Unlocking the Silent Prison: Using visual cues to communicate with persons with dementia

Michelle Bourgeois, Ph.D., CCC-SLP
The Ohio State University
Definition of Dementia

- Gradual decline in memory and cognitive function (thinking, planning, judgment)
- Deterioration occurs over a period of months or years
- Impairs ability to work and perform activities of daily living

(DSM-IV, 1994)
Memory Loss is the Core Symptom

- Other Symptoms include:
  - Language problems
  - Difficulty performing complex tasks & simple chores
  - Troublesome behaviors: wandering, agitation, irritability, delusions
  - Day-night disorientation
  - Depression
Clinical Problem 1

- Memory complaints
  - Loss of words, ideas, train of thought
  - Interfering with daily life
  - Social isolation

- Possible solution
  - Memory aid to include topics of conversation, words/ideas, familiar content
Memory Wallets

Conversational Data:
5-min prompted samples
Tell me about life.
Tell me about your family.
Tell me about your day.

Conversations lack content, are ambiguous, repetitive, confabulatory, and sometimes unintelligible.

Bourgeois, 1990
Replication of effects across dementia continuum:

Middle ............and Later stages
Modifying the text maintains function; Reading is a preserved skill
Clinical Problem 2

- Caregiver complaints about many other problem behaviors
  - Repetitive Questions
    - Where is my wife?
    - Where are we going today?
  - Restlessness, Pacing
    - Places to go...things to do.
  - Delusions, Hallucinations
    - You are not my husband.
    - There’s a construction crew in the backyard.
Written cues can have positive effects on challenging behaviors

I have lived in this house for 42 years.
My wife Jane lost her valiant fight with cancer on May 10, 1999 and rests peacefully here.

Buster was my favorite dog. He was my best friend for many years.

Bobby is at school today.

Ruth will pick me up at 3 o’clock.
Reminder cards and Memo Boards

Clinical Problem 3: Nursing Home Caregivers

Eating keeps me healthy and strong.

Showering makes me feel fresh and clean.
Clinical Problem 4: Learning to use Memory Aids

- Talk about memory cues in the environment; read them out loud together.
- Use rehearsal strategies, like Spaced Retrieval
  - (Camp et al., 1996; Brush & Camp, 1998; Bourgeois et al., 2003)
- A technique for successfully retrieving information from memory at increasing intervals
  - “What do you do to remember what activities I can do?”
    - “I read the memo board.”
  - “What do you do to remember your family?”
    - “I read my Memory Book.”
The Evolution of Memory Books:
Evaluating Communication-based Memory Interventions for persons with dementia

Interventions for Patients with Dementia and their caregivers

- Clinician
  - Memory Books
  - Spaced Retrieval

- Family Member
  - Memory Books
  - Graphic Cuing Systems
  - Skills Training
  - Hearing Aid Management

- Volunteers in Adult Day Care
  - Memory Books
  - Strength-based Activities

- Nursing Aide
  - Memory Books
  - Graphic Cuing + Training
Theoretical rationale for intervention strategies: A memory model

- Preserved memory systems
  - Enhance strength areas; procedural memory; overlearned processes

- Impaired memory systems
  - Reduce demands on impaired declarative memory systems by using cues and compensatory strategies
A Model of Memory
(Baddeley, 1995)

- **Sensory memory**
  - Problems with recognition and identification
    - Early stages: relatively preserved
    - Enhance sensory cues

- **Short term memory** (working, temporary)
  - Problems with encoding and decoding
    - Early stages: most impaired
    - Reduce demands with memory aids and strategies

- **Long term memory** (semantic, episodic, and procedural)
  - Problems with retrieval
    - Early stages: word retrieval problems
    - Later stages: procedural memories relatively preserved
    - Enhance cues and Reduce demands with memory aids
Enhance Sensory memory with Visual cues

Written Cues: Notes, Labels, Lists, Signs

Organizational Cues: Planners, Medication boxes

Environmental Cues: Objects, color-coding, special places
Short term Memory: Need to Encode information for later retrieval of Long term memories

Shopping organizers, reminder cards, memo boards, memory books, computers, cell phones, etc…
Before I sit down in my wheelchair, I will:

1. Feel for the chair with my legs.

2. Reach back for the arm rests.

Safe Swallowing Card

1. Take small bites, chew, and swallow.
2. Take tiny sips.
3. Tuck your chin.
4. Double swallow after each sip.

Countdown to Laundry Day…

√ I changed my clothes.
√ I changed my clothes.

I changed my clothes.

I changed my clothes.

I changed my clothes.

I changed my clothes.

Laundry Day!

I need to change my clothes everyday.
Need-Driven Compromised Behavior Model
(Algase et al, 1996)

- Theory of Unmet Needs
- Personal, social, environmental, physical, emotional needs
- Cannot communicate effectively due to language and cognitive changes
- Behaviors are expressions of need
- Misinterpreted as maladaptive

- MOST Behavior problems can be addressed with Communication-based treatments
Person-centered Care Approach (Kitwood, 1997)

(Brooker, 2004; Rader, 1995; Sabat, 2001; Thomas, 1996)

- Valuing people with dementia and those who care for them
- Treating people as individuals
- Looking at the world from the perspective of the person with dementia
- A positive social environment in which the person living with dementia can experience relative wellbeing
- People need comfort, attachment, inclusion, occupation, and identity
Personalized Interest Albums: Identity
Personalized Activity: Identity and Occupation

Montessori Sorting Game (Camp, 1999)
Book Clubs: Dementia-specific reading materials

Hearthstone Readers, Hearthstone Foundation, Woburn, MA

Lydia Burdick, Health Professions Press
Occupation and Role Maintenance:

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

With appropriate and personalized modifications and visual supports:

- Persons with dementia can:
  - participate in their lifelong interests and hobbies
  - maintain their personal identities and roles in the community
  - maintain a quality life
  - that is noticed and valued by others

Clinical Problem: Measuring Quality of Life

- Memory & communication problems limit responses of Persons with dementia
- Proxy informants view QoL negatively
- With visual cues, can persons with dementia express their own QoL opinions?
Residents with dementia are able to answer QoL questions reliably and overall provide more positive ratings of their QoL than NAs, especially Control group NAs.

- The Visually Enhanced condition improved NA ratings of resident QoL, but the Augmented Verbal condition did not.
Current Research

- Development of VoiceMyChoice™ preference tool
Continue to Develop Interventions based on Visual Context and Cues

- Create context to
  - reduce demands on impaired episodic & working memory,
  - facilitate recognition,
  - stimulate spared semantic & procedural memories,
  - stimulate preserved reading ability,
  - maintain social roles
For further information:

bourgeois.14@osu.edu