



## Evidence-Base Support for the *I'm Still Here*<sup>®</sup> Approach to Dementia Care

This document represents the evidence base for the clinical and behavioral outcomes associated with the *I'm Still Here*<sup>®</sup> approach. The comprehensive approach includes planning and organization of the residential and clinical environment for care, operational issues related to creating a compatible and health-supportive flow of the day, training for family members and paid staff in the *I'm Still Here*<sup>®</sup> resident skills-supportive approaches to communication, dining, engagement, care, and behavior, and pre-post research adding to the growing *I'm Still Here*<sup>®</sup> evidence base and program improvement.

This report includes results drawn from studies carried out by our Research Division, articles by *I'm Still Here*<sup>®</sup> research staff, and other articles in the field supporting the approach. Highlights include:

- **Falls**
  - A long-term care community saw a reduction in falls for persons with dementia after being trained on the *I'm Still Here*<sup>®</sup> approach. Prior to the training, the average number of falls per month was 15.0. After the training, the average number of falls plummeted to 7.7 per month.
- **Antipsychotic Use**
  - A long term-community saw a reduction in antipsychotic use after being trained on the *I'm Still Here*<sup>®</sup> approach. Prior to the training, an average of 36.3% of residents per month with dementia were receiving antipsychotics. After the training, an average of 22.3% of residents per month were taking antipsychotics. Furthermore, in the second quarter following the *I'm Still Here*<sup>®</sup> training, antipsychotic usage reached an all-time low of 12.5%.
- **Cognition**
  - Hearthside Book Club<sup>®</sup> (HBC) is one of the central activities used as part of the *I'm Still Here*<sup>®</sup> approach. In an NIH-funded study, participants with late stage dementia ( $n=13$ ) exhibited an increase in cognition after regularly participating in Hearthside Book Club for six weeks. Prior to participation in HBC, the mean Mini-Mental Status Examination (MMSE) total score was 9.0 (SD=1.6). After participation in HBC, the mean MMSE score was 12.3 (SD=4.1). The increase in MMSE scores was statistically significant ( $p<.01$ ).
- **Neuropsychiatric Symptoms/Challenging Behaviors**
  - In an NIH-funded study, participants ( $n=108$ ) who regularly participated in Hearthside Book Club for three months exhibited a reduction in Neuropsychiatric Systems / Challenging Behaviors, based upon the Neuropsychiatric Nursing Home (NPI-NH). Prior to participation in HBC, the mean score on the NPI-NH was 6.52 (SD=8.52). After

participation in HBC, the mean score was 4.86 (SD=6.25). This change was statistically significant ( $p<.05$ ).

- **Apathy**
  - In an NIH-funded study, participants ( $n=108$ ) who regularly participated in Hearthsides Book Club for three months exhibited a reduction in Apathy, based upon the Neuropsychiatric Nursing Home (NPI-NH). Prior to participation in HBC, 34% of participant exhibited apathy. After participation in HBC, 21% of participants exhibited apathy. This change was statistically significant ( $p<.01$ ).
- **Depression**
  - In an NIH-funded study, participants ( $n=9$ ) who were depressed at baseline and who regularly participated in Hearthsides Book Club for three months exhibited a reduction in depression, based upon the Geriatric Depression Scale (GDS-SF). Prior to participation in the mean GDS-SF score was 7.78 (1.30). After participation in HBC, the mean GDS-SF score was 5.07 (2.54). This change was statistically significant ( $p<.05$ ).
- **Engagement/Affect**
  - In an NIH-funded study, Hearthsides Book Club ( $n=108$ ) produced higher levels of positive engagement/affect and lower levels of negative engagement/affect, as compared to standard activities. Constructive Engagement increased from 0.85 (SD=0.42) to 1.58 (SD=0.32). Pleasure increased from 0.36 (0.29) to 0.69 (0.29). Other Engagement decreased from 0.33 (SD=0.34) to 0.07 (SD=0.10). Non-Engagement decreased from 0.34 (SD=0.37) to 0.11 (SD=0.25). All changes were statistically significant ( $p<.01$ ).

The following table summarizes the evidence base for I’m Still Here® care training and design responses. The table summarizes the impact of I’m Still Here® programs and approaches on persons with dementia, as well as on family members, and members of staff. Data were obtained from a variety of sources, including NIH-funded studies, internal research on residents, literature reviews, and pre/post surveys with attendees of I’m Still Here® trainings.

**Table 1: Evidence-base for I’m Still Here® Programs and Approaches – Domains Impacted**

Domain	Outcomes	Research Setting	Measures
Aggression (Any Type)	<i>Reduced physical and/or verbal aggression in I’m Still Here® residences with homelike qualities</i>	15 Special Care Units (427 residents)	CMAI
Aggression (Verbal)	<i>Residences with an appropriate sensory environment are correlated with reduced verbal aggression</i>	15 Special Care Units (427 residents)	
Antipsychotic Use	<i>Percentage of participants taking antipsychotics reduced after staff training in the I’m Still Here® Approach</i>	Residents with dementia in a nursing home with staff trained on the I’m Still Here® Approach	% of Residents Taking Antipsychotics

Domain	Outcomes	Research Setting	Measures
Apathy	<i>Reduction in apathy after regular participation in level-adjusted reading groups</i>	Persons with dementia attending adult day centers and living at assisted living facilities and nursing homes	NPI-NH
Challenging Behaviors	<i>Reduction in challenging behaviors after 3 months I'm Still Here® Programming</i>	New resident records	CMAI
Challenging Behaviors	<i>The use of private rooms that contain personal belongings is correlated with reduced challenging behaviors</i>	15 Special Care Units (427 residents)	
Cognition	<i>Improved cognition after regular participation in level-adjusted reading groups</i>	Persons in long term care with late-stage dementia participating in I'm Still Here® Reading groups led by those trained in I'm Still Here® approach.	MMSE
Depression	<i>Reduction in clinical depressive symptoms after regular participation in I'm Still Here® level-adjusted reading groups</i>	Persons living with dementia in assisted living facilities and nursing homes, who reported depression at baseline, who attend I'm Still Here® trained adult day centers	GDS
Depression	<i>Reduction in depressive symptoms after taking part in two Scripted-IMPROV performances</i>	Persons with dementia attending adult day centers and living at assisted living facilities and nursing homes, who also reported depression at baseline	
Depression	<i>Reduced depression correlates with the presence of camouflaged exits and easily accessible exit controls.</i>	15 Special Care Units (427 residents)	MOSES
Eating, Self-Performance	<i>Increased independence with eating after experiencing I'm Still Here® programs for 3 months</i>	New resident records	MDS
Eating, Staff Assistance	<i>Reduced reliance on staff with eating after I'm Still Here® Programming for 3 months</i>	New resident records	
Engagement	<i>Higher levels of positive engagement for I'm Still Here® residents, as compared to residents at a similar type of residence</i>	I'm Still Here® residents vs. similar sample of residents residing in a comparable long-term care facility	MPES

Domain	Outcomes	Research Setting	Measures
Engagement	<i>Higher levels of positive engagement and lower levels of negative engagement, as compared to standard programming, for persons who took part in Scripted-IMPROV performances</i>	Persons with dementia attending adult day centers who live at assisted living facilities and nursing homes	
Engagement	<i>Higher levels of positive engagement and lower levels of negative engagement, as compared to standard programming, for persons who regularly took part in reading groups</i>	Persons with dementia who attend adult day centers who live in assisted living facilities and nursing homes	
Falls	<i>Reduced falls per month after staff is trained in the I'm Still Here® Approach</i>	Persons with dementia residing in a nursing home that was trained on the I'm Still Here® Approach	Falls Per Month (on Average Over a Full Year)
Pleasure	<i>Increase in pleasure, as compared to standard activities, for persons who took part in reading groups</i>	Persons with dementia attending adult day centers and living at assisted living facilities and nursing homes	MPES
Pleasure	<i>Increase in pleasure, as compared to standard activities, for persons who took part in Scripted-IMPROV</i>	Persons with dementia attending adult day centers and living at assisted living facilities and nursing homes	MPES
Psychiatric Problems	<i>The use of private rooms that contain personal belongings correlates with reduced psychiatric problems</i>	15 Special Care Units (427 residents)	BEHAVE-AD
Psychiatric Problems	<i>Residences with an appropriate sensory environment correlates with reduced psychiatric problems</i>	15 Special Care Units (427 residents)	
Psychiatric Problems	<i>Residences with appropriate walking paths are correlated with reduced psychiatric problems</i>	15 Special Care Units (427 residents)	
Quality of Life	<i>Increase in quality of life after 3 months of I'm Still Here® programs</i>	New resident records	DEM-QOL
Quality of Life	<i>Increase in quality of life after regular participation in reading groups</i>	Persons with dementia attending adult day centers and living at assisted living facilities and nursing homes	

Domain	Outcomes	Research Setting	Measures
Quality of Life	<i>Higher quality of life for I'm Still Here® residents, as compared to similar samples of residents in the US and the UK</i>	I'm Still Here® residents vs. similar UK/USA samples	
Social Withdrawal	<i>The presence of several unique common spaces is correlated with reduced social withdrawal</i>	15 Special Care Units (427 residents)	MOSES
Staff Utilization of Best Practices	<i>Increased use of I'm Still Here® principles after participation in I'm Still Here® trainings</i>	Staff/Family Member Training Attendees	I'm Still Here® Principles Checklist
Stigma	<i>Higher percentage of I'm Still Here® residents believe that persons with dementia "know who they are" and "can remember things," as compared to a similar sample</i>	I'm Still Here® residents vs. similar UK/USA samples	Zeisel Stigma Scale
Stigma	<i>Reduced stigmatized beliefs after participation in an I'm Still Here® training</i>	Staff/Family Member Training Attendees	

## Evidence-Base Report

The Hearthstone Institute is committed to evaluating the impact of its signature education and embedding program on persons living with dementia. To assess impact, the evaluations carried out to compare data collected on residents before the training begins (Pre-Training) and again after the training is complete (Post-Training). The goal is to determine whether and to what extent persons with dementia are impacted when those with whom they interact receive training on the I'm Still Here® approach (Zeisel, 2009) on a regular basis.

Persons with dementia generally are expected to experience a decline in various parts of their lives as their condition progresses. For example, it is well-known that cognition is expected to decline as the condition progresses—in fact, a progressive decline in cognition is a primary symptom of dementia (Reisberg et al., 1985). Other changes also occur often in the person's life.

From a research perspective, it is argued by some that conducting a Randomized Control Trial is the gold standard of research – the best way to feel confident that a hypothesis is valid. Such trials randomly generate one group (the Treatment Group) that participates in the program being evaluated, and another Control Group that does not. In situations – such as for immersive programs like I'm Still Here® programs – where it is neither practical nor ethical to employ such a study design, other rigorous and equally convincing best-practice research designs are both and reliable – also gold standards.

This is the case for comprehensive real-world interventions such as I'm Still Here®.

## OUTCOMES

The results for each Domain / Measure are presented employing the following standard format: first a narrative description of outcomes related to the Domain / Measure is presented; then a chart visually represents the outcomes. As mentioned earlier, the statistical significance or directional trends of findings are identified in the narrative and in the charts by  $p < .01$ ,  $p < .05$  and  $p < .10$ .

The following illustrated examples indicate specific outcomes for residents and staff evaluated as part of I'm Still Here® standard Pre-Post Training. General findings outcomes are as follows:

I'm Still Here® education, training & embedding program at COMPANY produced the following positive outcomes:

1. Increase in engagement
2. Improvement / preservation in cognition
3. Increase in quality of life
4. Decrease in responsive behaviors
5. Increase in staff member knowledge

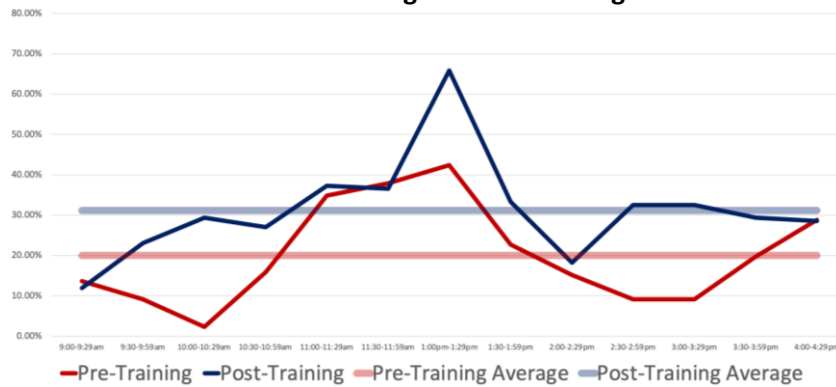
### Outcomes Example #1

A total of 17 nursing home residents living with dementia took part in an evaluation of the impact of Hearthstone's training and embedding programming. Data were collected on residents prior to the training / embedding ("Pre-Training") and then again after the training / embedding ("Post Training"). Approximately one year elapsed from Pre- to Post-Training. The following outcomes were observed:

1. There was a 32% statistically significant ( $p < .05$ ) decrease in neuropsychiatric symptoms from Pre-Training to Post-Training based upon the Neuropsychiatric Inventory – Nursing Home (NPI-NH). More specifically, the Frequency x Severity (F x S) total score at Pre-Training was 44.94. This figure dropped to 30.48 at Post-Training. This suggests that the Hearthstone training / embedding successfully reduced neuropsychiatric symptoms in residents with dementia. Such symptoms negatively affect the resident's quality life and make providing care challenging for care partners.
2. There was a 10% increase in quality of life based upon the Quality of Life – Alzheimer's Disease (QOL-AD) scale. More specifically, the QOL-AD total score at Pre-Training was 23.4. This increased to 25.9 at Post-Training. This increase approached significance ( $p = 0.07$ ). This suggests that residents directly benefited from the training/embedding by experiencing a higher quality of life.

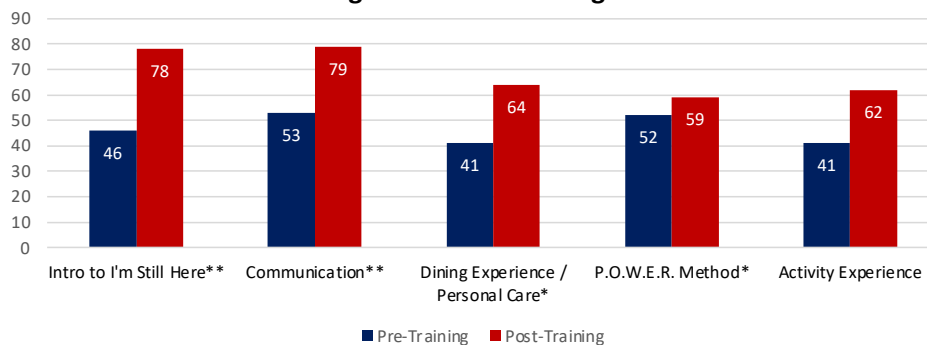
In addition, all nursing home residents were observed in activity programming during Pre- and Post-Training. As shown in Chart 1, there was an 11% statistically significant ( $p < .05$ ) increase in positive engagement from Pre- to Post-Training.

**CHART 1**  
**Nursing Home #1 Residents Positively Engaged Throughout the Day:**  
**Pre-Training vs. Post-Training**



Staff members also took quizzes before and after each training session. As seen in Chart 2, there was a statistically significant ( $p < .01$  or  $p < .05$ , as indicated by the asterisks (\*) in the chart) increase knowledge from Pre- to Post-Training for all training modules. As such, it is likely that the knowledge is the reason for the changes seen in the residents.

**CHART 2**  
**Nursing Home #1 Knowledge Transfer**



\*\* $p < .01$  for Pre-Trainings vs. Post-Training paired sample t-test

\* $p > .05$  for Pre-Trainings vs. Post-Training paired sample t-test

### Outcomes Example #2

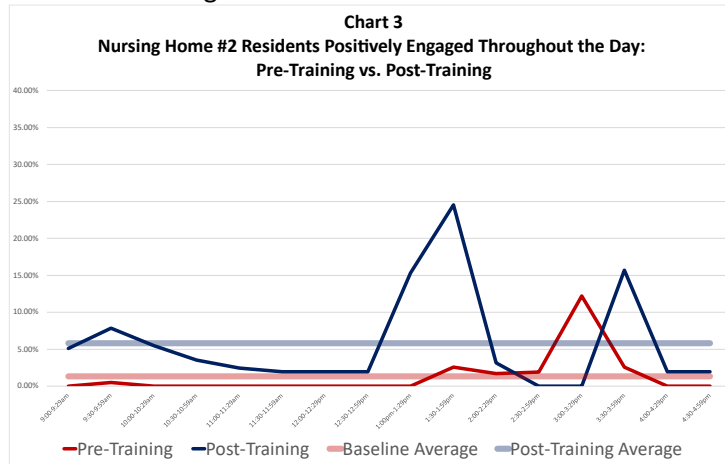
A total of 16 nursing home residents living with dementia took part in an evaluation of the impact of Hearthstone's training and embedding programming. Data were collected on at Pre-Training and then again at Post-Training. Approximately 10 months elapsed from Pre- to Post-Training. The following outcomes were observed:

1. There was a 41% statistically significant ( $p < .05$ ) decrease in depressive symptoms from Pre-Training to Post-Training based upon the Geriatric Depression – Short Form (NPI-NH). More specifically, the total score on the GDS-SF at Pre-Training was 3.9. This figure dropped to 2.3 at Post-Training. This suggests that the Hearthstone training / embedding successfully reduced depressive symptoms in residents with dementia.
2. There was a slight (5%) increase in cognition based upon the Brief Interview for Mental Status (BIMS). While this change was not statistically significant, the finding is notable since cognition typically declines in persons with dementia over time. One would certainly expect there to be a decline in the 10 months that elapsed between Pre- and Post-Training. As such, it appears that the Hearthstone training may have had a slightly protective effect on cognition.
3. There was a 6% increase in quality of life based upon the QOL-AD scale. More specifically, the QOL-AD total score at Pre-Training was 23.67. This figure increased to 25.13 at Post-Training.

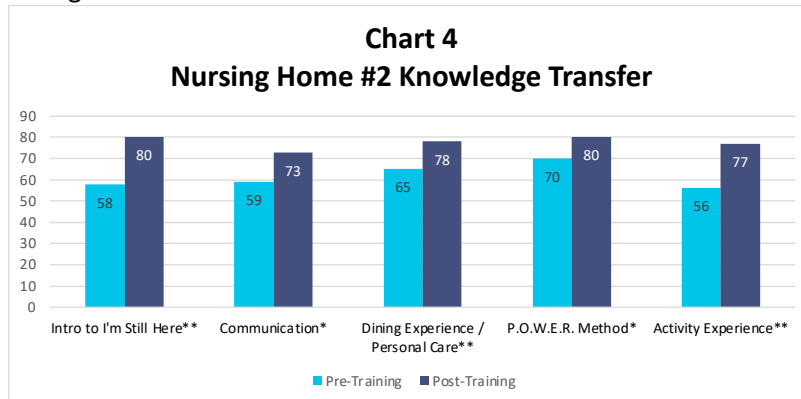


This increase approached significance ( $p=0.11$ ). This suggests that residents directly benefited from the training/embedding by experiencing a higher quality of life.

In addition, all nursing home residents were observed in activity programming during Pre- and Post-Training. As shown in Chart 3, there was a 5% statistically significant ( $p<.05$ ) increase in positive engagement from Pre- to Post-Training.



Staff members also took quizzes before and after each training session. As seen in Chart 4, there was a statistically significant ( $p<.01$  or  $p<.05$ , as indicated by the asterisks (\*) in the chart) increase knowledge from Pre- to Post-Training for all training modules. As such, it is likely that the knowledge is the reason for the changes seen in the residents.



\*\* $p<.01$  for Pre-Trainings vs. Post-Training paired sample t-test

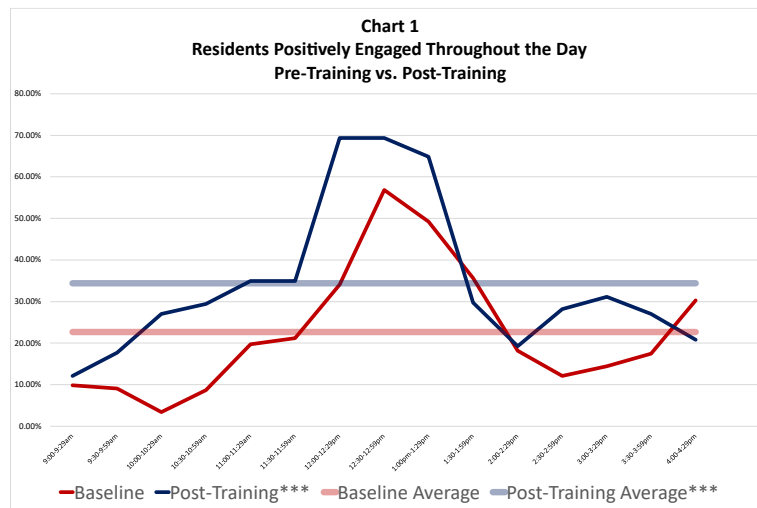
\* $p>.05$  for Pre-Trainings vs. Post-Training paired sample t-test

## ENGAGEMENT

- **DESIRED OUTCOME: Increase in Positive Forms of Engagement**

The data suggest that residents were more positively engaged after staff were trained on the I'm Still Here® approach. In Chart 1, the red lines represent positive engagement at Pre-Training, with the darker red line displaying the actual percentages of residents at each time of day and the lighter red line displaying the mean percentage across the entire day. The blue lines represent positive engagement at Post-Training (dark blue = actual percentage at each time of day; light blue = mean percentage across the entire day). The mean percentage of COMPANY residents positively engaged increased significantly from Pre-Training (mean = 23%) to Post-Training (mean = 34%). The data suggest that Hearthstone's training had a positive impact on engagement of residents living with dementia.



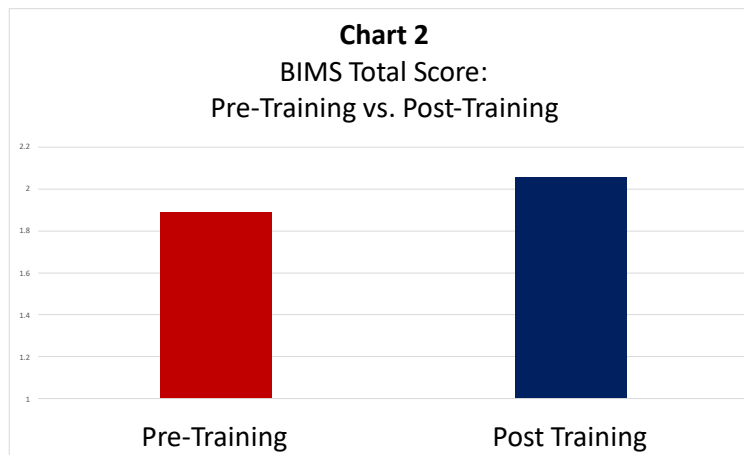


\*\*\* Change from Pre-Training to Post-Training was significant at the  $p < .01$  level

## COGNITION

- **DESIRED OUTCOME: Increase in Cognition or Preservation of Current Levels of Cognition**

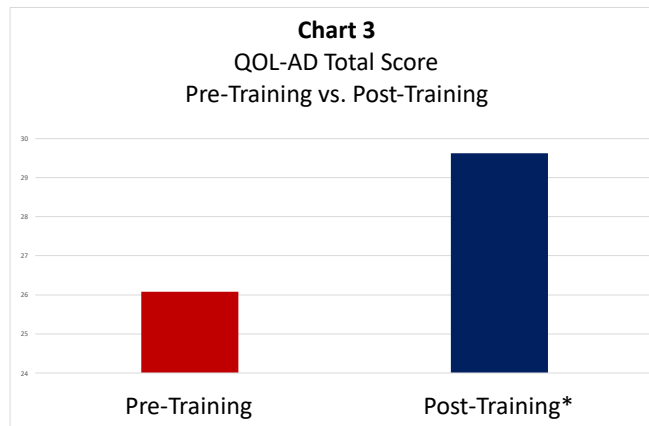
COMPANY residents experienced a 9% improvement in cognition from Pre- to Post-Training based on a BIMS mean of 1.89 at Pre-Training to a Post-Training mean of 2.06. Although the increase in cognition was small, any increase in cognition can be interpreted as a positive trend, because persons living with dementia typically experience a decline in cognition over time. The Pre- to Post-Training assessment reflected a 12-month period. Even if cognition had remained the same with no increase identified, this would be a positive finding.



## QUALITY OF LIFE

- **DESIRED OUTCOME: Increase in Quality of Life**

COMPANY A residents reported a statistically significant ( $p < .10$ ) 14% increase in Quality of Life (based on the QOL-AD) from Pre- (Mean=26.08) and Post-Training (Mean=29.61). As such, the data suggest that the Hearthstone training had a positive impact on Quality of Life.

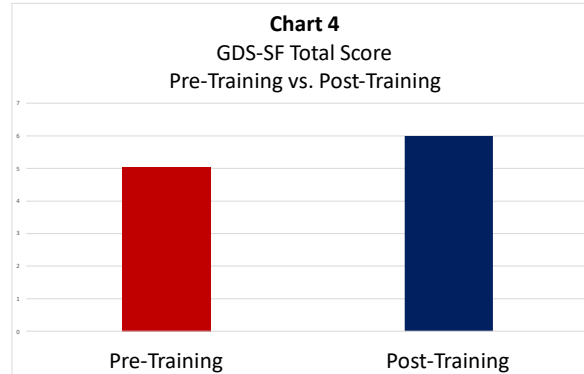


Change from Pre-Training to Post-Training was significant at the  $p < .10$  level

## DEPRESSION

- **DESIRED OUTCOME: Decrease in Depressive Symptoms**

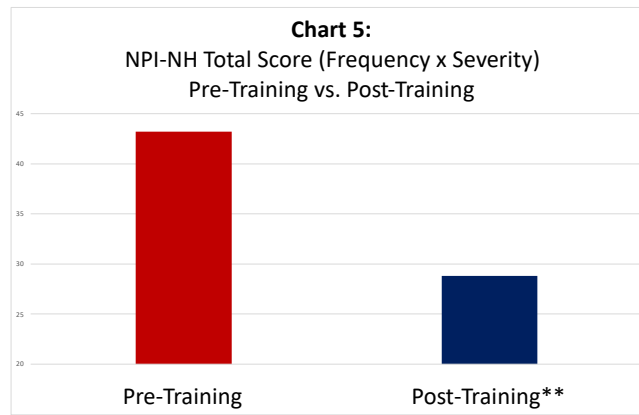
COMPANY A residents experienced a non-significant 19% increase in depressive symptoms (based on the GDS-SF) from Pre-training (Mean=5.05) to Post-Training (Mean=5.99). This slight increase in depressive symptoms is not surprising, as depression often increases in dementia over time. It is quite likely that, without the Hearthstone training, depression would have increased even more from Pre- to Post-Training.



## RESPONSIVE BEHAVIORS

- **DESIRED OUTCOME: Decrease in Responsive Behaviors**

COMPANY A residents experienced a 33% statistically significant ( $p < .05$ ) decrease in Responsive Behaviors, based on the *Frequency x Severity (F x S)* total score on the NPI-NH. At Pre-Training the score was 43.22, while at Post-Training the score was 28.79. This decrease in Responsive Behaviors suggests that the Hearthstone training reduced responsive behaviors in residents living with dementia.



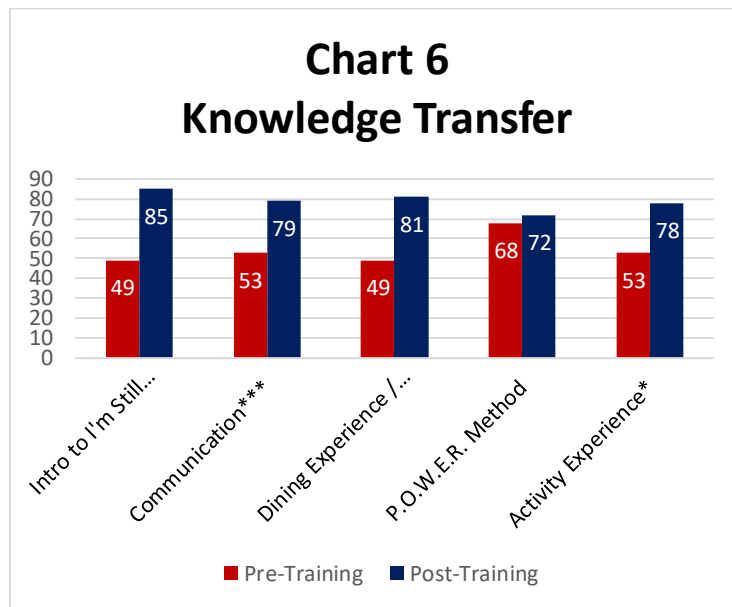
## KNOWLEDGE TRANSFER

- **DESIRED OUTCOME: Increase in Knowledge**

As shown in Table 2 and Chart 6 below, there were statistically significant improvements for most Training Modules from Pre-Training to Post-Training. The greatest increase was seen in *Introduction to I'm Still Here*® Training Module, due to the major culture change addressed in this module, as well as that the 49% Pre-Training score for this module left a lot of room for improvement. The smallest improvement was seen in the *P.O.W.E.R. Method* Training Module, due in part to the “ceiling effect” of the relatively high Pre-Training score. That is, staff members scored relatively high at Pre-Training (68%), meaning there was little room for improvement. Overall, the Hearthstone training resulted in a significant increase in knowledge for COMPANY A staff.

**TABLE 2. KNOWLEDGE TRANSFER**

	Pre-Training Mean % (SD)	Post-Training Mean % (SD)	Pre-Post CHANGE
<b>Introduction to I'm Still Here® (N=48)</b>	49%	85%***	<b>+36%</b>
<b>Communication (N=38)</b>	53%	79%***	<b>+26%</b>
<b>Dining Experience/Personal Care (N=31)</b>	49%	81%***	<b>+31%</b>
<b>P.O.W.E.R. Method (N=25)</b>	68%	72%	<b>+4%</b>
<b>Activity Experience (N=22)</b>	53%	78%*	<b>+25%</b>



\*\*\* Change from Pre-Training to Post-Training was significant at the  $p < .01$  level

\*\* Change from Pre-Training to Post-Training was significant at the  $p < .05$  level

\* Change from Pre-Training to Post-Training was significant at the  $p < .10$  level

## SUMMARY

I'm Still Here® education, training & embedding program at COMPANY `produced the following positive outcomes.

1. Increase in engagement
2. Improvement / preservation in cognition
3. Increase in quality of life
4. Decrease in responsive behaviors
5. Increase in staff member knowledge

## REFERENCES

The following section presents descriptions and references for the evaluation measures employed. These are followed by two lists of references to articles containing evidence in support of the approach. First are articles authored or co-authored by members of the research staff; second are supporting articles by other professionals in the field of nonpharmacological treatment for dementia.

### Evidence-Base Articles & Chapters – Research Division Authors

Zeisel, J. (1999). Life-Quality Alzheimer Care in Assisted Living. In Schwarz, B., & Brent, R. (Eds.).

(1999). *Aging, autonomy, and architecture: Advances in assisted living*. Baltimore, MD: JHU Press.

Zeisel, J. (2001). Universal Design to Support the Brain and its Development. In Preiser, W. F. *Universal design handbook*. New York, NY: McGraw-Hill.

Zeisel, J. (2005). Environment, neuroscience, and Alzheimer's disease. *Alzheimer's Care Today*, 6(4), 273-279.

- Zeisel, J. (2006). *Inquiry by design: Environment/behavior/neuroscience in architecture, interiors, landscape, and planning*. WW Norton & Co.
- Zeisel, J. (2007). Creating a therapeutic garden that works for people living with Alzheimer's. *Journal of Housing for the Elderly*, 21(1-2), 13-33.
- Zeisel, J. (2009). *I'm still here: A breakthrough approach to understanding someone living with Alzheimer's*. New York, NY: Penguin.
- Zeisel, J., Hyde, J., & Levkoff, S. (1994). Best practices: An Environment Behavior (EB) model for Alzheimer special care units. *The American Journal of Alzheimer's Care and Related Disorders and Research*.
- Zeisel, J., Hyde, J., & Shi, L. (1999). Environmental Design as Treatment for Alzheimer's Disease. In Volicer, L., & Bloom-Charette, L. (Eds.) *Enhancing the quality of life in advanced dementia* (pp. 206-221), Philadelphia, PA: Psychology Press.
- Zeisel, J., & Raia, P. (2000). Nonpharmacological treatment for Alzheimer's disease: A mind-brain approach. *American Journal of Alzheimer's Disease and Other Dementias*, 15(6), 331-340.
- Zeisel, J., Silverstein, N. M., Hyde, J., Levkoff, S., Lawton, M. P., & Holmes, W. (2003). Environmental correlates to behavioral health outcomes in Alzheimer's special care units. *The Gerontologist*, 43(5), 697-711.
- Zeisel, J. & Tyson, M. M (1999). Alzheimer's Treatment Gardens. In Marcus, C. C., & Barnes, M. (Eds.). (1999). *Healing gardens: Therapeutic benefits and design recommendations*. New York, NY: John Wiley & Sons.
- Camp, C. J., Breedlove, J., Malone, M. L., Skrajner, M. J., & McGowan, A. (2007). Adjusting activities to meet CMS guidelines using Montessori-Based Dementia Programming®. *Activity Director's Quarterly*, 8(1), 34-46.
- Camp, C. J., & Skrajner, M. J. (2004). Resident-assisted Montessori programming (RAMP): Training persons with dementia to serve as group activity leaders. *The Gerontologist*, 44, 426-431.
- Camp, C.J., Skrajner, M.S., & Gorzelle (2015). Engagement in dementia. In Volicer, L., & Hurley, A (Eds.), *Assessment Scales for Advanced Dementia* (71-78). Baltimore, Maryland: Health Professions Press.
- Camp, C. J., Skrajner, M. J., & Kelly, M. (2005). Early stage dementia client as group leader. *Clinical Gerontologist*, 28(4), 81-85.
- Camp, C. J., Skrajner, M. J., Lee, M. M., & Judge, K. S. (2010). Cognitive assessment in late stage dementia. In P. A. Lichtenberg (Ed.), *Handbook of assessment in clinical gerontology* (2<sup>nd</sup> edition). New York: John Wiley & Sons.
- Malone, M., Skrajner, M., Camp, C., Neundorfer, M., & Gorzelle, G. (2007). Research in practice II: Spaced retrieval, a memory intervention. *Alzheimer's Care Quarterly*, 8(1): 65-74.
- Neundorfer, M.M, Camp, C. J., Lee, M. M., Skrajner, M. J., Malone, M. L., & Carr, J. R. (2004). Compensating for cognitive deficits in persons aged 50 and over with HIV/AIDS: A pilot study of a cognitive intervention. *Journal of HIV/AIDS and Social Services*, 3, 79-97.
- Rose, M.S., Camp, C.J., Skrajner, M.J., & Gorzelle, G.J. (2003). Enhancing the quality of nursing home visits with Montessori-based activities. *Activities Directors' Quarterly*, 3, 4-10.
- Skrajner, M. J., & Camp, C. J. (2007). Resident-assisted Montessori programming (RAMP™): Use of a small group reading activity run by persons with dementia in adult day health care and long-term care settings. *The American Journal of Alzheimer's Disease & Other Dementias*, 22(1), 27-36.

Skrajner, M. J., Camp, C. J., Haberman, J. L., Heckman, T. G., Kochman, A., & Frentiu, C. (2009). Use of videophone technology to address medication adherence issues in persons with HIV. *HIV/AIDS (Auckland, NZ)*, 1, 23.

Skrajner, M. J., Camp, C. J., Heckman, T. G., Haberman, J. L., & Kochman, A. (2011). A fluctuating pattern of over- and under-adherence for HAART: A case study from a videophone intervention project. *Clinical Gerontologist*, 34(2), 144-153.

Skrajner, M. J., Haberman, J. L., Camp, C. J., Tusick, M., Frentiu, C., & Gorzelle, G. (2012) Training nursing home residents to serve as group activity leaders: Lessons learned and preliminary lessons learned from the RAP project. *Dementia*, 11(2), 263-274. 10.1177/1471301212437457

Skrajner, M. J., Haberman, J. L., Camp, C. J., Tusick, M., Frentiu, C., & Gorzelle, G. (2014). Effects of using nursing home residents to serve as group activity leaders: Lessons learned from the RAP project. *Dementia*, 13(2), 274-285.

Skrajner, M., Malone, M., Camp, C., McGowan, A., & Gorzelle, G. (2007). Research in practice I: Montessori-based dementia programming. *Alzheimer's Care Quarterly*, 8(1): 53-64.

## **Evidence-Base Articles for I'm Still Here® Approach – Generic**

Alessi CA, Martin JL, Webber AP, et al. Randomized, controlled trial of a nonpharmacological intervention to improve abnormal sleep/wake patterns in nursing home residents. *J Am Geriatr Soc*. May 2005;53(5):803-810.

Alessi CA, Yoon EJ, Schnelle JF, Al-Samarrai NR, Cruise PA. A randomized trial of a combined physical activity and environmental intervention in nursing home residents: do sleep and agitation improve? *J Am Geriatr Soc*. Jul 1999;47(7):784-791.

American Veterinary Medical Association. Guidelines for Animal Assisted Activity, Animal-Assisted Therapy and Resident Animal Programs. *Current as of 2007*. [http://www.avma.org/issues/policy/animal\\_assisted\\_guidelines.asp](http://www.avma.org/issues/policy/animal_assisted_guidelines.asp).

Atkins D, Best D, Briss PA, et al. Grading quality of evidence and strength of recommendations. *Bmj*. Jun 19 2004;328(7454):1490.

Ayalon L, Gum AM, Feliciano L, Arian PA. Effectiveness of nonpharmacological interventions for the management of neuropsychiatric symptoms in patients with dementia: a systematic review. *Arch Intern Med*. Nov 13 2006;166(20):2182-2188.

Batson K, McCabe B, Baun MM, Wilson C. *The effect of a therapy dog on socialization and physiological indicators of stress in persons diagnosed with Alzheimer's disease*. Thousand Oaks, CA: Sage Publications, Inc; 1998.

Baum EE, Jarjoura D, Polen AE, et al. Effectiveness of a group exercise program in a long-term care facility: a randomized pilot trial. *Journal of the American Medical Directors Association*. Mar-Apr 2003;4(2):74-80.

Beck CK, Vogelpohl TS, Rasin JH, et al. Effects of behavioral interventions on disruptive behavior and affect in demented nursing home residents. *Nurs Res*. Jul-Aug 2002;51(4):219-228.

Braben I. A Song for Mrs. Smith. *Nursing Times*. 1992;88(41):54.

Brottons M, Koger SM, Pickett-Cooper P. Music and dementias: A review of literature. *Journal of Music Therapy*. Win 1997;34(4):204-245.

Brozek JL, Akl EA, Alonso-Coello P, et al. Grading quality of evidence and strength of recommendations in clinical practice guidelines. Part 1 of 3. An overview of the GRADE approach and grading quality of evidence about interventions. *Allergy*. May 2009;64(5):669-677.

Campbell, D. T., & Stanley, J. C. (2015). *Experimental and quasi-experimental designs for research*. Ravenio books.

Carter ND, Kannus P, Khan KM. Exercise in the prevention of falls in older people: a systematic literature review examining the rationale and the evidence. *Sports Med*. 2001;31(6):427-438.

Centre for Evidence Based Medicine. Levels of Evidence (March 2009). <http://www.cebm.net/index.aspx?o=1025> Accessed Feb. 15, 2011.

Churchill M, Safaoui J, McCabe BW, Baun MM. Using a therapy dog to alleviate the agitation and desocialization of people with Alzheimer's disease. *J Psychosoc Nurs Ment Health Serv*. Apr 1999;37(4):16-22.

Clark ME, Lipe AW, Bilbrey M. Use of music to decrease aggressive behaviors in people with dementia. *J Gerontol Nurs*. Jul 1998;24(7):10-17. **43**

Cohen-Mansfield J, Libin A, Marx MS. Nonpharmacological treatment of agitation: a controlled trial of systematic individualized intervention. *J Gerontol A Biol Sci Med Sci*. Aug 2007;62(8):908-916.

Cuddy LL, Duffin J, Cuddy LL, Duffin J. Music, memory, and Alzheimer's disease: is music recognition spared in dementia, and how can it be assessed? *Med Hypotheses*. 2005;64(2):229-235.

Edwards NE, Beck AM. Animal-assisted therapy and Nutrition in Alzheimer's disease. *West J Nurs Res*. Oct 2002;24(6):697-712.

Eggermont LH, Scherder EJ. Physical activity and behaviour in dementia: A review of the literature and implications for psychosocial intervention in primary care. *Dementia: The International Journal of Social Research and Practice*. Aug 2006;5(3):411-428.

Forbes D, Forbes S, Morgan DG, Markle-Reid M, Wood J, Culum I. Physical activity programs for persons with dementia. *Cochrane Database of Systematic Reviews*. 2009(3).

Forbes D, Morgan DG, Bangma J, Peacock S, Adamson J. Light Therapy for Managing Sleep, Behaviour, and Mood Disturbances in Dementia. *Cochrane Database of Systematic Reviews*. 2009(3).

Francesse T, Sorrell J, Butler FR. The effects of regular exercise on muscle strength and functional abilities of late stage Alzheimer's residents. *American Journal of Alzheimer's Disease and Other Dementias*. 1997;12(3):122-127.

Gerdner LA. Effects of individualized versus classical "relaxation" music on the frequency of agitation in elderly persons with Alzheimer's disease and related disorders. *International Psychogeriatrics*. Mar 2000;12(1):49-65.

Gitlin LN, Winter L, Dennis MP, et al. A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *JAMA*. Sep 1 2010;304(9):983-991.

Gleeson M, Timmins F. The use of touch to enhance nursing care of older person in long-term mental health care facilities. *Journal of Psychiatric & Mental Health Nursing*. Oct 2004;11(5):541-545.

Goy E, Freeman M, Kansagara D. A systematic evidence review of interventions for non-professional caregivers of patients with dementia. A report by the Evidence-based Synthesis Program of Veterans Health Administration, Health Services Research & Development. Washington, DC. May, 2009.



Greer KL, Pustay KA, Zaun TC, Coppens P. A comparison of the effects of toys versus live animals on the communication of patients with dementia of the Alzheimer's type. *Clinical Gerontologist: The Journal of Aging and Mental Health*. 2001;24(3-4):157-182.

Groene RW. Effectiveness of music therapy 1:1 intervention with individuals having senile dementia of the Alzheimer's type. *Journal of Music Therapy*. 1993;30(3):138-157.

Hansen NV, Jorgensen T, Ortenblad L. Massage and touch for dementia. *Cochrane Database of Systematic Reviews*. 2009(3).

Henderson NK, White CP, Eisman JA. The roles of exercise and fall risk reduction in the prevention of osteoporosis. *Endocrinol Metab Clin North Am*. Jun 1998;27(2):369-387.

Hermans D, Htay UH, McShane R. Non-pharmacological interventions for wandering of people with dementia in the domestic setting. *Cochrane Database of Systematic Reviews*. 2009(3).

Heyn P, Abreu BC, Ottenbacher KJ. The effects of exercise training on elderly persons with cognitive impairment and dementia: a meta-analysis. *Arch Phys Med Rehabil*. Oct 2004;85(10):1694-1704.

Hoe, J., Hancock, G., Livingston, G., Woods, B., Challis, D., & Orrell, M. (2009). Changes in the quality of life of people with dementia living in care homes. *Alzheimer disease and associated disorders*, 23(3), 285.

Honda, Y., Meguro, K., Meguro, M., & Akanuma, K. (2013). Social withdrawal of persons with vascular dementia associated with disturbance of basic daily activities, apathy, and impaired social judgment. *Care Management Journals*, 14(2), 108-113.

Holliman DC, Orgassa UC, Forney JP. Developing an interactive physical activity group in a geriatric psychiatry facility. *Activities, Adaptation and Aging*. 2001;26(1):57-69.

Holt FE, Birks TPH, Thorgrimsen LM, Spector AE, Wiles A, Orrell M. Aroma therapy for dementia. *Cochrane Database of Systematic Reviews*. 2009(3).

Inouye SK, Bogardus ST, Jr., Charpentier PA, et al. A multicomponent intervention to prevent delirium in hospitalized older patients. *N Engl J Med*. Mar 4 1999;340(9):669- 676.

Kong EH, Evans LK, Guevara JP. Nonpharmacological intervention for agitation in dementia: a systematic review and meta-analysis. *Aging Ment Health*. Jul 2009;13(4):512- 520.

Kongable LG, Buckwalter KC, Stolley JM. The effects of pet therapy on the social behavior of institutionalized Alzheimer's clients. *Arch Psychiatr Nurs*. Aug 1989;3(4):191- 198.

Kumar, A., Sidhu, J., Goyal, A., & Tsao, J. W. (2018). Alzheimer disease.

Lauriks S, Reinersmann A, Van der Roest HG, et al. Review of ICT-based services for identified unmet needs in people with dementia. *Ageing Res Rev*. Oct 2007;6(3):223-246.

Livingston G, Johnston K, Katona C, Paton J, Lyketsos CG, Old Age Task Force of the World Federation of Biological P. Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *Am J Psychiatry*. Nov 2005;162(11):1996-2021.

Logsdon RG, McCurry SM, Teri L. Evidence-based psychological treatments for disruptive behaviors in individuals with dementia. *Psychol Aging*. Vol 22. 2007/03/28 ed. 2007:28-36.

Luijpen MW, Scherder EJ, Van Someren EJ, Swaab DF, Sergeant JA. Non-pharmacological interventions in cognitively impaired and demented patients--a comparison with cholinesterase inhibitors. *Rev Neurosci*. 2003;14(4):343-368.

- Martindale BP. Effect of animal-assisted therapy on engagement of rural nursing home residents. *American Journal of Recreation Therapy*. 2008;7(4):45-53.
- McCabe BW, Baun MM, Speich D, Agrawal S. Resident dog in the Alzheimer's special care unit. *West J Nurs Res*. Oct 2002;24(6):684-696.
- McCallion P, Toseland RW, Freeman K. An evaluation of a family visit education program. *J Am Geriatr Soc*. Feb 1999;47(2):203-214.
- McCurry SM, Gibbons LE, Logsdon RG, et al. Nighttime insomnia treatment and education for Alzheimer's disease: a randomized, controlled trial. *J Am Geriatr Soc*. May 2005;53(5):793-802.
- Mulrow CD, Gerety MB, Kanten D, et al. A randomized trial of physical rehabilitation for very frail nursing home residents. *JAMA*. Feb 16 1994;271(7):519-524.
- Music cognition in Alzheimer's disease. *Semin Neurol*. Jun 989;9(2):152-58.
- National Institute for Health and Clinical Excellence (NICE). Dementia: A NICE-SCIE Guideline on supporting people with dementia and their carers in health and social care. National Clinical Practice Guideline Number 42. Vol: The British Psychological Society and Gaskell; 2007.
- O'Connor DW, Ames D, Gardner B, King M. Psychosocial treatments of psychological symptoms in dementia: a systematic review of reports meeting quality standards. *Int Psychogeriatr*. Apr 2009;21(2):241-251.
- O'Connor DW, Ames D, Gardner B, King M. Psychosocial treatments of behavior symptoms in dementia: a systematic review of reports meeting quality standards. *Int Psychogeriatr*. Apr 2009;21(2):225-240.
- Opie J, Rosewarne R, O'Connor DW. The efficacy of psychosocial approaches to behaviour disorders in dementia: a systematic literature review. *Aust N Z J Psychiatry*. Dec 1999;33(6):789-799.
- Price JD, Hermans D, Grimley Evans J. Subjective barriers to prevent wandering of cognitively impaired people. *Cochrane Database of Systematic Reviews*. 2009(3).
- Proctor R, Burns A, Powell HS, et al. Behavioural management in nursing and residential homes: a randomised controlled trial. *Lancet*. Jul 3 1999;354(9172):26-29.
- Reisberg, B., Gordon, B., McCarthy, M., & Ferris, S. H. (1985). Clinical symptoms accompanying progressive cognitive decline and Alzheimer's disease. In *Alzheimer's dementia* (pp. 19-39). Humana Press.
- Ragneskog H, Brane G, Karlsson I, Kihlgren M. Influence of dinner music on food intake and symptoms common in dementia. *Scand J Caring Sci*. 1996;10(1):11-17.
- Richeson NE. Effects of animal-assisted therapy on agitated behaviors and social interactions of older adults with dementia. *Am J Alzheimers Dis Other Demen*. Nov-Dec 2003;18(6):353-358.
- Robinson L, Hutchings D, Corner L, et al. A systematic literature review of the effectiveness of non-pharmacological interventions to prevent wandering in dementia and evaluation of the ethical implications and acceptability of their use. *Health Technol Assess*. Aug 2006;10(26):iii, ix-108.
- Robinson L, Hutchings D, Dickinson HO, et al. Effectiveness and acceptability of non-pharmacological interventions to reduce wandering in dementia: a systematic review. *Int J Geriatr Psychiatry*. Jan 2007;22(1):9-22.
- Rolland Y, Pillard F, Klapouszczak A, et al. Exercise program for nursing home residents with Alzheimer's disease: a 1-year randomized, controlled trial. *J Am Geriatr Soc*. Feb 2007;55(2):158-165.
- Sherratt K, Thornton A, Hatton C. Music interventions for people with dementia: A review of the literature. *Aging & Mental Health*. Jan 2004;8(1):3-12.

Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith, P., ... & Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. *Health Technology Assessment (Winchester, England)*, 9(10), 1-iv.

Stevens J, Killeen M, Stevens J, Killeen M. A randomised controlled trial testing the impact of exercise on cognitive symptoms and disability of residents with dementia. *Contemp Nurse*. Feb-Mar 2006;21(1):32-40.

Suhr J, Anderson S, Tranel D. Progressive Muscle Relaxation in the Management of Behavioural Disturbance in Alzheimer's Disease. *Neuropsychological Rehabilitation*. 1999;9(1):31-44.

Sung HC, Chang AM. Use of preferred music to decrease agitated behaviours in older people with dementia: a review of the literature. *J Clin Nurs*. Oct 2005;14(9):1133-1140.

Swartz KP, Hantz EC, Crummer GC, Walton JP, Frisina RD. Does the melody linger on?

Teri L, Gibbons LE, McCurry SM, et al. Exercise plus behavioral management in patients with Alzheimer disease: a randomized controlled trial. *JAMA*. Oct 15 2003;290(15):2015- 2022.

Teri L, Huda P, Gibbons L, et al. STAR: a dementia-specific training program for staff in assisted living residences. *Gerontologist*. Oct 2005;45(5):686-693.

Teri L, Logsdon RG, McCurry SM. Nonpharmacologic treatment of behavioral disturbance in dementia. *Med Clin North Am*. 2002 May 2002;86(3):641-656.

Teri L, Logsdon RG, Uomoto J, McCurry SM. Behavioral treatment of depression in dementia patients: a controlled clinical trial. *J Gerontol B Psychol Sci Soc Sci*. Jul 1997;52(4):P159-166.

Teri L, McCurry SM, Logsdon R, et al. Training community consultants to help family members improve dementia care: a randomized controlled trial. *Gerontologist*. Dec 2005;45(6):802-811.

Teri LP, Gibbons LEP, McCurry SMP, et al. Exercise Plus Behavioral Management in Patients With Alzheimer Disease: A Randomized Controlled Trial. *JAMA*. 2003;290(15):2015-2022.

Van de Winckel A, Feys H, De Weerd W, et al. Cognitive and behavioural effects of music-based exercises in patients with dementia. *Clinical Rehabilitation*. May 2004;18(3):253-260.

Verkaik R, van Weert JC, Francke AL. The effects of psychosocial methods on depressed, aggressive and apathetic behaviors of people with dementia: a systematic review. *Int J Geriatr Psychiatry*. Apr 2005;20(4):301-314.

Vink AC, Birks J, Bruinsma MS, Scholten RJPM. Music therapy for people with dementia. *Cochrane Database of Systematic Reviews*. 2009(3).

Woods B, Spector AE, Jones CA, Orrell M, Davies SP. Reminiscence therapy for dementia. *Cochrane Database of Systematic Reviews*. 2009(3).

Zettler J. Effectiveness of simulated presence therapy for individuals with dementia: a systematic review and meta-analysis. *Aging Ment Health*. Nov 2008;12(6):779-785.

## Evidence-Base Methods

The domains and the Evidence Base methods used to assess change include the following.

### 1. Engagement

- **The Menorah Park Engagement Scale (MPES)** method (Camp, Skrajner, & Gorzelle, 2015) has been used for over 20 years to measure engagement /affect in persons with dementia. To assess a person's engagement during an activity, an observer trained in the method observes the person repeatedly for five seconds, recording the person's predominant behavior each time. The MPES measures four types of engagement: *Constructive Engagement*: motor/verbal behavior exhibited clearly in response to the target activity; *Passive Engagement*: listening/watching a target activity; *Other Engagement*: motor/verbal behavior exhibited in response to something other than the target activity; and *Non-Engagement*: outward signs / indicators of apathy, such as sleeping, closing one's eyes, and staring into space. In this evaluation, the MPES was used to track the percentage of residents Constructively or Passively Engaged at various times during the day.

#### 4. Cognition

- a. The **Brief Interview for Mental Status (BIMS) scale** is conducted via direct interview with the resident. The BIMS has three sections. The first section of the BIMS tests *immediate recall* and *attention* by verbally presenting three words to the person and immediately asking her to repeat them. The second section of the BIMS assesses *orientation*. The person is asked to identify what month we are in currently, which year it is, and what day of the week it is. The third section of the BIMS tests *short-term memory*. After the distracting task of orientation questions, it asks the person to recall the three words they had to repeat earlier. If they cannot recall the words, they are given a cue to help trigger the memory, such as "something to wear" to determine if that helps them recall and say the word "sock." The total score on the BIMS ranges from 0-15, with higher scores indicating better cognition. The numeric value can be interpreted as follows: 13 to 15 points, intact cognition; 8 to 12 points, moderately impaired cognition; and 0-7 points: severely impaired cognition.

#### 5. Quality of Life

- a. The **Quality of Life-Alzheimer's Disease (QOL-AD) scale** is conducted via direct interview with the person, with a proxy version available if the person is unable to respond to the questions. The validated QOL-AD scale has been used for many years by researchers to examine the impact of various interventions for persons with dementia. It consists of 13 items, each of which has four options. The total QOL-AD score ranges from 13-52, with higher scores indicating higher quality of life. We are presently reviewing other slightly longer Quality of Life measures for those living with dementia, such as the Dementia Related Quality of Life scale (DEMQOL; Smith et al, 2005).

#### 6. Depression

- a. The **Geriatric Depression Scale-Short Form (GDS-SF)** is conducted via direct interview with the person, though a proxy can answer the questions if the person is unable to respond. The GDS-SF has 15 items, each of which has a "yes/no" response. The total score ranges from 0-15, with higher scores indicating more depressive symptoms. A score above 5 is considered an indicator of depression.

#### 7. Responsive Behaviors

- a. The **Neuropsychiatric Inventory-Nursing Home (NPI-NH)** conducted by interviewing a proxy (caregiver), examines the following responsive behaviors: delusions, hallucinations, agitation / aggression, depression / dysphoria, anxiety, apathy / indifference, irritability / lability, elation / euphoria, disinhibition, and aberrant motor behavior. For each item, the proxy rates frequency on a scale of 0 to 4 (0=not at all, 1=occasionally, 2=often, 3=frequently, or 4=very frequently) and severity on a scale of 0 to 3 (0=not at all, 1=mild, 2=moderate, and 3=severe). For each responsive behavior, a *Frequency times Severity* score is then calculated, referred to as F x S. For example, if the person exhibits agitation often (2) and the severity is moderate (2), the F x S score is

4. If the person does not exhibit a symptom, the F x S is zero. The total F x S score across all Responsive Behaviors is then calculated. The total F x S score can range from 0 to 120, with higher scores indicating more responsive behaviors. Besides examining the total score, it is also common for researchers to examine specific items from the scale—e.g., analyzing if there is a change in the F x S score for agitation in particular, from Pre-Training to Post-Training.

**8. Knowledge Transfer (Staff)**

- a. **Pre-Post Quizzes, before** and after each training session, were administered to staff who attended the training. We examined whether or not there was an increase in knowledge after each training.

## Methods Abbreviations and References

Abbreviation	Reference(s)
BEHAVE-AD = Behavioral Pathology in Alzheimer's Disease	Reisberg, B., Auer, S. R., & Monteiro, I. M. (1997). Behavioral pathology in Alzheimer's disease (BEHAVE-AD) rating scale. <i>International Psychogeriatrics</i> , 8(S3), 301-308.
CMAI = Cohen-Mansfield Agitation Inventory	<p>Cohen-Mansfield, J., Marx, M., &amp; Rosenthal, A. (1989). A description of agitation in a nursing home. <i>Journals of Gerontology</i>, 44(3), M77-M84. Retrieved from PsycINFO database.</p> <p>Cohen-Mansfield, J., &amp; Billig, N. (1986). Agitated behaviors in the elderly I. A conceptual review. <i>Journal of the American Geriatrics Society</i>, 34, 711-721.</p> <p>Cohen-Mansfield, J. (1986). Agitated behaviors in the elderly II. Preliminary results in the cognitively deteriorated. <i>Journal of the American Gerontological Society</i>, 34, 722-727.</p> <p>Finkel, S.I., Lyons, J.S., &amp; Anderson, R.L. (1992). Reliability and validity of the Cohen-Mansfield Agitation Inventory in institutionalized elderly. <i>International Journal of Geriatric Psychiatry</i>, 7, 487-490.</p>
DEMQOL = Dementia Quality of Life	<p>Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R., Foley, B., Smith, P., ... &amp; Knapp, M. (2005). Measurement of health-related quality of life for people with dementia: development of a new instrument (DEMQOL) and an evaluation of current methodology. <i>Health Technology Assessment</i> (Winchester, England), 9(10), 1-93.</p> <p>Smith, S. C., Lamping, D. L., Banerjee, S., Harwood, R. H., Foley, B., Smith, P., ... &amp; Knapp, M. (2007). Development of a new measure of health-related quality of life for people with dementia: DEMQOL. <i>Psychological medicine</i>, 37(05), 737-746.</p>
GDS = Geriatric Depression Scale	<p>Sheikh, J.I., &amp; Yesavage, J.A. (1986). Geriatric Depression Scale (GDS): Recent evidence and development of a shorter version. In T.L. Brink (Ed.), <i>Clinical Gerontologist: A Guide to Assessment and Intervention</i> (pp. 165-173). NY: The Haworth Press.</p> <p>Yesavage, J.A., Brink, T.L., Rose, T.L., Lum, O., Huang, V., Adey, M., &amp; Leirer, V.O. (1982- 1983). Development and validation of a Geriatric Depression Screening Scale: A preliminary report. <i>Journal of Psychiatric Research</i>, 17(1), 37-49.</p>

Abbreviation	Reference(s)
MDS = Minimum Data Set	<p>Burrows, A. B., Morris, J. N., Simon, S. E., Hirdes, J. P., &amp; Phillips, C. H. A. R. L. E. S. (2000). Development of a minimum data set-based depression rating scale for use in nursing homes. <i>Age and ageing</i>, 29(2), 165-172.</p> <p>Hartmaier, S. L., Sloane, P. D., Guess, H. A., Koch, G. G., Mitchell, C. M., &amp; Phillips, C. D. (1995). Validation of the minimum data set cognitive performance scale: agreement with the mini-mental state examination. <i>The Journals of Gerontology Series A: Biological Sciences and Medical Sciences</i>, 50(2), M128-M133.</p> <p>Hawes, C., Morris, J. N., Phillips, C. D., Mor, V., Fries, B. E., &amp; Nonemaker, S. (1995). Reliability estimates for the Minimum Data Set for nursing home resident assessment and care screening (MDS). <i>The Gerontologist</i>, 35(2), 172-178.</p>
MMSE = Mini Mental State Exam	Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. <i>Journal of psychiatric research</i> , 12(3), 189-198.
MOSES = Multidimensional Observation Scale for Elderly Subjects	Helmes, E. (1987). Multidimensional Observation Scale for Elderly Subjects (MOSES). <i>Psychopharmacology bulletin</i> , 24(4), 733-745.
MPES = Menorah Park Engagement Scale	Camp, C.J., Skrajner, M.S., & Gorzelle (2015). Engagement in dementia. In Volicer, L, & Hurley, A (Eds.), <i>Assessment Scales for Advanced Dementia (71-78)</i> . Baltimore, Maryland: Health Professions Press.
NPI = Neuropsychiatric Index – Nursing Home	<p>Cummings, J. L. (1997). The Neuropsychiatric Inventory Assessing psychopathology in dementia patients. <i>Neurology</i>, 48(5 Suppl 6), 10S-16S.</p> <p>Wood, S., Cummings, J. L., Hsu, M. A., Barclay, T., Wheatley, M. V., Yarema, K. T., &amp; Schnelle, J. F. (2001). The use of the neuropsychiatric inventory in nursing home residents: characterization and measurement. <i>The American Journal of Geriatric Psychiatry</i>, 8(1), 75-83.</p>
Zeisel Stigma Scale	A grant proposal was submitted to the National Institute on Aging to evaluate the psychometric properties of the Zeisel Stigma Scale.





# Distal

## Quality of Life

### Quality of Life—Alzheimer’s Disease (QOL-AD)

The QOL-AD measures five domains of quality of life: interpersonal, environmental, functional, physical, and psychological (Logsdon et al., 1999). The scale includes thirteen items: physical health, energy level, moods, living situation, memory, family, marriage, friends, overall self, ability to do chores around the house, ability to do things for fun, money, and overall life. There are two versions of the scale: a patient version and a caregiver version. The total score is calculated separately for the patient version and the caregiver version, with possible scores ranging from 13 to 52.

Quality of Life—AD (QOL-AD) Participant Version				
<i>I want to ask you some questions about your quality of life and have you rate different aspects of your life using one of four words: poor, fair, good, or excellent.</i>				
<i>When you think about your life, there are different aspects, like your physical health, energy, family, money, and others. I'm going to ask you to rate each of these areas.</i>				
<i>We want to find out how you feel about your current situation in each area.</i>				
<i>If you're not sure about what a question means, you can ask me about it. If you have difficulty rating any item, just give it your best guess.</i>				
1. Physical health	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
2. Energy	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
3. Mood	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
4. Living situation	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
5. Memory	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
6. Family	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
7. Marriage	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
8. Friends	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
9. Self as a whole	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
10. Ability to do chores around the house	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
11. Ability to do things for fun	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
12. Money	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
13. Life as a Whole	<input type="radio"/> Poor 1	<input type="radio"/> Fair 2	<input type="radio"/> Good 3	<input type="radio"/> Excellent 4
OVERALL TOTAL				

## Depression

### Geriatric Depression Scale-Short Form (GDS-SF)

The GDS-SF is a self-report measure of depression in older adults (Sheikh & Yesavage, 1986). Individuals respond in a “Yes/No” format. The GDS was originally developed as a 30-item instrument but was revised down to fifteen items, chosen because of their high correlation with depressive symptoms in previous validation studies.

Of the 15 items, 10 items indicate the presence of depression when answered positively while the other 5 indicate depression when answered negatively. This scale can be completed in about 5 to 7 minutes, making it ideal for people who are easily fatigued or are limited in their ability to concentrate for longer periods of time.

Geriatric Depression Scale—Short Form (GDS-SF)		
<i>The GDS-SF is a screening tool, not a diagnosis. However, a score above 5 suggests depression.</i>		
<i>Choose the best answer for how you have felt over the past week.</i>		
Question	Column A	Column B
1. Are you basically satisfied with your life?	<input type="radio"/> Yes-0	<input type="radio"/> No-1
2. Have you dropped many of your activities or interests?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
3. Do you feel that your life is empty?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
4. Do you often get bored?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
5. Are you in good spirits most of the time?	<input type="radio"/> Yes-0	<input type="radio"/> No-1
6. Are you afraid that something bad is going to happen to you?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
7. Do you feel happy most of the time?	<input type="radio"/> Yes-0	<input type="radio"/> No-1
8. Do you often feel helpless?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
9. Do you prefer to stay at home, rather than going out and doing things?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
10. Do you feel that you have more problems with memory than most?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
11. Do you think it is wonderful to be alive now?	<input type="radio"/> Yes-0	<input type="radio"/> No-1
12. Do you feel worthless the way you are now?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
13. Do you feel full of energy?	<input type="radio"/> Yes-0	<input type="radio"/> No-1
14. Do you feel that your situation is hopeless?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
15. Do you think that most people are better off than you are?	<input type="radio"/> Yes-1	<input type="radio"/> No-0
COLUMN TOTALS		
OVERALL TOTAL, Items #1-15 (COLUMN A + COLUMN B)		

# Behavioral /Neuropsychiatric Symptoms

## Neuropsychiatric Inventory – Nursing Home (NPI-NH)

This measure is designed for use with people with AD and other dementias to evaluate frequency and severity of 10 neuropsychiatric symptoms, often referred to as challenging behaviors (Cummings et al., 1994; Wood et al., 2000). These include: apathy, agitation, irritability, dysphoria, disinhibition, anxiety, hallucinations, delusions, euphoria, and abnormal motor output.

Each behavior is rated as absent or present. In addition, if the behavior is present, its frequency is rated on a scale of one to four, and its severity is rated on a scale of one to three. For each item, Frequency is multiplied by Severity to create an F x S score for that item. A total score on the NPI-NH is calculated by adding up all of the F x S scores. Therefore, total scores on the NPI-NH (F x S) can range from 0-120, with higher scores indicating increased frequency and severity of neuropsychiatric symptoms / challenging behaviors in the individual.

Neuropsychiatric Inventory-Nursing Home (NPI-NH)									
Item	Present?	Frequency			Severity			Fre. x Sev.	
1. Delusions	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
2. Hallucinations	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
3. Agitation	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
4. Depression/ Dysphoria	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
5. Anxiety	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
6. Apathy	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
7. Irritability	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
8. Euphoria	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
9. Disinhibition	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
10. Aberrant Motor Behavior	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
11. Night time behavior	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
12. Appetite / Eating Changes	Yes No <input type="radio"/> <input type="radio"/>	1	2	3	4	1	2	3	
<b>Total Neuropsychiatric Inventory Score</b> (out of 144)									

## Cognition

### Brief Interview for Mental Status (BIMS)

The BIMS measure is used to get an overview of how well a person is functioning cognitively at the moment. It is used to determine an individual's attention, orientation and ability to register and recall new information. The BIMS is broken into three different sections. The first section of the BIMS tests the ability to repeat information through immediate recall and assesses attention. The second section of the BIMS assesses orientation. The third section of the BIMS tests short-term memory after the distracting task of orientation questions. To reach a final score, add up the total points from all three tests. The total possible BIMS score ranges from 00 to 15, with higher scores indicating that a person is more cognitively intact.

Brief Interview for Mental Status (BIMS)	
<b>C0200. Repetition of Three Words</b>	<p>Ask resident: "I am going to say three words for you to remember. Please repeat the words after I have said all three. The words are: sock, blue, and bed. Now tell me the three words."</p> <p>Number of words repeated after first attempt</p> <p>0. None Actual words said by resident: _____</p> <p>1. One _____</p> <p>2. Two _____</p> <p>3. Three _____</p> <p>After the resident's first attempt, repeat the words using cues ("sock, something to wear; blue, a color; bed, a piece of furniture"). You may repeat the words up to two more times.</p>
<b>C0300. Temporal Orientation (orientation to year, month, and day)</b>	<p>Ask resident: "Please tell me what year it is right now."</p> <p>A. Able to report correct year Actual year stated by resident: _____</p> <p>0. Missed by &gt; 5 years or no answer</p> <p>1. Missed by 3-5 years</p> <p>2. Missed by 1 year</p> <p>3. Correct</p> <p>Ask resident: "What month are we in right now?"</p> <p>B. Able to report correct month Actual month stated by resident: _____</p> <p>0. Missed by &gt; 1 month or no answer</p> <p>1. Missed by 6 days to 1 month</p> <p>2. Accurate within 5 days</p> <p>Ask resident: "What day of the week is today?"</p> <p>C. Able to report correct day of the week Actual day of the week stated by resident: _____</p> <p>0. Incorrect or no answer</p> <p>1. Correct</p>
<b>C0400. Recall</b>	<p>Ask resident: "Let's go back to an earlier question. What were those three words that I asked you to repeat?"</p> <p>If unable to remember a word, give cue (something to wear; a color; a piece of furniture) for that word.</p> <p>A. Able to recall "sock" Actual word stated by resident: _____</p> <p>0. No - could not recall</p> <p>1. Yes, after cueing ("something to wear")</p> <p>2. Yes, no cue required</p> <p>B. Able to recall "blue" Actual word stated by resident: _____</p> <p>0. No - could not recall</p> <p>1. Yes, after cueing ("a color")</p> <p>2. Yes, no cue required</p> <p>C. Able to recall "bed" Actual word stated by resident: _____</p> <p>0. No - could not recall</p> <p>1. Yes, after cueing ("a piece of furniture")</p> <p>2. Yes, no cue required</p>
<b>C0500. BIMS Summary Score</b>	<p>Add scores for questions C0200-C0400 and fill in total score (00-15)</p> <p>Enter 0 if the resident was unable to complete the interview</p> <p>Select One:</p> <p><input type="radio"/> 13-15: Cognitively Intact</p> <p><input type="radio"/> 08-12: Moderately Impaired</p> <p><input type="radio"/> 00-07: Severe Impairment</p>

This report was prepared by John Zeisel, Mike Skrajner, Gregg Gorzelle, Sharon Johnson with the assistance of the full Research Team.