Innovative Treatments for Persons with Dementia

2015 Research Symposium

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Denver, CO; November 14, 2015

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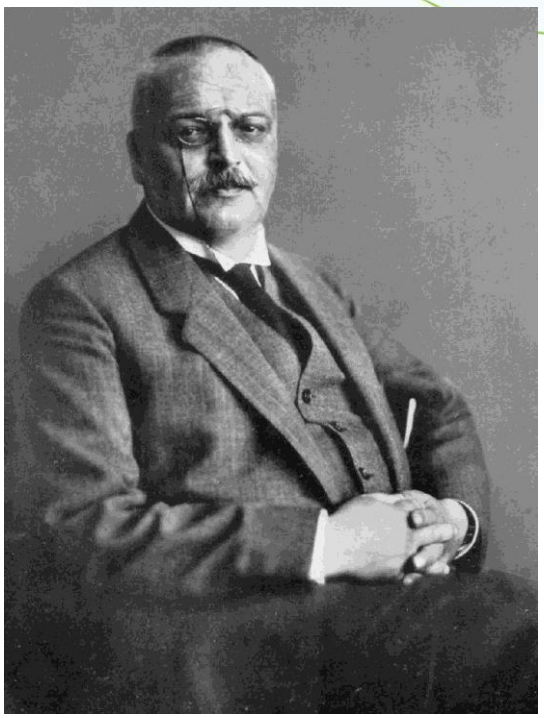
Treatment of Dementia: History

- 1907 Alois Alzheimer, MD first described pathology + clinical symptoms of presenile dementia, Alzheimer's Disease
- 1980's Dementia patients referred to SLP for assessment & treatment
- 1993 Publication of *Arizona Battery of Communication Disorders of Dementia* (Bayles & Tomoeda)



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Past 30 years…..

- Comprehensive descriptions of many subtypes
- DSM-V renamed the condition:
  - Major, or Mild, Neurocognitive disorder due to
    - Alzheimer's disease
    - Frontotempporal disease
    - Vascular disease
    - Traumatic breain injury
    - Substance/medication use
    - HIV infection
    - Prion disease
    - Parkinson's disease
    - Huntington's disease
    - Another medical condition
    - Multiple etiologies
    - Unspecified

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Treatment: Medical and Behavioral

Medical

- Multiple theories of causation (Armstrong, 2013)
  - Exacerbation of aging
  - Degeneration of cholinergic and cortico-cortical pathways
  - Environmental factors (exposure to aluminum, head injury, malnutrition)
  - Genetic factors (mutations of amyloid precursor protein and presenilin genes, & allelic variation in apolipoprotein E)
  - Mitochondrial dysfunction
  - Compromised blood brain barrier
  - Immune system dysfunction, and
  - Infectious agents
- Multifactorial disorder, internal & external factors increase rate of normal aging, leading to abnormal aggregation of β-amyloid and tau and spreading from temporal lob to association and primary sensory areas of the brain = heterogeneity of characteristics

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Medications for Cognitive symptoms

- FDA has approved
  - Cholinesterase inhibitors (Aricept, Exelon, Razadyne)
    - May delay symptoms for 6-12 months for 50% of patients
    - Gastrointestinal side effects are common
  - Glutamate regulator (Memantine (Namenda))
    - May delay worsening of symptoms for some people
    - Side effects: dizziness, headache, gastrointestinal

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Medications for Behavioral Symptoms

- Behavior Changes
  - Irritability, anxiety, depressions
  - Anger, agitation, aggression
  - Restlessness, hallucinations, sleep disturbances
  - Antidepressants (Celexa, Prozac, Zoloft, Desyrel)
  - Anxiolytics (Ativan, Serax)
  - Antipsychotics (Abilify, Haldol, Zyprexa, Seroquel)

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Behavioral Treatment: Nonpharmacological approaches

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Past 30 years….

- Reality Orientation
  (Folsom,1967)
  "To Maintain previously acquired skills by providing prompts and cues, rather than to teach new skills"- Promising evidence (Spector, Wood, & Orrell, 2000)
- Validation therapy
  (Feil, 1982) "To accept the reality and personal truth of another's experience" – Insufficient evidence of efficacy of this approach (Neil & Wright, 2003).

- Cognitive Stimulation
- "Involves engagement in a range of activities and discussions, typically conducted in groups, aimed at general enhancement of cognitive and social functioning" (Clare & Woods, 2003; Aquire, Woods, Spector & Orrell, 2013)
- – Benefits Cognition, well-being, quality of life, communication & social interaction.

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COGNITIVE Training & Intervention

Cognitive training

structured practice on standard tasks aimed at improving specific cognitive functions, such as attention, memory and executive functions.

– Limited evidence of effects on cognition, mood, or activities of daily living (Bahar-Fuchs, Clare & Woods, 2013)

Cognitive intervention

any intervention strategy or technique to **explicitly target cognitive and communicative functioning** of individuals with dementia.

Does not include "…those forms of psychosocial intervention that might perhaps indirectly benefit cognitive functioning, such as for example, relaxation sessions or music therapy" (Clare & Woods, 2003; Hopper et al., 2013).

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Cognitive Stimulation Approaches:
Early Intervention for Healthy Aging to MCI?

- Increased awareness of deficits & fear of AD
- Increased risk for conversion to AD
- Popularity of "self-help" memory programs
  - Crossword puzzles, Sudoku, computer games
- Equivocal effects of cognitive "stimulation" approaches (Pillai et al., 2011; Salthouse, 2006)
  - ASHA Special Interest Group 2, Perspectives Issue (May, 2013).

    MCI & Healthy Aging: Characteristics, Evaluation & Treatment

    (Rogalski, Fleming, Bourgeois, Key-DeLyria, & Quintana)

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Social Activity

- Inconclusive effects on slowing decline or reducing risk of dementia (Plassman et al., 2010)

- Longitudinal studies:
  - Increased immediate and delayed 10-word recall test (Ertel et al., 2008)
  - Increased perceptual speed (Lovden et al., 2005)
  - 70% decrease in global cognitive decline (James et al., 2011)

- Reverse causation? (Small et al., 2012; Bielak et al., 2007; Gow et al., 2012)
  - Lower cognitive levels lead to poorer social engagement

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Exercise

- Association between physical activity and decreased risk of cognitive decline (Plassman et al., 2010; Lautenschlager et al., 2012)
- Conflicting evidence on type, duration, frequency, intensity
- Aerobic exercise increases brain volume in areas important for learning and memory (e.g., Colcombe et al., 2006; Gordon et al., 2008)
- Low-level exercise (walking) linked to memory encoding and positive neuronal changes (Floel et al., 2010)

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Video Games

- Nindendo Big Brain Academy: Wii
  - (Ackerman et al., 2010)
  - Practice effects only

- "Rise of Nations" (Basak et al., 2008)
  - Improved untrained visual STM, WM, task-switching
  - Some transfer of training effects

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Cognitive Training: Evidence of effects for healthy adults

Verhaeghen et al. (1992); meta analysis of 31 studies involving 1,536 persons; mean age = 69.1 yrs

- Mnemonics Training: Method of Loci, Name-Face, Peg word, Imagery, Organization strategies
- After training, average person performed at the 77th percentile for their age group

- Treatment gains were largest when
  - the subjects were younger,
  - when training was carried out in small groups, and
  - when sessions were relatively short.

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Active Study (Advanced Cognitive Training for Independent and Vital Elderly (Willis et al., 2006; Unverzagt et al., 2009))

- 2,802 participants randomized to 1 of 4 groups
- Ten session training for
  1. Memory (mnemonics: organization, visualization, association for word lists),
  2. Inductive reasoning (finding patterns in letter or word series)
  3. Speed of processing (visual search on computer screen and identifying object) or
  4. No contact control

Cognitive training improved cognitive abilities specific to the training and maintained for 5 years; but limited effects on IADLs and HRQoL.

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Lessons learned from Cognitively Healthy Adults (McDougall, 2009)

- Learning 1-2 memory strategies is better than no intervention
- BUT …
- Future studies need to
  - Increase awareness and knowledge (metamemory)
  - Decrease negative beliefs (self-efficacy)
  - Decrease negative memory-related affect (anxiety)

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Encouraging Evidence for MCI from Systematic Reviews

- Positive results with persons with documented cognitive disorders
  - Dementia (Hopper et al., 2013)
  - TBI (Sohlberg et al., 2007)
- Positive results with persons with MCI
  - MCI (Jean et al., 2010); 15 studies
  - MCI (Stott & Spector, 2011); 10 studies
  - MCI (Li et al., 2011); 17 studies
  - MCI (Simon et al., 2012); 20 studies

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Cognitive Training

- Computerized Cognitive Training (Kueider et al., 2012)
  - Target multiple cognitive domains
  - 3-12 weeks, 1-5 times/wk
  - Task-specific improvement
    - Memory, visuospatial abilities, processing speed
- Improvement in Memory with Plasticity-Based Adaptive Cognitive Training (IMPACT) (Smith et al., 2009)
  - Task-specific improvement in processing speed
  - Generalized improvement to memory, attention

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Cognitive Training for MCI can…

- Improve memory and cognitive functioning
- Increase positive memory self-efficacy
- Improve affective and quality of life responses
- Especially when training addresses client and/or family goals

But approaches that focus on restoring underlying cognitive processes **alone**

  - May not generalize to everyday functions, or
  - Maintain for very long

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Best Approach? Multi-faceted!

- Active lifestyle (social, mental, physical) may protect against dementia (Fratiglioni et al., 2004; Paillard-Borg et al., 2012)

- Exergaming (combining physical and cog activity) produces additive neuroprotective benefits (Anderson-Hanley et al., 2012; Maillot et al., 2012)

- Being social while exercising produces additive benefits (Jedrziewski et al., 2010)

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Cognitive Interventions (Hopper et al., 2013)

Research Question	Outcome Measures	Number of Studies
What is the effect of cognitive intervention on **measures of cognitive-communication impairment** for individuals with dementia?	Impairment measures	26
What is the effect of cognitive intervention on **measures of cognitive-communication activity limitations/participation restrictions** for individuals with dementia?	Activity/participation measures	21
Both	Both types of measures used in one study	4

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Types of Cognitive Interventions Reviewed

Intervention techniques used alone or in combination with another technique	Number of studies
Spaced Retrieval Training	13
Errorless Learning Strategies	14
Specific Verbal Instruction Strategy	11
Vanishing Cues	3
Other	8

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Spaced Retrieval Training (13 studies)

- Strengthening conceptual associations through repeated activation of stimulus-response pairing; Intervals between recall are lengthened to facilitate production of a high number of correct responses over longer periods of delay (Camp and colleagues)

- Improved Recall accuracy
  - Factual information (e.g., faces, names, objects)
  - Tasks to perform in the future (e.g., prospective memory tasks)
- Improved Activity/Participation Outcomes
  - Use of a calendar
  - Use of face-name associations in context
  - Use of radio and VCR
  - Use of mobile-phone and voicemail
  - Making change and balancing a checkbook
  - Decreased repetitive question asking

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Errorless Learning (14 studies)

- Procedures that are structured to reduce the opportunity for errors during learning trials
  (Baddeley & Wilson, 1994; Clare & Jones, 2008)

- Improved factual information/associations between faces, names, occupations, objects and pictures
- Improved procedural problem-solving task

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Verbal Instruction Strategy (11 studies)

- Provision of verbal prompts to complete tasks
  - Prompts delivered by Electronic Memory Aid (EMA)
  - Prompts provide specific steps to complete ADL-tasks such as Setting the table
- All participants demonstrated improved performance of the steps of the ADLs
- Limitations:
  - Generalization to untrained ADLs unknown
  - No maintenance effects reported

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Vanishing Cues (3 studies)

- Cues or prompts are gradually faded in relation to the learning progress (Glisky, Schacter, & Tulving, 1986)

Method 1: Backward chaining	Method 2: Forward chaining
1. Cues provided at the start of training	1. Withhold cues at the start of training
2. Remove cues one at a time	2. Add cues one at a time
3. Remove cues following successful trials	3. Add cues following incorrect responses
	4. Continue until correct response achieved
	5. Fade cues

Individuals with mild to moderate AD learned factual information using VC. But - overall results are inconclusive.

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Other Interventions

- 8 additional studies, *n* = 167
- Tested a single or mixed intervention technique, including
  - Memory Books,
  - Montessori techniques,
  - Mnemonics, Visualization, etc.
- Findings were generally positive for learning outcomes (5 - Impairment, 1 - A/P, 2 – Both)

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Memory Books/Wallets

(Bourgeois, 1990; 1992; Bourgeois et al., 1997; Bourgeois, 2007)

- Designed to present factual information in written and picture format (visual cues)
- Tailored to the individual and represent meaningful facts and events (declarative & episodic memory)

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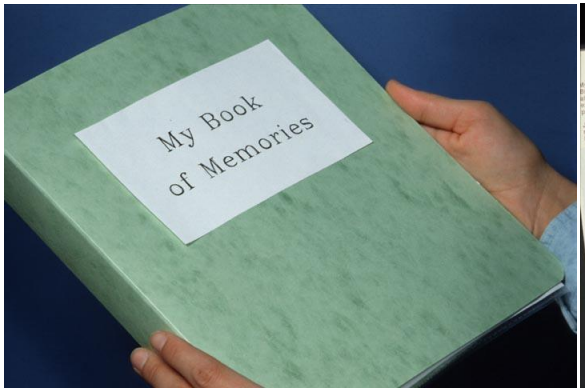
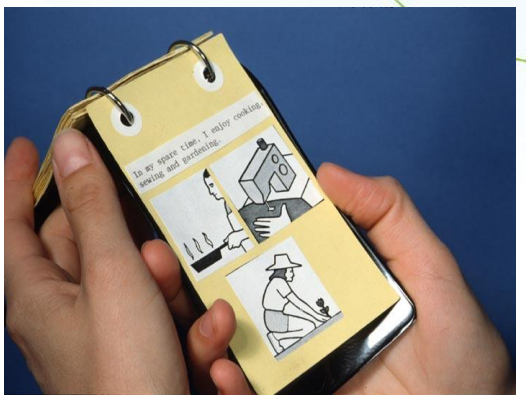
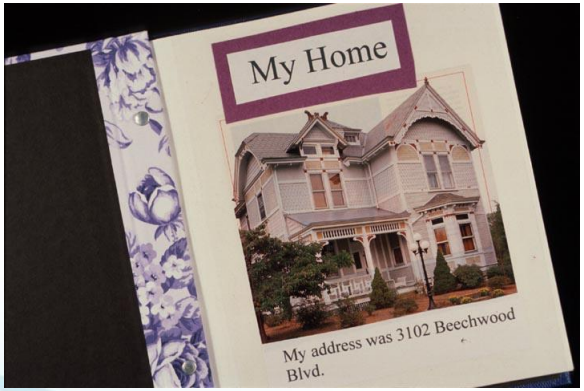
Memory Books & Wallets







Increase in factual statements and novel content; reduction of repetitive, error, and confabulatory utterances.

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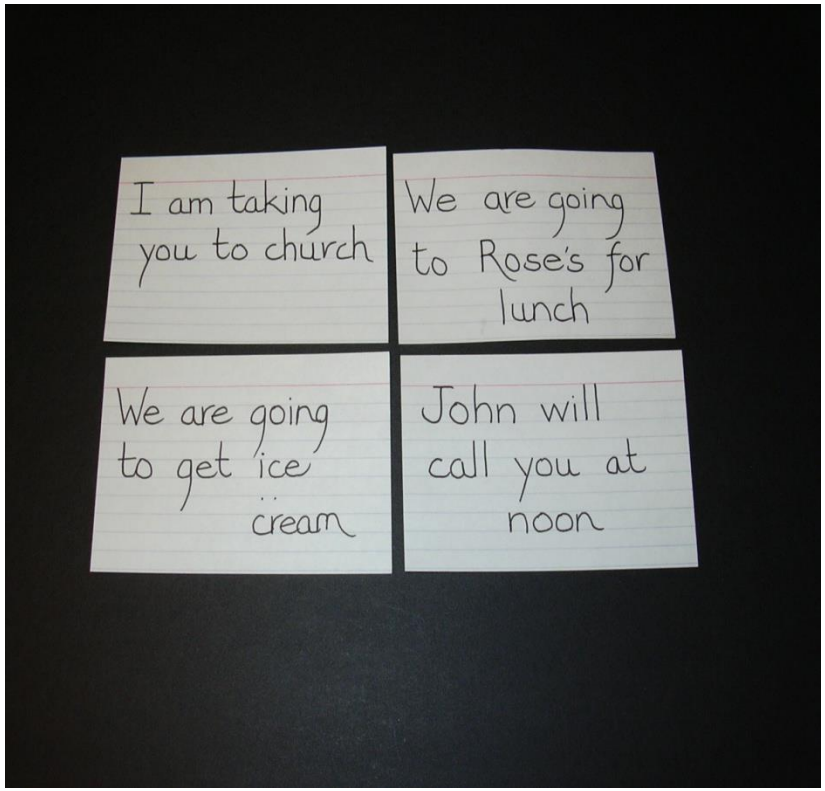

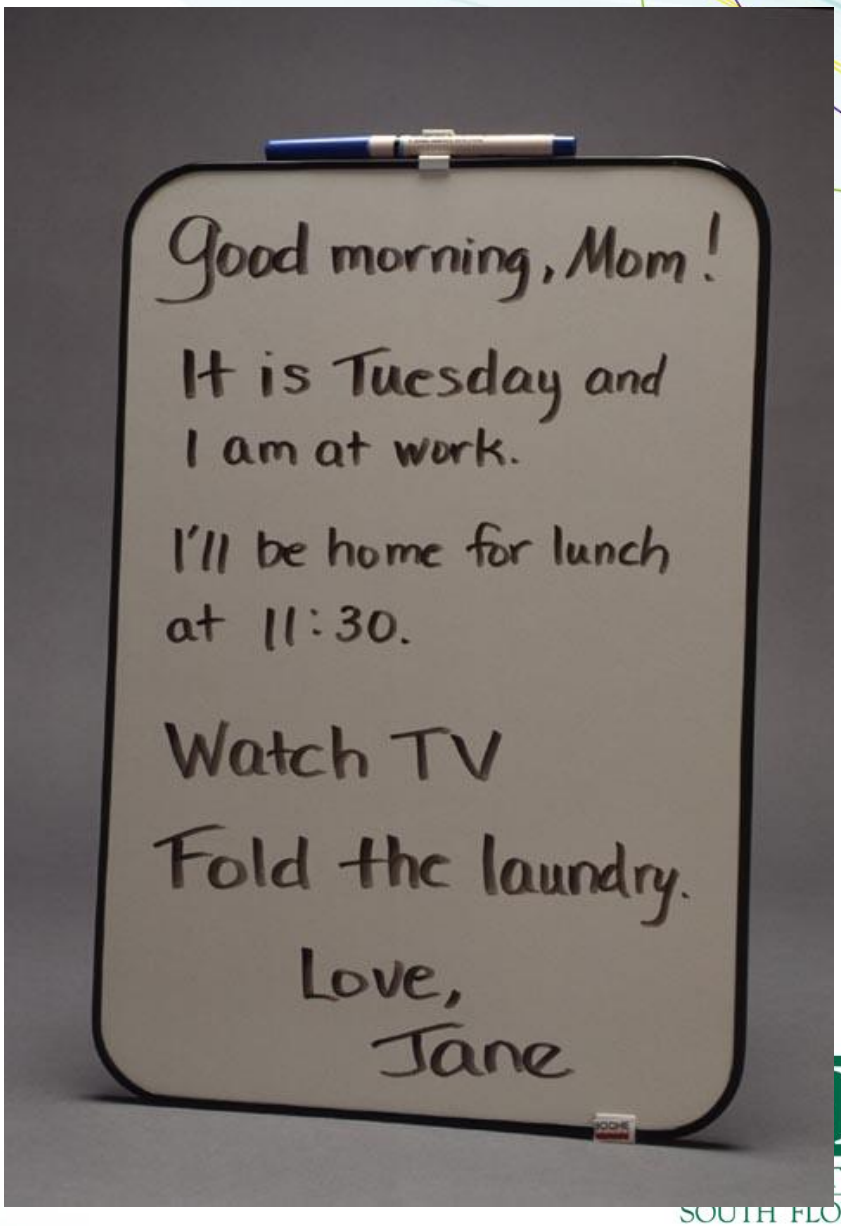

Reminder cards and Memo Boards

Reductions in repetitive questioning and other repetitive behaviors (Bourgeois, et al., 1997)

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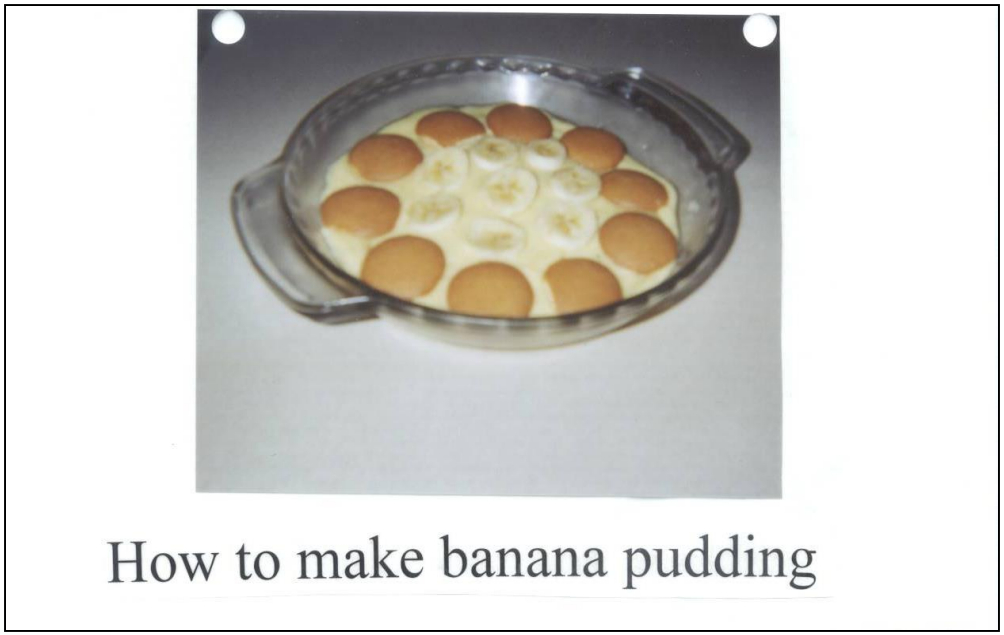
Role Maintenance Studies:

1. What advice can you give me about marriage? Raising kids?
2. Teaching children to make a recipe.



Improved conversational content in advice condition compared to social conversation; Demonstrated equivalent teaching behaviors to persons without dementia with use of cue cards (Dijkstra et al.,2006)

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Interventions based on Visual Cues

- stimulate preserved reading ability,
- stimulate spared semantic & procedural memories,
- reduce demands on impaired episodic & working memory,
- facilitate recognition,
- maintain social roles

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Interventions to improve Auditory Cues

- Hearing Aid intervention (4-13 hours per day)
  - reduced 1-4 hearing related problem behaviors per person:
    - Negative statements, repeated questions, TV/radio too loud, “I can’t hear you,” searching, pacing, “Hearing things,” forgetting.
  - Reduced scores on HHIE for all 8 persons

- Palmer, C., Adams, S., Bourgeois, M., Durrant, J., & Rossi, M. (1999)
- Palmer, C., Adams, S., Durrant, J., Bourgeois, M., & Rossi, M. (1998)

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Where do we go from here?

- Before Dementia Dx
  - Prevention of Cognitive decline
    - Cognitive training, Socialization, Exercise
- During Early Dementia
  - Management of Cognitive decline
    - Cognitive interventions, Cognitive Stimulation
- During Middle-Late Dementia
  - Focus on Quality of Life

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Is this inevitable?

How can we change this?

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Determine what is Meaningful; What is a Quality Life?

- Food and Shelter
- Someone to love, to talk to
  - Someone who loves you
- Something meaningful to do
  - A reason to get up in the morning
  - Enjoyable activities, interests
- Feeling useful and part of a community
  - Feeling appreciated for your contributions

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How will we do this?

- Reconsider our usual approach to Rehab
  - Referral – **Assess** – Treat – Evaluate – Discharge
  - Clinician-focused approach
- Start at the End
  - Patient desires/discharge objectives – Assess - Treat
  - Patient-centered approach
- Flip the rehab model

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- FIRST,
  - Determine Patient opinions, desires, values
    - What do they want to be able to do?
    - What is meaningful to them?
- THEN,
  - Figure out what Assessments to use
    - to discover barriers to doing these desired things
    - to document baseline functioning
    - to measure progress or satisfaction
- IN ORDER TO
  - Design intervention to achieve patient goals

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ASHA Changing Health Care Landscape Summit (2012)

- **The Affordable Health Care Act of 2012**
- Critical need for **patient-centered care** that includes
  - measuring things that patients care about and notice, and
  - considering the patient's perspective in determining the value of services.
- **Patient-reported outcomes** will be used
  - to measure functional improvement (or decline),
  - assess treatment effectiveness, and
  - investigate patients' experiences of such phenomena as the burden of disability and quality of life.

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Changes in HealthCare

- PROMIS: Patient reported outcomes measurement information system
- www.nihpromis.org

  Amtmann, D., Cook, K., Johnson, K., & Cella, D. (2011). The PROMIS Initiative: Involvement of Rehabilitation Stakeholders in Development and Examples of Application in Rehabilitation Research. Arch Phys Med Rehabil, Vol 92, Suppl 1, S12-S19.

- www.nihtoolbox.org

  NIH Toolbox Cognition Battery: This battery, recommended for ages 7+, consists of tests to assess Executive Function, Attention, Episodic Memory, Language, Processing Speed and Working Memory.

- www.neuroqol.org
  - Quality of Life-Cognition Battery: Applied Cognition-General Concerns, Applied Cognition- Executive Function, Communication

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Applied Cognition- General Concerns

Please respond to each question or statement by marking one box per row.

	In the past 7 days…	Never	Rarely (once)	Sometimes (2-3 times)	Often (once a day)	Very often (several times a day)
NQCOG64	I had to read something several times to understand it……	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG65	I had trouble keeping track of what I was doing if I was interrupted……	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG66	I had difficulty doing more than one thing at a time……	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG68	I had trouble remembering new information, like phone numbers or simple instructions……	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG72	I had trouble thinking clearly……	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG75	My thinking was slow……	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG77	I had to work really hard to pay attention or I would make a mistake……	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

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Applied Cognition - Executive Function

Please respond to each question or statement by marking one box per row.

How much DIFFICULTY do you currently have…

		None	A little	Somewhat	A lot	Cannot do
NQCOG16	checking the accuracy of financial documents, (e,g., bills, checkbook, or bank statements)?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG17	counting the correct amount of money when making purchases?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG22	reading and following complex instructions (e.g., directions for a new medication)?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG24	planning for and keeping appointments that are not part of your weekly routine, (e.g., a therapy or doctor appointment, or a social gathering with friends and family)?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG25	managing your time to do most of your daily activities?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG27	taking care of complicated tasks like managing a checking account or getting appliances fixed?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG28	keeping important personal papers such as bills, insurance documents and tax forms organized?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

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Communication

Please respond to each question or statement by marking one box per row.

		None	A Little	Somewhat	A lot	Cannot Do
NQCOG01	How much DIFFICULTY do you currently have writing notes to yourself, such as appointments or 'to do' lists?.....	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG04	How much DIFFICULTY do you currently have understanding family and friends on the phone?.....	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG08	How much DIFFICULTY do you currently have carrying on a conversation with a small group of familiar people (e.g., family or a few friends)?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG10	How much DIFFICULTY do you currently have organizing what you want to say?.....	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
NQCOG11	How much DIFFICULTY do you currently have speaking clearly enough to use the telephone?.....	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1

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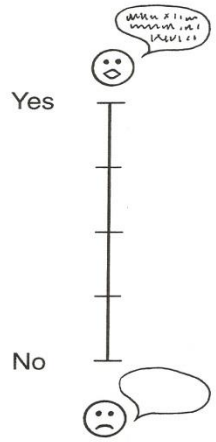
Quality of Life Measurement

ASHA Quality of Communication Life Scale (Paul-Brown et al., 2004)

2. It's easy for me to communicate.



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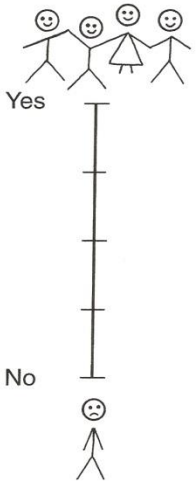
3. My role in the family is the same.



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Dementia Quality of Life Scale (Brod et al., 1999)

DIRECTIONS TO INTERVIEWER: *Present the patient with the appropriate scale before asking the group of questions for that scale. Ask the first question in the group and then read off (and point to) the answer choices for that question. Repeat the scale choices as necessary for subsequent questions. Repeat the item stem for each question.*

SCALE #1

NOTE: Continue with scale #1, and read the following: "Do you have any questions about how to use this scale? …now I am going to ask you some questions about YOU."

Recently, how much have you enjoyed:

_____ 1. Listening to music

_____ 2. Listening to the sounds of nature (birds, wind, rain)

_____ 3. Watching animals or birds

_____ 4. Looking at colorful things

_____ 5. Watching the clouds, sky, or a storm

SCALE #2

NOTE: Read the following: "This next scale is about how often YOU have had certain feelings. The scale goes from never to seldom, to sometimes to often, to very often (point to each choice on the scale as you read it off)... do you have any questions about how to use the scale?"

Recently, how often have you felt:

_____ 6. Useful

_____ 7. Embarrassed

_____ 8. Lovable

_____ 9. Confident

_____ 10. Satisfied with yourself

_____ 11. That people liked you

_____ 12. That you've accomplished something

Recently, how often have you:

_____ 13. Found something that made you laugh?

Recently, how often have you felt:

_____ 14. Afraid

_____ 15. Happy

_____ 16. Lonely

_____ 17. Frustrated

_____ 18. Cheerful

_____ 19. Angry

_____ 20. Worried

_____ 21. Content

_____ 22. Depressed

_____ 23. Hopeful

_____ 24. Nervous

_____ 25. Sad

_____ 26. Irritable

_____ 27. Anxious

_____ 28. How often do you joke or laugh with other people?

_____ 29. How often are you able to make your own decisions?

Optional Overall Item

SCALE #3

NOTE: Read the following: "This scale is to rate what YOU think your quality of life is, it goes from bad to fair, to good, to very good, to excellent."

_____ Overall-How would you rate your quality of life?

Thank you for your time

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Measuring QoL, Preferences and Choices

Name:_____Date:_____ PRE
POST

VoiceMyChoice Preference Assessment Form

1. **Food:**
   a. Roasted chicken _____ always sometimes never
   b. Pancakes _____ always sometimes never
   c. Apple pie _____ always sometimes never
   d. Soup and crackers_____ always sometimes never
   e. Bananas _____ always sometimes never
2. **Activities:**
   a. Bingo _____ always sometimes never
   b. Reading _____ always sometimes never
   c. Gardening _____ always sometimes never
   d. Keeping pets _____ always sometimes never
   e. Word games _____ always sometimes never
3. **Daily Living:**
   a. Taking a shower_____ always sometimes never
   b. Exercising _____ always sometimes never
   c. Napping _____ always sometimes never
   d. Eating meals _____ always sometimes never
   e. Going for walks _____ always sometimes never
4. **Socializing/Communication:**
   a. Talking on the phone _____ always sometimes never
   b. Talking with residents _____ always sometimes never
   c. Family visits_____ always sometimes never
   d. Holding hands _____ always sometimes never
   e. Praying _____ always sometimes never
5. **Pain:**
   a. Headache _____ always sometimes never
   b. Arthritis/ joint pain _____ always sometimes never

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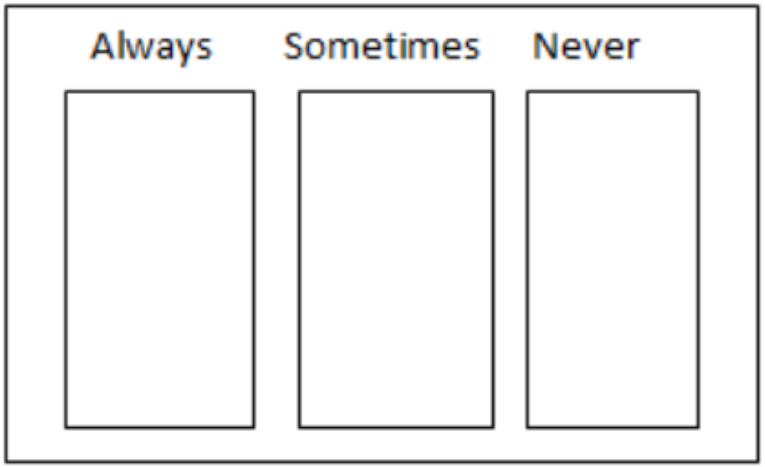
- V

Bourgeois, Camp, & Zeisel, 2010



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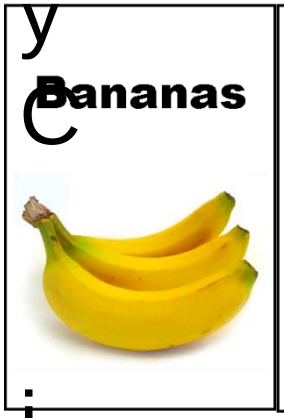

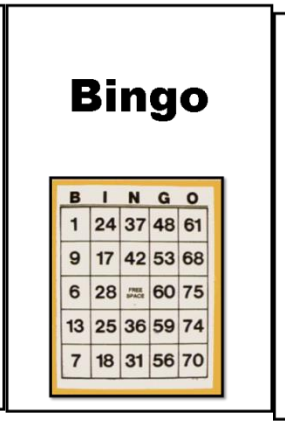

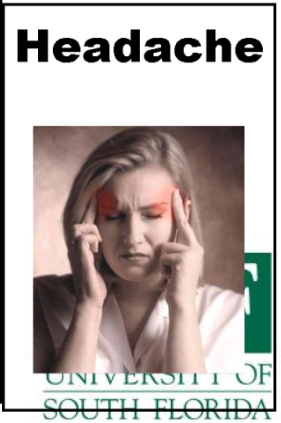

What's possible:
A Meaningful, quality of life in a Nursing Home – A Montessori Approach

https://www.youtube.com/watch?v=1LCRrcxlrXE

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Montessori Principles
adapted for Dementia (Bourgeois et al., 2015)

- Independence
  - through creation of roles and implementation of routines
- Freedom of Choice
- Environment is adapted and prepared
  - (recognizable, signs, visual cues)
- Materials are familiar & aesthetically pleasing
  - Meaningful to the client
- Activities are always demonstrated
- Learning progresses in a sequence
  - from simple to complex and from concrete to abstract
  - Takes advantage of procedural memory
  - Activities control for error

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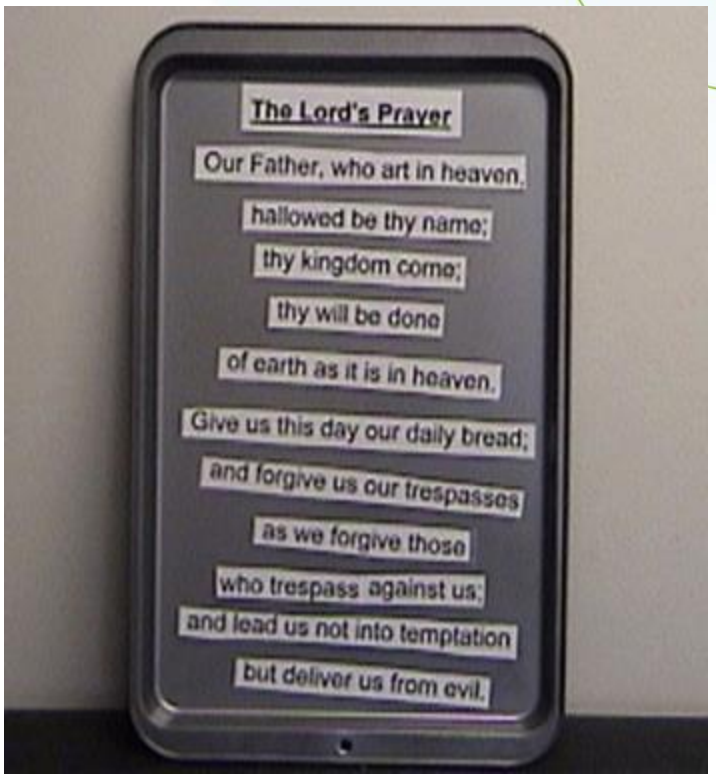
Montessori activities



Montessori Sorting Game

(Camp et al., 1997; Judge et al., 2000)

Promotes Personal Role and Identity Maintenance

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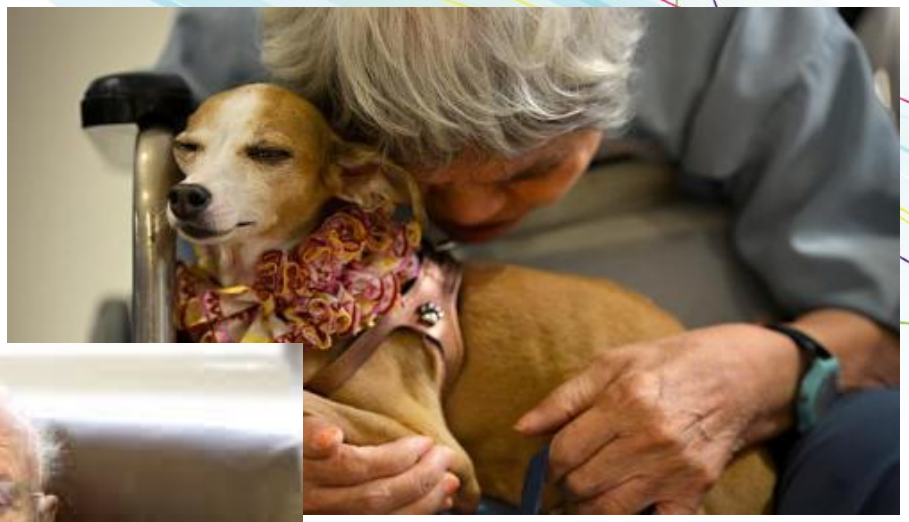

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Zeisel & Camp, 2011

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Innovative Treatments for Persons with Dementia

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