recorded in Chart 3. A total of 31 observations were included in the final analysis. The results from this descriptive analysis are considered the Key Findings.

The second analysis was a modeling study focused on finding between-visit changes in survey scores. The purpose of the secondary analysis was to seek out associations between scores as they changed and to evaluate for statistically significant relationships in the timing of the observed score changes on surveys. Because there were multiple types of dementia present in the PWD and many different severities of disease represented, the analysis was done at the level of the individual MK participant and their caregiver. This part of the secondary results focused on observing trends in four bivariate relationships: changes in SLUMS score to changes in GDS; changes in SLUMS to changes in QoL as reported by the family; and changes in SLUMS to changes in QoL as reported by the PWD. Changes in SLUMS score were compared to changes in the Cornell score as a method of modeling quality assurance.

Prior to modeling, the data was processed. Pre-processing included data type conversions from integer into numeric and missing data extrapolation using a Last Observation Carry Forward method for data sections with no recorded values.

To facilitate a pairwise search for statistical associations, bivariate relationships were explored graphically. Based on the pairwise search outcome, two linear models were created. Due to the low number of observations, 95% Confidence Intervals were used as markers of significance instead of p-values. Beta in these linear models was interpreted in reference to a 1-point decrease in the SLUMS score.

	Overall (N=31)
Cornell.Depression.Scale	
Mean (SD)	6.29 (3.73)
Median [Min, Max]	6.00 [0, 14.0]
Caregiver.Burden.ScaleFTLDA.	
Mean (SD)	24.6 (16.5)
Median [Min, Max]	22.0 [5.00, 57.0]
QOL.AD.patient	
Mean (SD)	41.3 (5.82)
Median [Min, Max]	43.0 [29.0, 50.0]
QOL.AD.family.member	
Mean (SD)	39.1 (5.74)
Median [Min, Max]	41.0 [22.0, 46.0]
GDS.SF	
Mean (SD)	2.34 (2.31)
Median [Min, Max]	2.00 [0, 10.0]
SLUMS	
Mean (SD)	12.5 (7.86)
Median [Min, Max]	11.0 [2.00, 30.0]

Chart 3: Descriptive Statistics, Mean and Median Overall Scores from the MK Pilot Study

Key Findings

Primary and secondary results revealed interesting trends in the data on the group and individual levels, respectively.

Primary Results: Group-level Effects and Descriptive Statistics

As expected in a group of PWD, at the start of the study, mean SLUMS scores were below the highest possible score expected on this survey tool when dementia is present and the person being screened has more than a high school education (20). In fact, the mean initial SLUMS score for this pilot group hovered around 13. Over the subsequent 48 month, the mean score on this measure of cognitive funding declined by ~41% to 8.

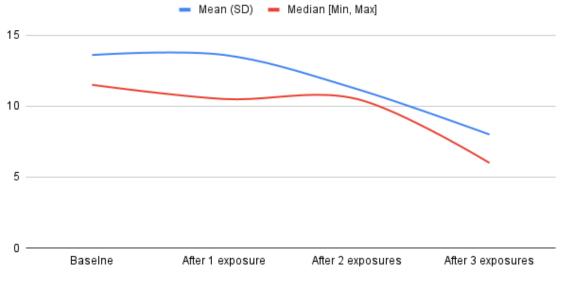


Fig 2: Trend in MK Participant Scores on the St. Louis University Mental Status exam

What was not expected was that, despite precipitous declines in mental status, over the same duration, MK participants' depression scores reflected improved mood on both measures of depression: PWD self-report via the GDS and mood symptoms by primary caregivers via the Cornell.

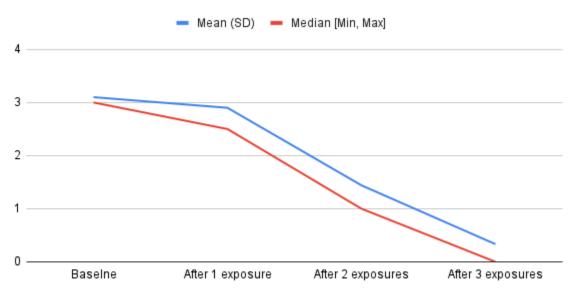


Fig 3: Trend in MK Participant Scores on the Geriatric Depression Scale

MK Participant Scores on the SLUMS at baseline and after 1, 2, or 3 MK Sessions

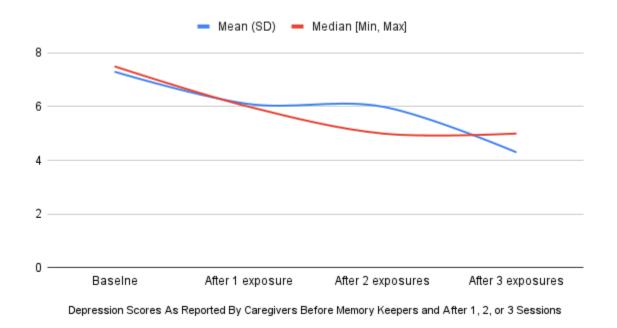
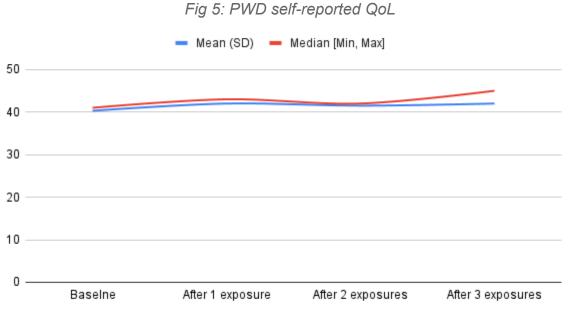


Fig 4: Trend in MK Participant Scores on the Cornell Scale of Depression in Dementia

On the GDS, depression is rated to be likely when the score is over 5. Over the 2-year pilot study, PWD who participated in MK reported a decline in their depression from 3.1 to 0.3. During that same exposure period, the loved ones who cared for the PWD reported via the Cornell - where major depression is screened as being present when the scores are 10 and higher - that mean score had dropped: from 7 to 4.3.



Patient's Self-Reported Score on the QOL-AD at baseline and after 1, 2, or 3 MK Sessions

PWD mean self-reported quality of life scores, meanwhile, drifted slowly upwards over the 48-month pilot from 40.3 to 42. On the QOL-AD Survey Tool, 52 is the highest

possible score, reflecting a report of "Excellent" on all life measures). When the MK pilot study began, caregivers reported that their loved ones had a QoL corresponding to a mean score of 39.2/52. Families still participating after 48 weeks reported that their loved ones had a quality of life that had an average value of 42.5/52. Caregivers also reported that by the end of the 2-year interval, they felt less burdened on the average.

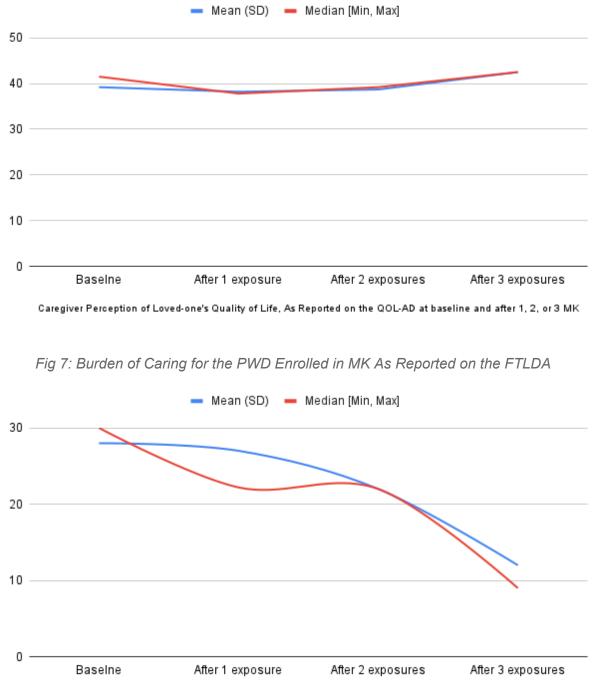


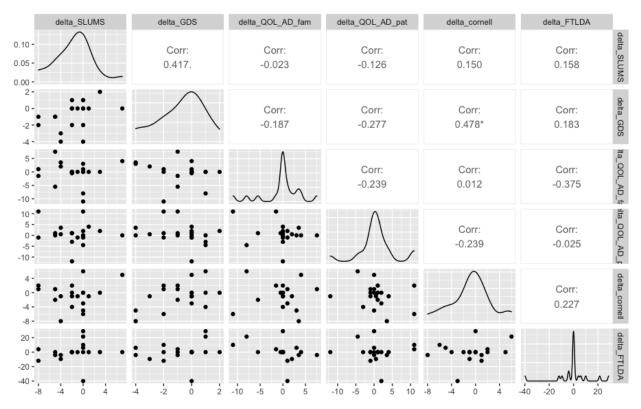
Fig 6: PWD QoL As Reported by the Caregiver

Caregivers' Self-Reported Burden of Caring and Living with Person with Dementia Before and After 1, 2, or 3 MK

Secondary Results: Modeling Effects and Associations

Pairwise Comparisons

The first step in running an analysis searching for trends in the data involved setting up pairwise comparisons. To that end, this scatterplot matrix in Fig. 8 was created. This matrix contains a visual representation of how all of the changes are related to each other, statistically as well as graphically.





The associations of possible interest suggested by this data include (1) the relationship between the per-participant change in GDS score over time/repeated exposures to MK and the per-participant change in SLUMS score over the same time period and exposures and (2) the relationship between changes on both family and PWD QOL-AD scores and changes in SLUMS scores. With a correlation of 0.478, scores changes on the Cornell & GDS appear to have the strongest association. This trend is to be expected, as both scales measure depression. Intuitively, two scores that derive from depression that were observed by descriptive statistics to decrease over time should have a strong association. Their strong association in this matrix acts as a kind of quality-control demonstration.

Linear Model

Modeling (1) the relationship between changes in the SLUMS score and changes in the GDS with a standard linear model that uses SLUMS scores as the predictor gives the result in Table

1. Here, there is a -0.437 decrease in GDS on average between visits when SLUMS is not changing. When the model lets SLUMS scores change over time, for every 1 point decrease in SLUMS, GDS changes (self-reported depression decreases) by -0.196 (CI -0.4 - 0.0154). Similarly, in Table 2, for every 1 point decrease in SLUMS, Cornell changes (family-reported depression decreases) by -0.145; in Table 3, for every 1 point decrease in SLUMS, QOL as reported by the patient goes up by 0.174 units; in Table 4, for every 1 point decrease in SLUMS, QOL as reported by the patient's caregiver goes up by 0.02 units.

term	estimate	std.error	statistic	p.value	conf.low	conf.high
<chr></chr>	<db1></db1>	<db1></db1>	<db1></db1>	<db1></db1>	<db1></db1>	<db1></db1>
1 (Intercept)	-0.437	0.380	-1.15	0.266	-1.24	0.362
2 delta_SLUMS	0.196	0.101	1.95	0.067 <u>2</u>	-0.015 <u>4</u>	0.407

Table 1: Change in GDS scores on average between visits as SLUMS is either (1) held constant or (2) allowed to change. CI 95%

term	estimate	std.error	statistic	p.value	conf.low	conf.high
<chr></chr>	<db1></db1>	<db1></db1>	<db1></db1>	<db1></db1>	<dbl></dbl>	<db1></db1>
1 (Intercept)	-0.518	0.849	-0.611	0.549	-2.30	1.26
2 delta_SLUMS	0.145	0.224	0.645	0.527	-0.327	0.616
	0.145	0.224	0.645	0.527	-0.527	0.01

Table 2: Change in Cornell scores on average between visits as SLUMS is either (1) held constant or (2) allowed to change. CI 95%

term	estimate	std.error	statistic	p.value	conf.low	conf.high
<chr></chr>	<db1></db1>	<db1></db1>	<db1></db1>	<db1></db1>	<dbl></dbl>	<db1></db1>
1 (Intercept)	0.447	1.22	0.366	0.718	-2.12	3.01
2 delta_SLUMS	-0.174	0.323	-0.538	0.597	-0.852	0.504

Table 3: Change in QOL-AD Patient scores on average between visits as SLUMS is either (1) held constant or (2) allowed to change. CI 95%

term	estimate	std.error	statistic	p.value	conf.low	conf.high
<chr></chr>	<db1></db1>	<db1></db1>	<db1></db1>	<db1></db1>	<dbl></dbl>	<db1></db1>
1 (Intercept)	-0.267	1.03	-0.258	0.799	-2.44	1.91
2 delta_SLUMS	-0.026 <u>4</u>	0.273	-0.096 <u>6</u>	0.924	-0.601	0.548

Table 4: Change in QOL-AD Family scores on average between visits as SLUMS is either (1) held constant or (2) allowed to change. CI 95%

Figures 9 and 10 show this outcome in a graphical, slightly more intuitive way. Figure 9 shows how depression and mental status decrease "between Visits", where "Visit" is a single exposure to MK, and concatenate Visits are equivalent to subsequent exposures. Figure 10 shows how

reported quality of life rises after subsequent exposures, even in the face of advancing dementia as reflected in falling mental status scores.

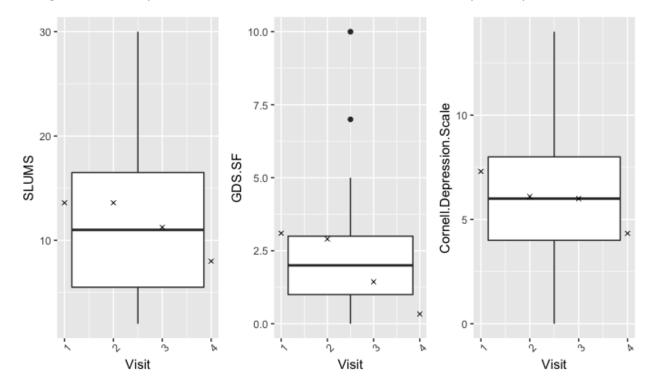
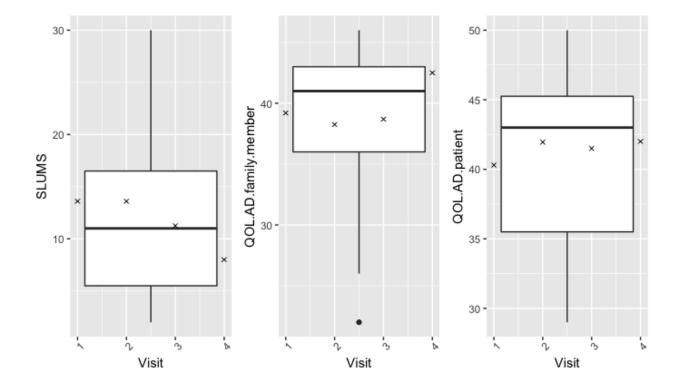


Figure 9: How depression on two measures decreases over subsequent exposures to MK

Figure 10: How Quality of Life on two measures inccrease over subsequent exposures to MK



Paired T-Test: Visit 1 and 3 GDS Scores

Reviewing the trends in the values and CI's shown in Tables 1-4 implies that there may be a statistically relationship worth exploring: specifically, whether the changing GDS scores between the first and 3rd MK sessions is statistically significant (Table 1).

To determine the level of significance in this trend, a paired T-test was performed on a per-individual level. For this, first-visit depression scores were found for every MK PWD participant and compared to (if present) the scores on the third visit. In the end, seven MK PWD participants were entered into the analysis.

The null hypothesis in this T-Test is that the mean lag between Visit 1 and 3 - the mean difference in scores between the beginning of the MK program (Visit 1) and the end of the second MK session (Visit 3) - is zero, and there is no statistically significant difference in the GDS scores over time. Rejecting the null hypothesis would imply that the true mean of the difference in scores over time is not zero. The results of the paired T-test were as follows:

t = 2.1213, df = 6, p-value = 0.07814 alternative hypothesis: true mean is not equal to 0 95 percent confidence interval: -0.1973383 2.7687668 sample estimates: mean of x 1.285714

Though the p-value in this T-Test does not reach statistical significance at alpha = 0.05, with 7 participants, if one were interested in using the p-value to determine significance, a less stringent alpha would be reasonable. Relying instead on the CI, which is large in this case, to compare means of depression scores between visit 3 and 1, one sees that the mean value to trending towards significance. This trend in the T-test data works out equally well for the median values of GDS between Visits 1 (pre-exposure) and Visit 3 (post 2 exposures)

Conclusion

This study was exploratory and its goals where to observe: to look at the pilot data for coherence, trends, and associations that might lend themselves to futher study and statistical analysis. In this context, no definitive conclusion regarding the potential effectiveness of online, small-group CST programs. With these data, limited as they are, one can speak to the existence of a possible trend in improving mood and QoL in PWD and their caregivers - one which should be explored in an ongoing way as more data become available.

By 2050, 21.4 percent of the US population will be 65 and older (He, 2016). Unless medical science delivers us a cure for dementia of all kinds, in less than thirty years, more than 10 million people will be living with dementia and dying of dementia-related issues in this country. Between diagnosis and death, these PWD will have extensive care needs. American nursing homes are already strained to their limit. The capacity to

expand services at the community level, organizational, and society-level does not yet exist, but it needs to exist. It needed to exist yesterday.

Meeting those needs where PWD and their families live will be critical to sustain the economy, as more and more people have loved ones with dementia in their homes, and allow the healthcare system, such as it is, to continue functioning. The course of the disease set that is dementia, which can strike at nearly any phases of adult life is unrelenting, yet not entirely without recourse. CST and other therapeutic modalities carry the potential to help families cope with dementia and its sequelae at home while awaiting the day we can put this disease in book and try to forget it ever existed.

Constraints

The constraints upon interpreting these data are many. As is true for in-person group therapy, Not all MK participants were present for every session. Participants were heterogeneous in factors that can influence disease progress as well as scores on and participation in neuropsychological screening tests including age, level of education, underlying physical health, underlying mental health, socioeconomic status, type of dementia, severity of dementia, and years since diagnosis.

Furthermore, not all participants took all the tests (SLUMS, QOL-AD Family, QOL-AD Family, Cornell Depression Scale, Geriatric Depression Scale). Post-session tests were not administered a uniform amount of time after the end of each MK session. Some people took the test shortly after their MK session ended. Others may have taken the tests weeks later. Some of these tests, like the GDS, are validated as screening tools.

Assumptions

Due to the small number of observations, many assumptions had to be made in order to conduct this exploratory analysis. Two major assumptions, neither of which are valid on their own, were made. Using Last Observation Carried Forward (LOCF) to fill in gaps in the data (from where participants could not cognitively participant in an assessment or were absent during the screening) entailed assuming that the scores did not change between visits. Function, mood, memory, and QOL scores not changing over time in the context of a degenerative disease state is unlikely. The LOCF assumption was made here out of necessity and convenience. As more data are collected, there will be less need for this assumption. If the assumption continues to be made for the sake of improved data analysis, as more data are collected, the magnitude of the effect of the LOCF assumption will wane.

The second assumption that was made involves the error normality. With only 31 observations, error is likely not normal. However, as can be seen in figure 10, it trends towards normal. It is reasonable therefore to assume that with more observations, normality in the data would be reached.

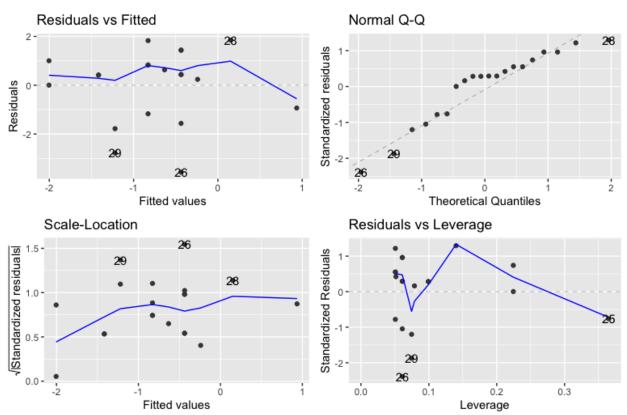


Figure 10: Checking Normality Assumptions, GDS Model

Future Directions

Continuing this study with the current PWD and by recruiting new participants into the MK program will provide an expanded data set with which to conduct a more comprehensive analysis. If a control group of PWD who are not participating in MK could be surveyed using the same six instruments, groupwise comparisons might be more possible. If a formal study is to be conducted, concerted efforts should be made to recruit people of color, women, members of the LGBTQ community, and people from all SES and educational backgrounds. These data and other data collected in the progress of MK research should be kept open-access and available to the public so that other research groups and institutions performing similar research can locate it and pooled data analysis may be conducted.

References

Alzheimer's Association (2022). Alzheimer's Disease Facts and Figures. Alzheimers Dement 2022;8.

Chancellor B, Duncan A, Chatterjee A. Art therapy for Alzheimer's disease and other dementias. J Alzheimers Dis. 2014;39(1):1-11. doi: 10.3233/JAD-131295. PMID: 24121964.

Meek S (Ed) (2018). Alzheimer's Association Dementia Care Practice Recommendations. The Gerontological Society of America. https://academic.oup.com/gerontologist/article-abstract/58/suppl 1/NP/4847791

Deshmukh, S. R., Holmes, J., & Cardno, A. (2018). Art therapy for people with dementia. The Cochrane database of systematic reviews, 9(9), CD011073. https://doi.org/10.1002/14651858.CD011073.pub2

Division of Psychiatry, University College London (2019). Making a difference 3: Individual Cognitive Stimulation Therapy. A manual for carers. p. 5 Hawker Publications. Hampshire, UK.

He W, Goodkind D, Kowal P (2016). U.S. Census Bureau, International Population Reports, P95/16-1, An Aging World: 2015, U.S. Government Publishing Office, Washington, DC. https://www.census.gov/library/publications/2018/acs/acs-38.html

Howe E. (2008). Improving the quality of life in patients with Alzheimer's disease. Psychiatry (Edgmont (Pa. : Township)), 5(8), 51–56.

Kumar, A. M., Tims, F., Cruess, D. G., Mintzer, M. J., Ironson, G., Loewenstein, D., Cattan, R., Fernandez, J. B., Eisdorfer, C., & Kumar, M. (1999). Music Therapy Increases Serum Melatonin Levels in Patients with Alzheimer's Disease. Alternative therapies in health and medicine, 5(6), 49-57.

Junaid, O., & Hegde, S. (2007). Supportive psychotherapy in dementia. Advances in Psychiatric Treatment, 13(1), 17-23. doi: 10.1192/apt.bp.105.002030

Logsdon, R. G., McCurry, S. M., & Teri, L. (2007). Evidence-Based Interventions to Improve Quality of Life for Individuals with Dementia. *Alzheimer's care today*, *8*(4), 309–318.

Mapelli, D., Di Rosa, E., Nocita, R., & Sava, D. (2013). Cognitive stimulation in patients with dementia: randomized controlled trial. *Dementia and geriatric cognitive disorders extra*, *3*(1), 263–271. <u>https://doi.org/10.1159/000353457</u>

Orrell, M., Yates, L., Leung, P., Kang, S., Hoare, Z., Whitaker, C., Burns, A., Knapp, M., Leroi, I., Moniz-Cook, E., Pearson, S., Simpson, S., Spector, A., Roberts, S., Russell, I., de Waal, H., Woods, R. T., & Orgeta, V. (2017). The impact of individual Cognitive Stimulation Therapy (iCST) on cognition, quality of life, caregiver health, and family relationships in dementia: A randomised controlled trial. *PLoS medicine*, *14*(3), e1002269. <u>https://doi.org/10.1371/journal.pmed.1002269</u>

Roberts AW, Ogunwole SU, Blakeslee L, Rabe MA (2018). The Population 65 Years and Older in the United States: 2016. American Community Survey Reports. ACS-38.

Spector A, Thorgrimsen L, Woods B, et al. Efficacy of an evidence-based cognitive stimulation therapy programme for people with dementia: randomized controlled trial. Br J Psychiatry. 2003;183:248–254. [PubMed] [Google Scholar]

Stephenson, R.C. (2015). Color my words: How art therapy creates new pathways of communication. In L. Carozza (Ed.) Communication and aging: Creative approaches to improving the quality of life (pp. 247-267). San Diego, CA: Plural Publishing, Inc.

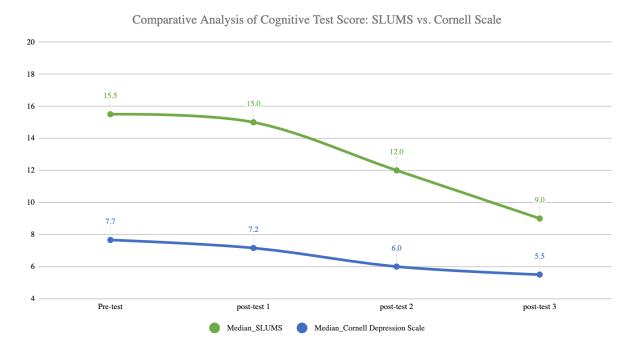
US Census Bureau (2016).

Select Maps on the Population 65 and Older in the United States by County: 2013-2017. <u>https://www.census.gov/library/visualizations/time-series/demo/nia_county_maps.html</u>. Accessed May 2, 2022.



Comparative Graphs for 2023 Data

Additional data collected between 2022 and 2023 expounds on the white paper exploring our program's effects on quality of life and mood. With a larger participant pool, the results are consistent, indicating improved mood and quality of life, along with a reduction in caregiver burden.

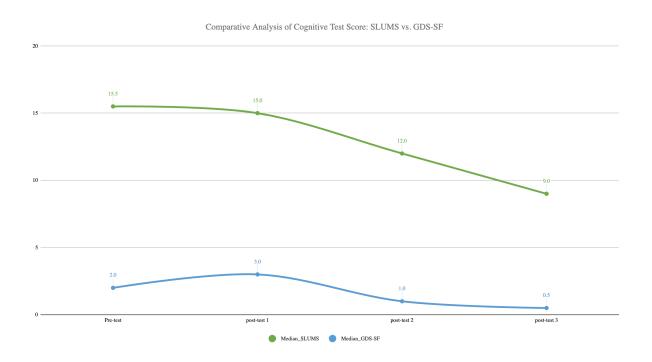


It measures Mental Status and cognitive function in persons with suspected or diagnosed dementia. A lower score means worse Mental Status.

Cornell Scale for Depression in Dementia (Cornell)

It measures Depression Symptoms in Dementia. A lower score means less Depression Symptoms in Dementia

This trend suggests that despite the cognitive decline inherent in their condition, the intervention could be having a positive impact on the patients' mood and emotional well-being, leading to reduced symptoms of depression.

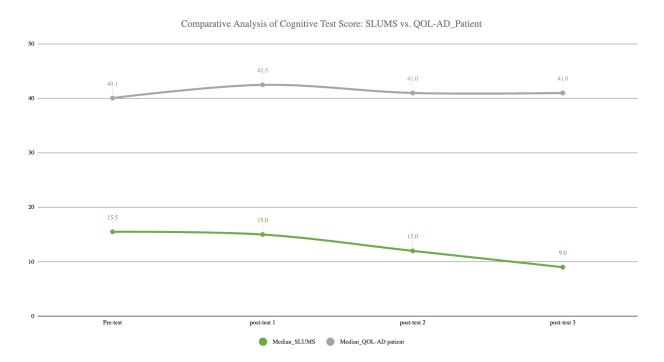


It measures Mental Status and cognitive function in persons with suspected or diagnosed dementia. A lower score means worse Mental Status.

Geriatric Depression Scale (GDS)

It is a self-report measure of depression in older adults. A lower score on the GDS indicates less severe depressive symptoms.

While cognitive function is declining, the emotional state of the patients, as indicated by the lower GDS scores, appears to be improving, which could be significant for overall patient care and quality of life.

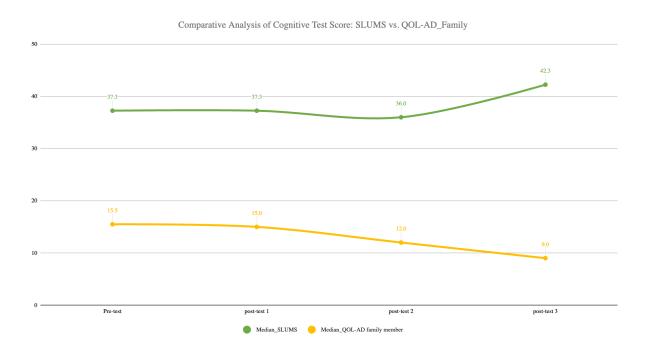


It measures Mental Status and cognitive function in persons with suspected or diagnosed dementia. A lower score means worse Mental Status.

QOL-AD patient

It measures the quality of life reported by patient.

The QoL-AD patient scores appear relatively stable, suggesting that the patients' quality of life has remained consistent despite the cognitive deterioration.



Measures Mental Status and cognitive function in persons with suspected or diagnosed dementia. A lower score means worse Mental Status.

QOL-AD Family

Measures the quality of life reported by the caregiver.

Although the cognitive condition of the patients deteriorates, the intervention provided could be improving aspects of life quality observed by family members.