Enhancing Communication for Individuals with Dementia – Part 2

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Disclosure

1. I do not hold currently and have not held in the past a financial interest, financial arrangement or financial affiliation with the Alzheimer Society of London and Middlesex that could be perceived as a direct or indirect conflict of interest in the content of today's program.

2. I do not have an affiliation (financial or otherwise) with a pharmaceutical, medical device or communications organization (e.g., media outlets, publishing company, etc.).

3. I confirm that my presentation and any recommendations are balanced and reflects the current scientific literature.

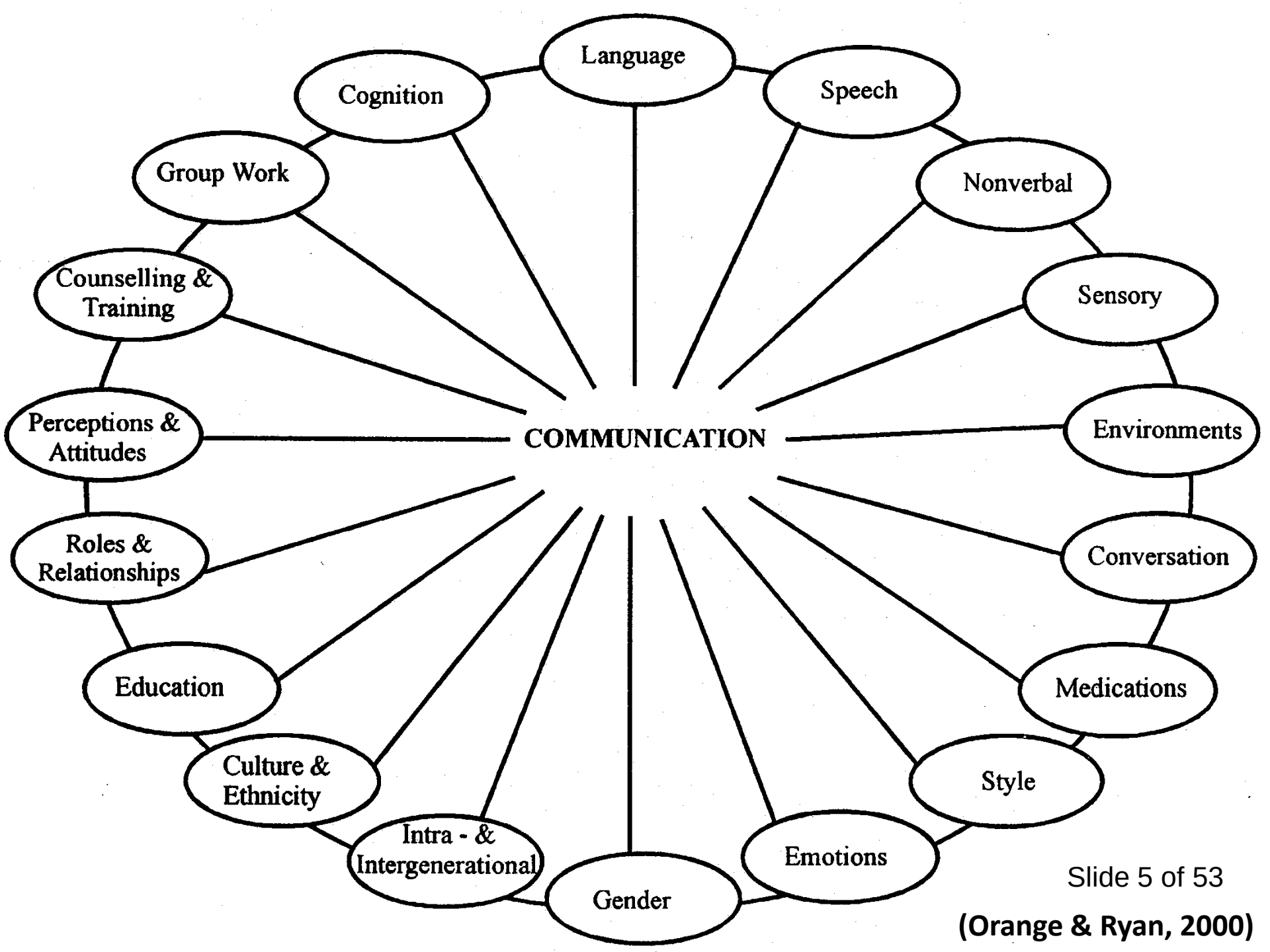
Disclosure

4. I hold currently the following grants:

    a. SSHRC-PEG: HAroLD and social participation
    b. OBI-ONDRI: Multidimensional analyses of dementias
    c. CCNA: Multidimensional analyses of dementias
    d. CCABHI-SPARK: HAroLD and modifiable risk factors for dementia
    e. Employment Skills Development Canada – Be EPIC: Communication education and training of PSWs in person-centred care of persons living with dementia

Outline

1. Strategies to enhance communication
    a. Individualized
    b. What is your agenda or purpose?
    c. Optimize residual skills
    d. Levels of success



(Orange & Ryan, 2000)

Cognition

- Capitalize on episodic and semantic autobiographical memories
  - Remote vs. recent memories

- Use memory notebooks and wallets for episodic memory cues (Bourgeois 1990, 91, 92, 96, 97)

- Montessori programming and spaced retrieval training (e.g., Camp et al., 1996, 2006; Cherry et al., 2004; Hawkley et al., 2004; Hopper et al., 2005; Mahendra,et al., 2006)

Cognition: Memory – Conversation Books

- External, compensatory memory aids that cue, evoke and reinforce specific behaviours

- Draw on preserved skills sets”
  - Recognition
  - Long term episodic memory (biographical)
  - Habitual and over-learned skills
  - Oral reading skills

- Includes declarative sentence and picture:
  - Biographical, daily routine, orientation information

Bourgeois, 2007; 2001

What are They?

- **Memory wallet:** collection of declarative sentence and picture stimuli which are designed to prompt recall of the stated facts and other related factual information
  - Topics: biography, family, daily life/schedule , orientation, information
  - Wallet-type cover
  - 20-30 index cards
  - Easy to carry around
- **Memory book:** enlarged version of memory wallet
- iPad also can display pictures and sentences

(Bourgeois, 2007, p.12-15)

Cognition: Memory – Conversation Books

- Generally consist of biographical information, photos of family members, and descriptions of important events
- Brief and simple memory aids seek to capitalize on patient's automatic communication abilities, with the goal of improving the structure and quality of communication with others
- Provide semantic support in to the form of sentences, words and images, and access to other semantic information stored in LTM.
- The written support can be used to compensate for certain comprehension deficits that may appear when instructions are provided verbally.
- Can remind individual or current tasks or topic of conversation thus enabling them to better participate in conversations

(Bourgeois et al., 1990, 1992, etc; Egan et al., 2010)

Developing a Memory Aid Stimuli

(Bourgeois, 2007)

- Size, format, and number of pages based on clients' needs and desired functions
- Typically 20-30 statements related to 3-4 themes with picture
- Determining size of the font
  - notice the ease or difficulty the client reads at different font sizes
- Bourgeois Oral Reading Screen

Information chosen

- Facts that are important to the client, that he/she wants to talk about
- Facts important to the caregiver

- Sentences
  - Short MLU (early = 12-15; later stage 8-10)
  - Simple structure – single active declarative (uses the verb *to be* or *to have, (*“Dean and Myriam go grocery shopping on Mondays.”)

- Use the person's vocabulary
- How would the person say the sentence?

- Pictures
  - There are always ways to illustrate sentences even if photographs are not available
  - Chose graphically simple visually uncluttered pictures
  - Adjust the size of the picture
  - Take your own photos

Getting the Conversation Started and Keeping it Going

- Asking individual to have a conversation
- Guiding the conversation onto specific topics and redirecting the conversation back to the topic if needed
- Reassuring the person and helping out when she/he get stuck or can not find right word
- Smiling and acting interested
- Thanking the person for talking with you

- What to avoid during conversations
  - Do not quiz the person especially for information you already know
  - Do not correct or contradict

iPad use to Enhance Conversations Between Persons Living with Dementia and their Family Caregivers

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Statement of the Problem & Research Questions (RQ)

- Researchers have yet to look at overlap among 3 concepts, specifically using an electronic notebook on an iPad

RQ:

1. Does the collaborative use of an electronic conversational memory notebook increase the use of person-centred communication in dementia family caregiver dyads?

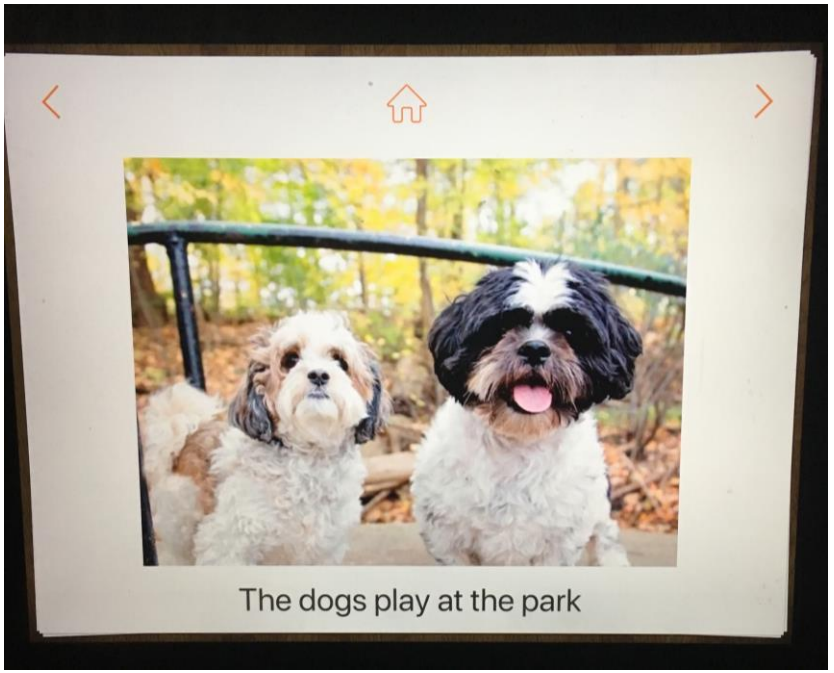
2. Does previous knowledge and familiarity with using iPads impact participants' abilities to apply person-centred communication strategies?

3. Do participants perceive that their knowledge of person-centred communication increased after completing the study?

Participants

- 7 persons diagnosed with mild to moderate AD, 7 family caregivers (6 spouse, 1 adult-child)
- 40 photos uploaded to iPad Pictello software
  - 20 baseline, 20 intervention

Pictello Application



Timeline and Procedures

Week 1

- Screened on cognition, vision, hearing, depression, relationship harmony
- Questionnaire on iPad and person-centred communication knowledge

Week 2

- Discussed first group of 20 family photos 2-3x/wk.

Week 3

- Received specialized education and training on person-centred communication
- Typed and recorded simple active declarative sentences for intervention phase photos

Timeline and Procedures

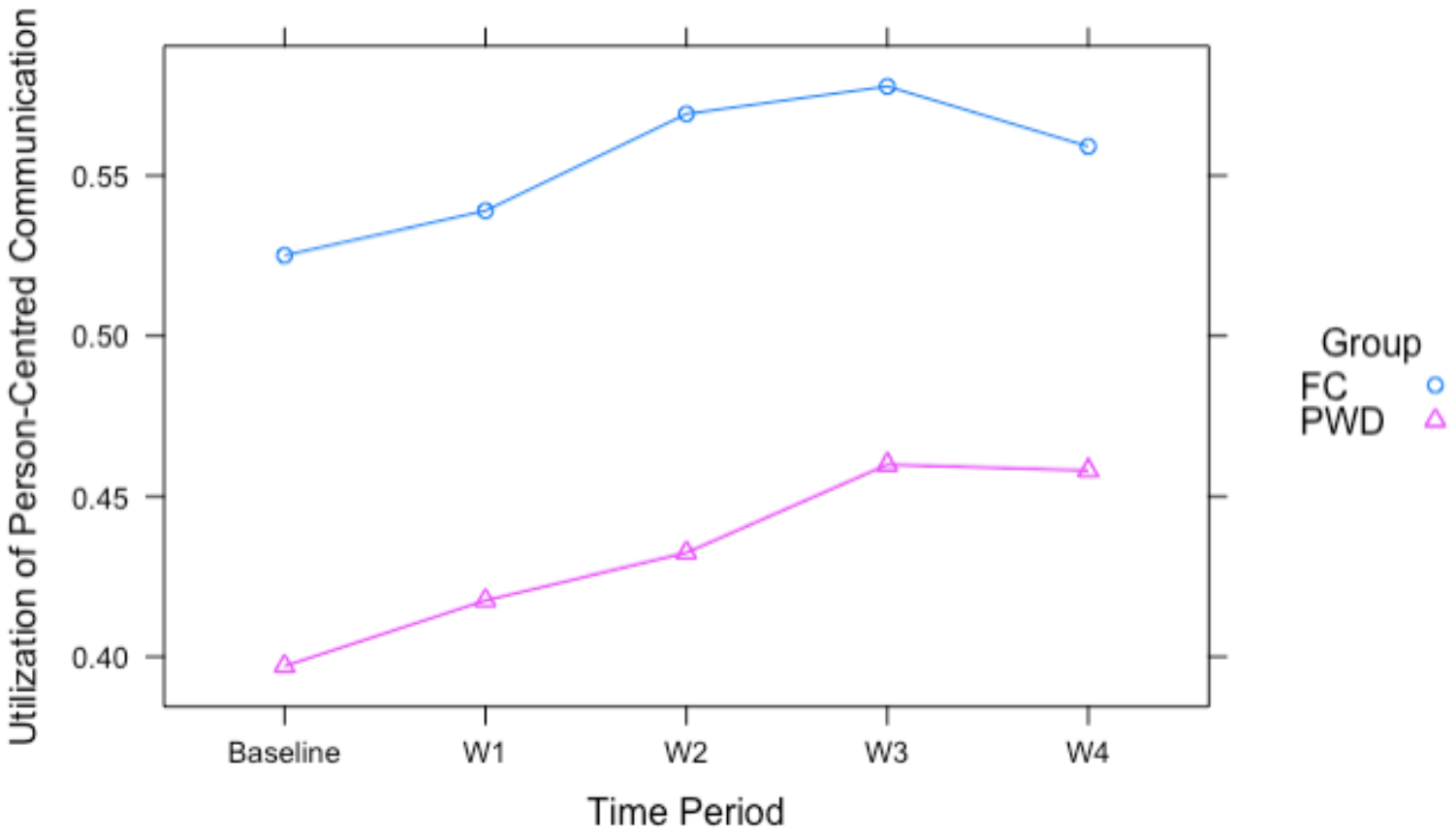
Weeks 3 - 6

- Practiced applying person-centred communication strategies to conversations about photos
- Recordings collected every 2 weeks

End of Week 6

- Administered second questionnaire on iPad and perceived person-centred communication knowledge

Person-Centred Strategy use over Time



Note. FC= Family Caregiver; PWD = Person with Dementia

Results

RQ 2

- No significant change in iPad knowledge for both persons with dementia and family caregivers

RQ 3

- Significant change in perceived person-centred communication knowledge for both persons with dementia and family caregivers
  - Persons with dementia: $t(6) = 5.73$, $p = .001$
  - Family caregivers: $t(6) = 5.00$, $p = 0.002$

Discussion- RQ 1

Main Effects

- Beneficial way to promote meaningful engagement

- **Group Differences**
  - Family caregivers play primary role in self-identity
  - Family caregivers did not face cognitive impairments

- **Time Differences**
  - Active engagement in education and training

Discussion- RQ 1

Interaction Model

- **Group Differences**
  - Persons with dementia are still able to learn new information
- **Time Differences**
  - Highly harmonious relationships

Discussion - RQ 2 and 3

RQ 2

- iPad use could have impacted ability to apply person-centred communication
- Many participants had previous knowledge

RQ 3

- Supports RQ 1
- Both proportion increase and perceived increase

Cognition (Cont'd)

- Obtain attention before communicating; alerting
  - Verbal – title and name
  - Appropriate touching – alerting
  - Eye contact
  - At person's level
- Eliminate distractions/noise – across all senses
- Do not argue the logic of an idea – 'Reality Orientation' often is not useful

Cognition – Reminiscence Rx

- Reminiscing is a type of discourse that recalls “long forgotten”, personal experiences from one’s past
- Emphasis is placed on remembering life experiences for the pleasure of re-experiencing happy or satisfying occasions, and for sharing experiences
- Activates attention, semantic and episodic memory processes, and language associated with relevant concepts, events, and feelings
- Gives the person with dementia conversational control
- Can enhance narrative discourse, conversational discourse, and verbal and nonverbal skills
- Can also improve self-esteem, provide relief from depression, and increase spiritual well-being
- R Rx provides an opportunity for professional caregivers to listen and interact with patients on a personal level

(Kim et al., 2006; see Woods et al., 2005 for Cochrane Review)

Cognition – Reminiscence Rx (Cont'd)

- Use multi-sensory personally relevant stimuli (e.g., books, pictures, objects, music, videos, etc
- Small group size (i.e., 4 to 8); enables participants to develop trust and willingness to share personal information
- Participants with similar cognitive-linguistic and social skills; however, various ages, employment, education, and socio-economic backgrounds can increase richness
- Topic selection – 'event' approach-historical themes; 'calendar' approach holidays; 'ladder of life' approach-developmental milestones of life

Bruce, Hodgson, & Schweitzer (1999) Resource – Reminiscing with People with Dementia; A Handbook for Carers

Cognition – Simulated Presence Rx

- Family member/caregiver makes audio- or video-recording about positive events in life of PWD; played to simulate presence of Fx
- Family member should convey positive emotion through voice and content
- Creates environment that is reassuring and familiar; can reduce responsive behaviours through stimulation of preserved memories and create positive emotions through stimulation of those memories
- Shown to reduce social isolation, agitation, and verbal or physical aggression
- Evidence only for moderate-severe dementia, but may have a positive impact on people with mild dementia as well

(Bayles et al., 2020)

Spaced Retrieval Training (SRT)

Camp (1989)

- "Gives individuals practice at successfully recalling information over progressively longer intervals of time"

- **"**To enable individuals to remember important information for clinically meaningful periods of time"

http://www.myersresearch.org/SR_info.pdf

SRT (Lee et al., 2009)

- Based on "expanding rehearsal technique"
- Spacing vs. massed practice + reduced cognitive effort
- Reduced learner effort
- Errorless learning
- Difficulty of items matched to learner's ability
- Training is social and enjoyable

Speech

- Normal rate (~150-180 words/min) (Bourgeois et al., 2003;Burgio et al., 2001;Dijkstra et al., 2002; Small, Andersen, & Kempler, 1997; Small, Kemper et al.,1997;Tomoeda et al., 1990)
- Normal pitch or slightly lower
- Highlight important information
  - Sound and syllable stress
  - Clear intonation patterns
  - Pauses (chunk information)
- Person sitting or standing supports respiration vs. lying down

Nonverbal

- Use calm, non-threatening and ‘inviting’ gestures, facial expressions, posture and position
  - Eye contact culturally, age and sex dependent
- Match nonverbal with speech and language
  - See ‘Elderspeak’
- Use appropriate touch (limbs vs. central part of body) along with spoken language to gain attention
- Get to person’s level – sitting or standing

Sensory

- Have hearing, vision and tactile sensations tested routinely
  - Effects on mobility
- Use supportive devices regularly
  - Glasses, hearing aids and other assistive listening devices, lens magnifiers, book holders, etc.
- Hearing aids, listening devices and glasses fully functioning
  - Microphone, Telephone, OFF, Noise Suppression
  - Trouble shooting assistive devices
    - Hearing aid battery life (*M* = 10-14 days @ 15-16 hrs./day)

Sensory (Cont'd)

- Minimize 'noise' across all senses (cognitive considerations)
- Also consider multiple, integrated sensory stimulation
  - Aromas, music, taste, massage, etc.

Environments

- Physical Considerations
  - Light
  - Temperature
  - Floor
    - Carpets vs. tile vs. linoleum
  - ‘Noise’/distractions
  - Distance from rooms
  - Location
  - Confidentiality
  - Furniture
    - Arrangement
    - Access
- Psychosocial Considerations
  - Create a ‘culture of communication’
    - Communication is valued as important

Montessori-Based Programming: Hx

(Orsulic-Jeras et. al., 2001)

- Developed by Italian educator, Maria Montessori, in early 1900's
- Based on the belief that learning can occur by alternating the ways of experiencing the environment
- Results showed that problem/responsive behaviours decreased when structure and purposeful activities were introduced

Goal of Montessori-Based Interventions

(Mahendra, N. et al., 2006)

"To design interventions for persons with dementia…to provide these individuals with opportunities to be meaningfully stimulated, engaged, socially interactive and, involved in activities of daily living."

Montessori Principles

(Mahendra et al., 2006)

1. Design a prepared environment, adapted for persons with dementia, with intent of providing meaningful stimulation and purposeful activities
2. Progress from simple and concrete to complex and abstract activities
3. Break down activities into component parts and train one component at a time using external cues to reduce errors and to minimize the risk of failure (i.e., errorless learning)
4. Allow learning to progress sequentially (learn in stages through observation and recognition to recall and demonstration)
5. Use real-life, tangible materials that are functional and aesthetically pleasing
6. Emphasizing auditory, visual and tactile discrimination through activities

Conversation Strategies (Sacks et al., 1978)

1. Turn-Taking and Organization (i.e., turn length and order)
   - Not usually impaired until the late clinical stage (Causino Lamar, 1994; Ripich et al., 1991)

2. Sequential Organization – recurring patterns
   - Retained until the late stage

Conversation Strategies (Cont'd)

3. Topic (Acton et al., 1999, *N*=20)

- Positive comments about family caregivers
- Awareness of cognitive limitations
- Humour
- Repetitive ideas
- Positive comments about the past
- Spiritualism, religion and faith
- Their own usefulness (caring for others and themselves)

Conversation Strategies (Cont'd)

3. Topic (Abbott & Orange, 2001; Garcia & Joanette, 1997; Mentis et al., 1995)

- Autobiographical memories accessed (i.e., episodic memory)
- Topics focused primarily on immediate context (Wilks & Ste. Pierre, 1995)
- Open ended questions useful for conversation initiation (Tappen et al., 1995)
- Topic introductions occurred at instances of communication misunderstandings (TSR sequences)
  - Initiators, extenders, and closers

Type and manner of topic introductions related to TSR sequences

- Introductions problematic for middle stage dyads
- Reintroductions problematic for early and middle stage dyads

Conversation Strategies (Cont'd)

4. Communication Misunderstandings - (Orange et al., 1996, 1998; Small et al., 2000, Watson et al., 1999, etc.)

- Use clear signals
  - Possible misunderstandings ("Do you mean _____?)
    - Requests for confirmation and specification
  - Avoid not so clear, non-specific terms ("Eh?", "What?", "Pardon me?", "Huh?")

- Repair Processes
  - Repetition and paraphrasing (i.e., substitutions) more successful than elaborations (i.e., adding new information)
  - Use synonyms rather than adding new information to fix misunderstandings

- Three signals and repairs then continue on same or different topic
- Take responsibility for misunderstanding vs. blaming PWD

Medications

Several classes (i.e., types) of medications well known to interfere with cognition, language and communication:

- Sedatives (i.e., sleeping pills -> drowsiness, less attentive, lethargy)
- Antidepressants (i.e., to elevate mood -> blurred vision)
- Anxiolytics (i.e., tranquilizers, to calm mood -> drowsiness, learning difficulty, sustained attention problems)
- Antipsychotics (i.e., to treat psychoses and obsessive compulsive disorders -> slurred speech (dysarthria),
  mental slowing, problems with sustained attention)

Medications (Cont'd)

- Anticoagulants (i.e., blood thinners -> increased drowsiness)
- Antihypertensives (i.e., lower blood pressure -> distractibility, irritability, problems with sustained attention)
- Narcotic based analgesics (i.e., strong pain killers such as morphine -> reduces attention span, distractibility, slurred speech, blurred vision)

Emotions

- Respond to **message** not **words**
  - Words may give one message (e.g., anger) but real meaning may be fear or frustration – consider Validation Therapy
  - Use calming communication after verbal outbursts; do not respond to words but potential underlying message
- Words can have multiple interpretations, especially if emotionally charged
  - For examples:
    - “I need to see my wife/husband/mother/father.”
    - “You're not my wife/husband/daughter/son.”
    - “I need to go home. This is not my home”

Emotions (Cont'd)

- Acknowledge/validate isolation, loneliness, and loss related to communication problems
- Use compassionate speech tone and inviting nonverbal gestures to acknowledge feelings of loneliness, anxiety, helplessness, and to acknowledge visual and auditory hallucinations
- Provide opportunities to express anxieties and frustrations

Emotions (Cont'd)

- Avoid saying information in the presence of the person with dementia which you do not want her/him to know
- Show an interest in what person says
- Thank her/him for talking with you; this expresses your appreciation for her/his willingness to talk
- Act as the "comforter" and not the "bad guy"; soothe rather than provoke

Gender (Tanner, 1990)

- Men use direct questions vs. women who use indirect questions
- Women use modals “would”, “could”, “should”, etc.
- Men use directives vs. women who use tag questions

Communication Enhancement Education and Training Programs

FOCUSED program (Ripich et al., 1995, 1996)

- 6 modules
  1. Introduction to AD and communication
  2. Memory and depression
  3. Importance of communication in AD
  4. Cultural aspects of communication
  5. The FOCUSED program
     F = Face to face
     O = Orientation to the topic, repeat key words
     C = Continuity (stay on topic)
     U = Unsticking (shared background knowledge), suggest words
     S = Structured (give choices in questions)
     E = Exchange (maintain interactions)
     D = Direct statements, nouns vs. pronouns,
  6. Implementing FOCUSED techniques at each stage of AD

Communication Enhancement Education and Training Programs

- Training program for professional/formal caregivers

- Designed to be implemented by speech-language pathologists or other professionals educated and trained in communication, aging and dementia

Goals of Program:

1. increase knowledge about communication skills and deficits in this population
2. improve communication between themselves and clients, family members, and each other

- 12 modules, quizzes, overheads, etc.

(Santo Pietro & Ostuni, 2003)

Communication Enhancement Education and Training Programs

TRACED program (Small et al., 2005; 2012)

Compensatory strategies

1. Using one-idea sentences
2. Asking questions that do not place demands on recent memory
3. Speaking at a normal rate without exaggerated intonation
4. Eliminating distractions
5. Redirecting with cueing cards for repetitions
6. Using specific cues to signal need for repair
7. Avoiding ambiguous reference
8. Not suddenly shifting the topic
9. Repeating when necessary and according to whether the listener misunderstood vs. forgot what was said

Communication Enhancement Education and Training Programs

TRACED program (cont'd)

Connecting strategies

1. Encourage: making comments that support or facilitate the family member's participation in a conversation
2. Invite: making comments that suggest a place for the family member in the activity or conversation
3. Assist: supplying a possible answer when the family member has difficulty, but not to answer for her/him
4. Support conversation: providing a context for apparently unconnected statements or by selecting and expanding a topic that is introduced out of context
5. Link-up: partnering and making comments that indicate a caring, shared history
6. Expand: building on words or ideas shared by the family member
7. Positivism: using positive suggestions instead of directives

Other Considerations (Cont'd)

- Be EPIC – Person-centred communication, education and training program for PSW (Savundranayagam, et al 2019, 2020)
- Brain Storms – 52 week, cognitive-communication stimulation program for persons with dementia
- Music, pet, stuffed animals/dolls, massage, gardening, art therapies, poetry, etc.
- Student partnerships (conversation notebooks, dance, physical activity and exercise programming) (Arkin et al., 1991-2001)
- ADL based programming (e.g., Breakfast Clubs) (Boczko & Santo Pietro; Small et al., 2000)

Other Considerations (Cont'd)

- Computer-assisted cognitive interventions (See Mahendra et al., 2005)
- TANDEM – Communication training for informal caregivers of people with dementia (Haberstroh et al, 2011)
- Cognitive Stimulation Therapy (CST) (Spector et al., 2010)