

# Enhancing Personhood in Individuals with Alzheimer's Disease and Related Dementias Through Supportive Communication

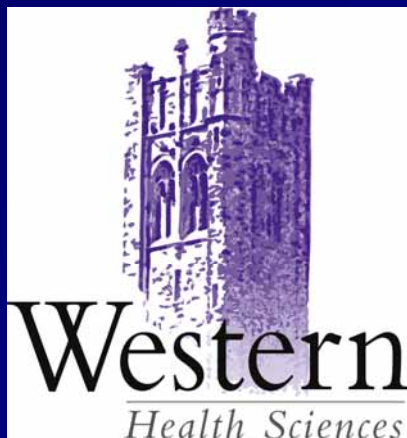
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*Partners in Care* ... Unlimited Possibilities

**Alzheimer Society** Manitoba  
Dementia Care & Brain Health

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JB Orange, PhD  
Associate Professor and Director  
School of Communication Sciences and Disorders  
Faculty of Health Sciences  
University of Western Ontario  
London Ontario CANADA N6G 1H1  
T 519-661-2111 X88921 F 519-850-2369  
[JBOrange@UWO.ca](mailto:JBOrange@UWO.ca)  
<http://publish.uwo.ca/~jborange/>

# Potential Conflicts of Interest: Current Funding Sources

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## 1. CIHR

- Canadian Dementia Knowledge Translation Network (CDKTN)

## 2. Canadian Association of Speech-Language Pathologists and Audiologists

- Establishing the psychometric properties of the Self-Assessment Communication Skills (SACS)

# Outline

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1. Complexity of human communication
2. Dementia and communication
3. The 'self' and personhood

# Speech

(production and perception)

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- Medium of oral communication that employs a linguistic code
- Communication through vocal symbols (i.e., sounds)
- Complex, dynamic neuromuscular processes:
  - Articulation
  - Resonance
  - Phonation
  - Respiration
  - Prosody (e.g., pitch, speech rate, stress, etc.)

# Language

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- A shared set of mutually agreed upon symbols used to represent concepts or ideas
- Symbols governed by set of rules:
  - Phonology (sound positions and combinations)
  - Grammar (The boy randed to the store.)
  - Syntax (to store the boy the ran)
  - Semantics (define “car”)
  - Pragmatics (multiple interpretations of words, phrases, clauses, or sentences - contextual influence, e.g., “run”, “cold shoulder”)

# Communication

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1. Exchange of concepts or ideas between two or more entities
  - Dynamic role exchange between speaker and listener
2. Mechanism whereby we establish, maintain and change relationships
  - Consists of multiple forms
    - Socially motivated and mediated = interactional
    - Agenda driven = transactional (e.g., ordering food in a restaurant)

# Speech, Language, Hearing and Communication

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## Output/Expression

- Spoken
- Written
- Nonverbal (e.g., gaze, facial expression, posture, proximity, touch, gestures, pantomime, finger spelling, sign language, etc.)

## Input/Understanding

- Auditory (**listening**) comprehension
- Reading (**seeing**) comprehension
- Nonverbal
- Senses of smell, touch and taste

# Cognition

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- Mental processes where sensory information is transformed, reduced, elaborated, stored, recovered and used
- Processes of gaining knowledge, organizing information (new or old), and using what has been learned
- Includes, but is not limited to:
  - Memory systems and processes
  - Attention systems and processes
  - Judgment
  - Reasoning - decision making
  - Insightfulness
  - Other systems and processes

# Dementia

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- ❖ Syndrome of acquired, progressive, persistent decline in 3 of 5 spheres of mental activity

(Cummings, Benson, & LoVerme, 1980)

1. Memory

2. Language and communication

3. Personality

4. Visuospatial skills

5. Cognition (e.g., reasoning, abstraction, judgement, etc.)

# DSM IV-TR (2000)

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- Multiple cognitive deficits of gradual onset and continual decline including both:
  - A. **Memory impairment**
  - B. One (or more) of the following:
    1. Language problems
    2. Movement programming problems (**apraxia**)
    3. Perceptions stripped of meaning (**agnosia**)
    4. Disturbance in executive functioning (e.g., planning, organizing, sequencing ideas, etc.)
- Cognitive deficits:
  1. Cause significant impairment in social or occupational functioning
  2. Represent significant decline from previous functioning
- Not due to other CNS conditions, systemic conditions known to cause dementia, substance abuse induced dementia, delirium, another primary psychiatric disorder

# Dementia Epidemiology – Worldwide\*

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- 27.7 million people with dementia in 2006 (25 M in 2000)
  - 46% Asia
  - 30% Europe
  - 12% North America
- 4.6 M new cases each year
- 63 M in 2030
- 81 M in 2040
- 114 M in 2050
- Most live in developing countries (60% 2001 to 71% 2040)
- \$156 B (2005 US \$) costs for dementia care/yr worldwide

\* Wimo et al., 2003; Winblad

<http://www.alz.org/preventionconference/pc2005/062005costad.asp>; Ferri et al., 2005

# Epidemiology and Demographics: Prevalence – Canada\*

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- 450,600 (8% of 65+) (% distribution: community = institutions)
- 111,000 new cases/yr (70,000 DAT) (CSHA, 2000)
  
- ~1.5-2 ♀: 1 ♂
- 2.4% 65-74 yrs
- 34.5% 85+ yrs
  
- 592,000 cases by 2021 (65 yrs + = 23-24% total pop)
- # cases will triple by 2031 (over ¾ million)

(CSHA I Working Group, 1994, *CMAJ*)

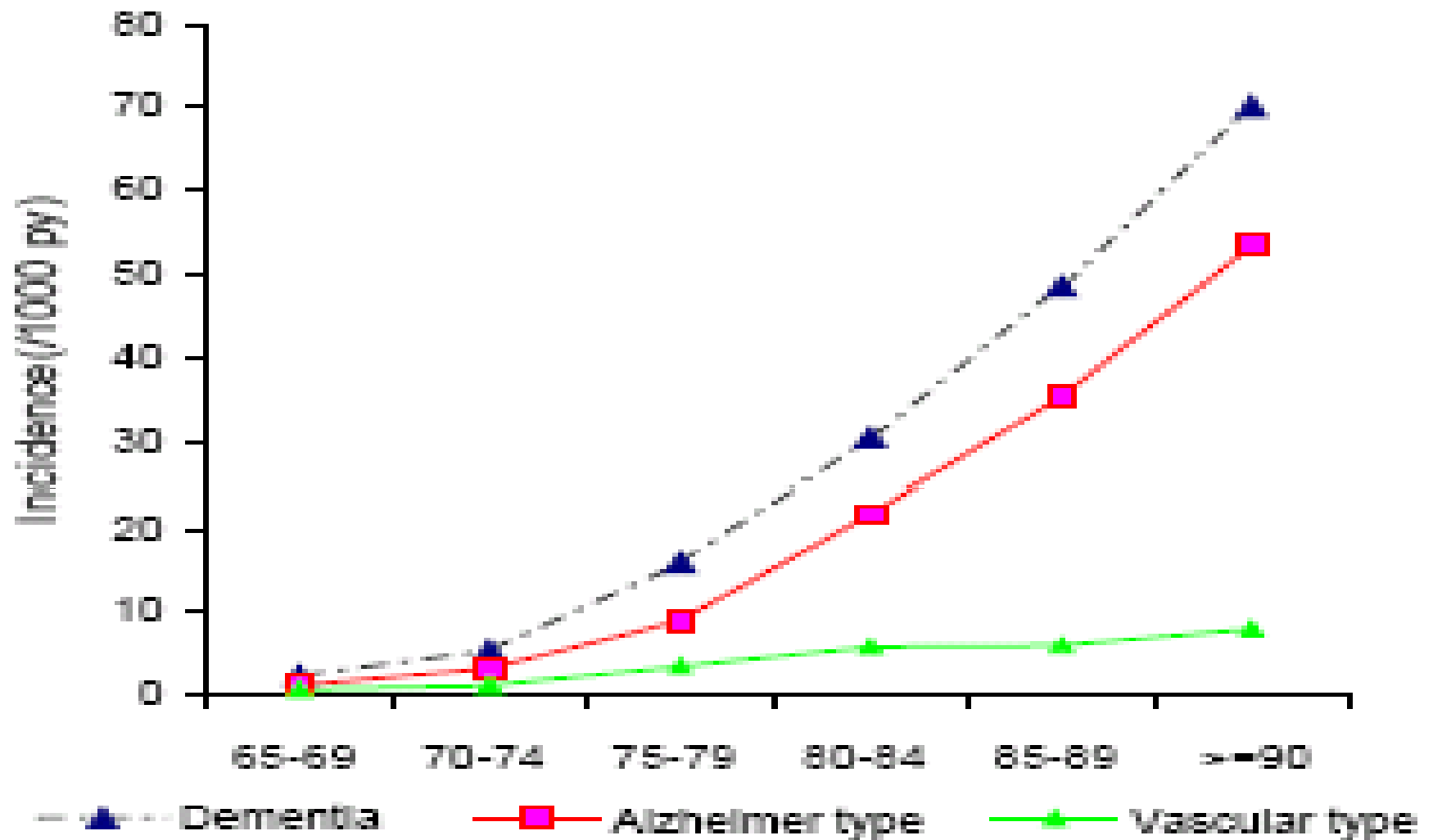


Fig. 1. Incidence of all dementias, Alzheimer and vascular type of dementia (per 1000 person-years): pooled analyses of 8 studies from the EURODEM group (Fratiglioni et al., 2000).

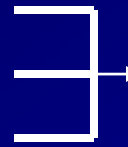
# Unfair Comparisons but Comparisons Nonetheless

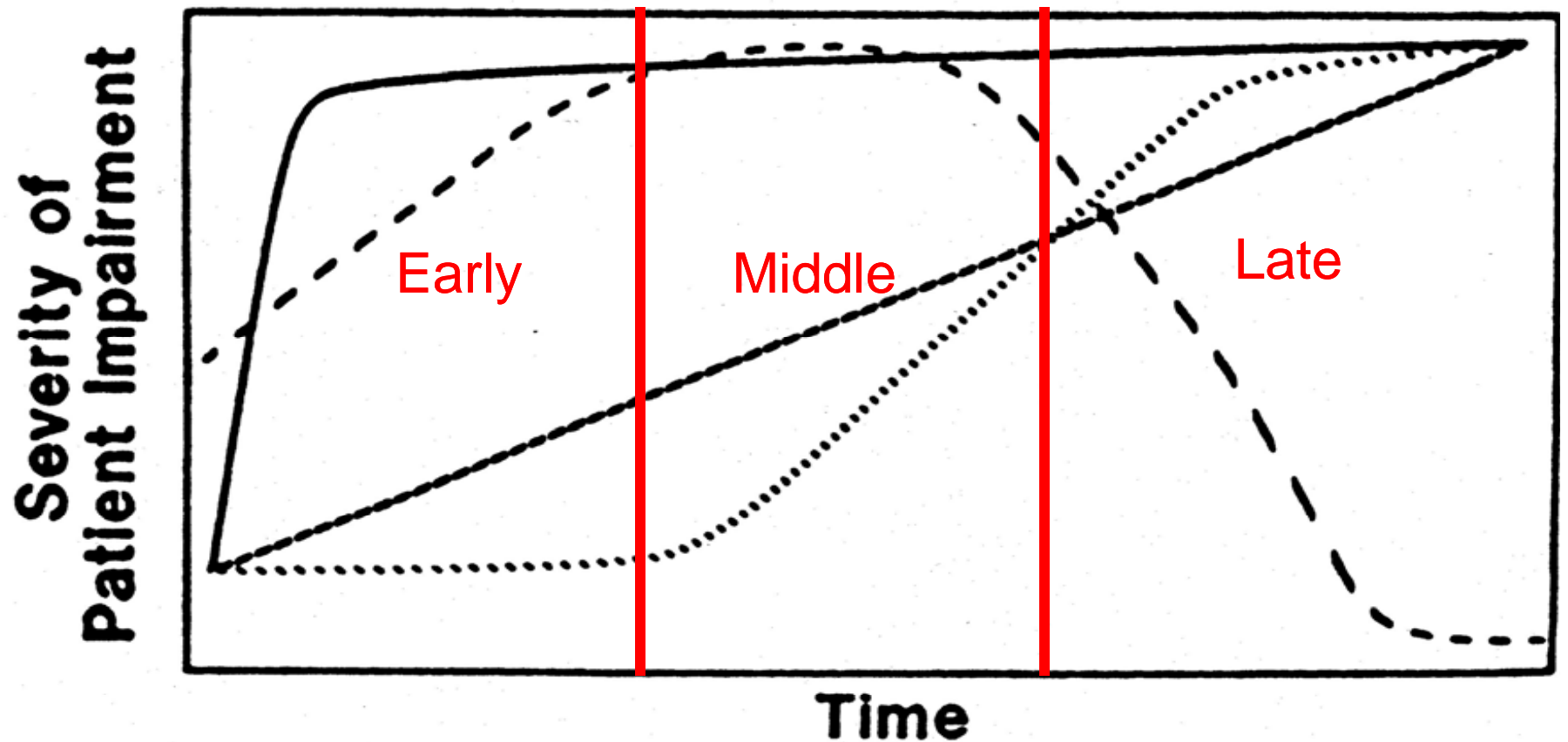
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- 450,600 Canadians with dementia ([www.alzheimer.ca/](http://www.alzheimer.ca/))
  - 111,000 new cases/yr
    - ~ 70,000 DAT/yr
    - 67,600 ♀
    - 44,000 ♂
- 4.5+ million in the USA with dementia ([www.alz.org/](http://www.alz.org/))
- 5 million + in China with dementia
- 1.11 to 2.5 million people worldwide with MS ([www.msif.org](http://www.msif.org) and [www.who.int/mental\\_health/neurology/neurogy\\_atlas\\_lr.pdf](http://www.who.int/mental_health/neurology/neurogy_atlas_lr.pdf))
- 160/1000,000 or ~ 9.7 million worldwide with Parkinson's disease ([www.who.int/mental\\_health/neurology/neurogy\\_atlas\\_lr.pdf](http://www.who.int/mental_health/neurology/neurogy_atlas_lr.pdf))
- ~ 100,000 Canadians with Parkinson's disease ([www.parkinson.ca/](http://www.parkinson.ca/))

# Examples of Types of Dementia

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- DAT/AD
    - Familial-DAT
    - Early onset-DAT
    - Down's syndrome-DAT
  - Mixed (DAT + VaD)
  - Vascular dementia (VaD)
  - Dementia with Lewy bodies (DLB)
  - FTLD (FLD [Fv] + PPA [Fv] + semantic dementia [Tv])
  - Dementia lacking distinctive histology (DLDH)
  - Binswanger disease
  - PPA
  - FTLD
  - Pick's
- 
- Pick Complex
- Dementia with motor neurone disease
    - Parkinson's, ALS, MS, HC, etc.
  - AIDS dementia complex (ADC)
  - Progressive supranuclear palsy (PSP) and corticobasal degeneration (CBD)
  - Creutzfeldt-Jakob disease (CJD)
  - Normal pressure hydrocephalus (NPH)
  - Syphilis
  - Wernicke-Korsakoff syndrome



- Intellectual Impairment
- Higher Level Self-care (IADL) Impairment
- ..... Basic Level Self-care (ADL) Impairment
- Disruptive Personality and Behavioral Problems

**Figure 2. Severity of dementia and type of patient impairment.**

From: Haley, W.E., & Pardo, K.M (1989). Relationship of severity of dementia to caregiver stressors. *Psychology and Aging*, 4, 389-392.

# Overall Preserved Abilities

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- Use of procedural memories (playing the piano, singing, playing card games, etc.)
- Ability to access early life memories for DAT but not for semantic dementia
- Ability to recite, read aloud and sing with good pronunciation and grammar
- Ability to engage in social ritual
- Desires for interpersonal communication

# Speech in DAT

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- Dysarthria → None
- Pitch changes → None
- Volume control → No problems
- Speaking rate → Normal
- Apraxias → Limb praxis problems early; verbal and oral apraxias can appear later

# Language and Communication in DAT

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- Language and communication problems prominent in DAT but also evidence of preserved skills
  - Subtle onset; problems prominent with progression
- Profiles vary by clinical stage
  - Markers of onset and progression
- Language and communication of utmost concern to caregivers
- Heterogeneity (i.e., broad range of skills) within each stage
  - stage

# DAT - Early Stage

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- Individuals aware of communication difficulties
- Word finding problems for names of people, places, objects and actions
  - Circumlocutions, gesture or associated word used as strategy for word finding problems
- Uses clichés and stereotyped phrases
- Communicates sufficiently for most social situations
- Problems understanding:
  - Complex sentences and concepts (e.g., metaphors and proverbs)
  - Humour, analogies, sarcasm, abstract expressions
- Generally only a few minor problems understanding what is said in 'everyday' conversations

# DAT - Middle Stage

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- Person less aware of language and communication problems
- Pronounced word finding problems; circumlocution
  - Empty and irrelevant utterances (e.g., words such as “**thing**”, “**this**”, and “**that**” often used in place of substantive nouns)
- Frequently repeat words, utterances, and ideas
- Disinhibited; inappropriate utterances (i.e., poor sensitivity to ‘where’ and with ‘whom’ he/she is speaking – context and partner factors)
- Digresses and rambles; poor topic maintenance
- Problems understanding simple commands
- Can be lost in multi-partner conversations

# DAT - Late Stage

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- Highly variable
- Spoken vocabulary severely reduced - unrelated words in utterances
- Repeats self and what others say – perseverative
- Word order and word agreement impaired
- "Islands" of fluent, coherent language
- Speech disturbances emerge (i.e., stuttering and pronunciation errors)
- Relies on intonation, syllable and word stress patterns, emotional tone of voice, and familiarity of voice and music

**So What!**

# Caregivers and Dementia

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- Approximately 50% of Canadians diagnosed with dementia continue to live at home (CSHA-I, 1994)
- Family members are typically the primary care providers of individuals with dementia
- Dementia caregivers experience more stress and negative outcomes than those caring for non-demented elderly family members (Clipp & George, 1993; Ory, Hoffman, Yee, Tennstedt & Schulz, 1999)

# Caregivers' Perspectives of Language and Communication in Dementia

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- Identify problems early
- Far reaching effects on social and emotional well-being
- Perceived to be a primary problem in caregiver coping and increased risk for institutionalization

# Spouses' Perceptions

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“Sometimes I find it difficult when he is home that **he sits there not talking**. I have to do the talking, but it's like to the wall. **I don't get anything back**” (Small, Geldart, & Gutman, 2000, p. 297).

“He is not the man he once was. **You lose your husband**. When I come home now, full of stories, I **don't tell them**. It takes such a **long time to explain**. His **language is seriously affected, understanding** as well as **saying things**” (Murray, Schneider, Banerjee, & Mann, 1999, p. 664).

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“I **cannot confide** in him anymore. It upsets him, and **he couldn't understand**. We talk about simple things – what to wear, what day it is, what time it is. I have been **exhausted** by his **repeated questions**” (Wright, 1993, p. 49)

“I **cannot have a conversation** with him. He **cannot understand** me and **gets angry**” (Murray et al., 1999, p. 664)

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Well naturally, it (verbal problems) has to have some impact. We have been not only husband and wife but the **best of friends**. I have always felt that he was my best friend. I could tell him anything and work things out between us. But of course **it's not the same** and I do miss it. (Orange, 1991)

Well, not really our relationship. No it's just, I **mourn** the days when we could discuss anything and everything. That's the only thing. (Orange, 1991)

# Parent-Child Relationships

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In other words, we never had anybody to talk to anymore ... He was there physically, but he wasn't there ... He didn't recognize who I was, **I sort of lost that thing, the father-son relationship**, and it was hard. (Parsons, 1997, p. 398)

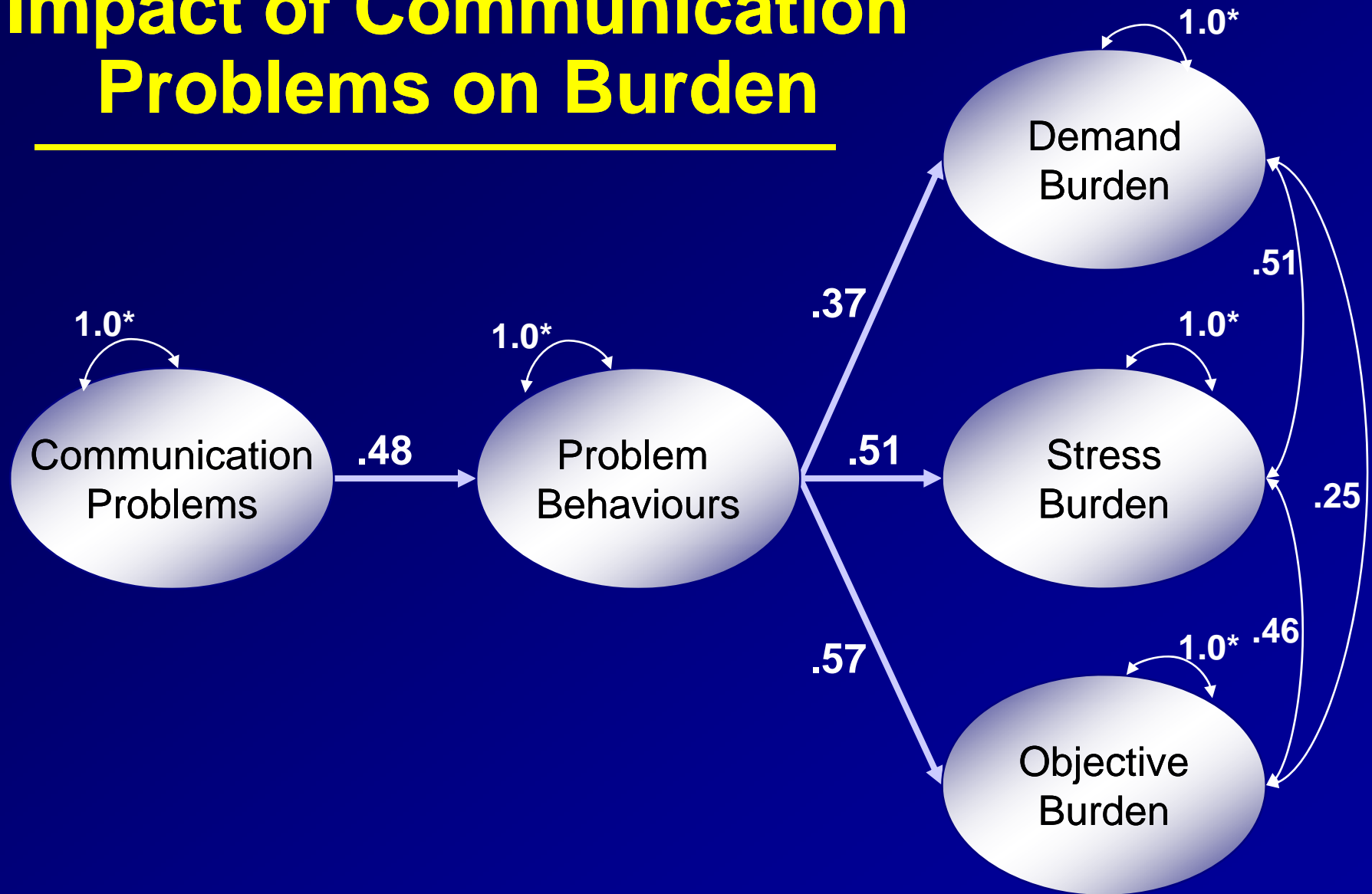
It had to curtail my social life, things I wanted to do. **It's almost better if a person were dead** because it is final. (Parsons, 1997, p. 398)

# SLP as Spouse

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Based on my years of listening to (his) (sic) speech and language, I have concluded that effective conversation is not predictable. It meanders, going from topic to topic and containing an element of surprise. (SLP and Family caregiver - Neustadt, 2001, p. 6)

# Impact of Communication Problems on Burden



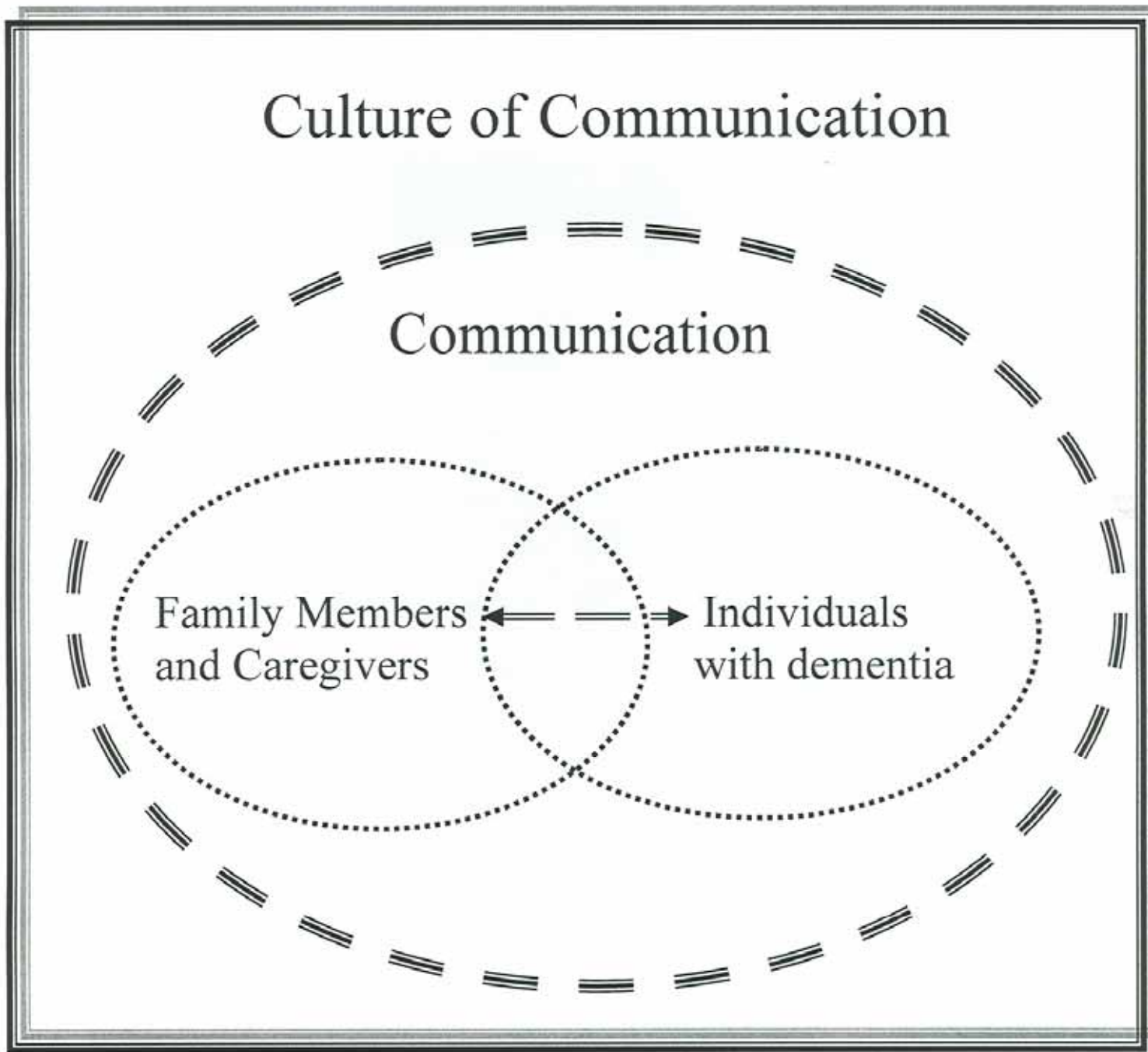
(Savundranayagam, Hummert, & Montgomery, 2005)

# Culture of Communication

Communication

Family Members  
and Caregivers

Individuals  
with dementia



# Communication Predicament and Enhancement Models

(Orange et al., 1995; Ryan et al., 1986,1995)

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- Importance of modifying communication based on individual capability rather than the stereotypical cues of older adults
- Caregiver communication enhancement programs – reflects dyadic nature of communication

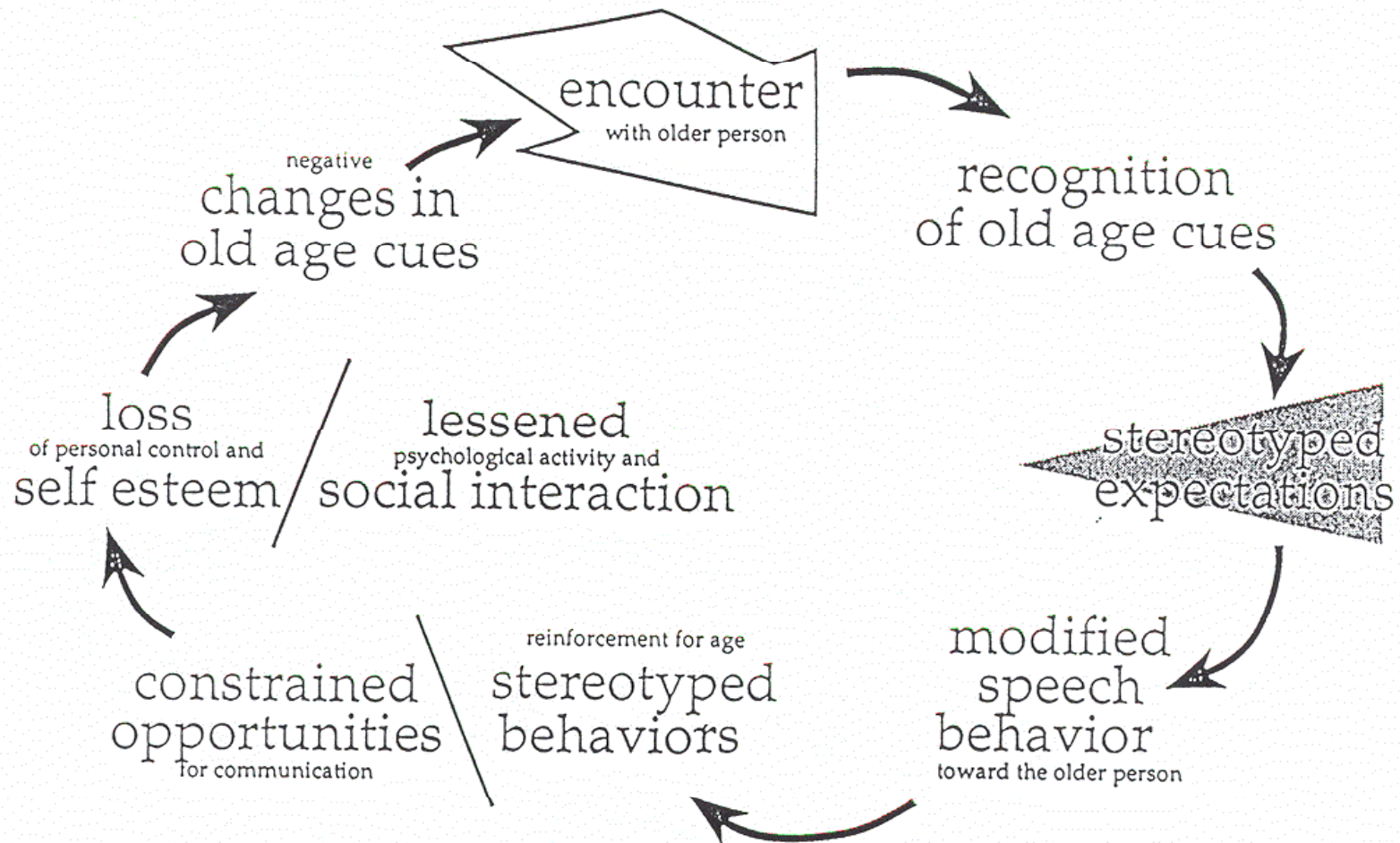
# Communication - Institutional

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## Institutional caregivers and verbally disruptive residents

- Social isolation
  - Cognitive impairments including perceptions and memory systems and processes
  - Depression
  - Environmental minimalism and overload
  - Medical and sensory conditions
  - Others
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- ❖ Over accommodated communication (secondary baby talk, patronizing talk, elderspeak)

# The Communication Predicament of Elderly People



(Ryan et al., 1986)

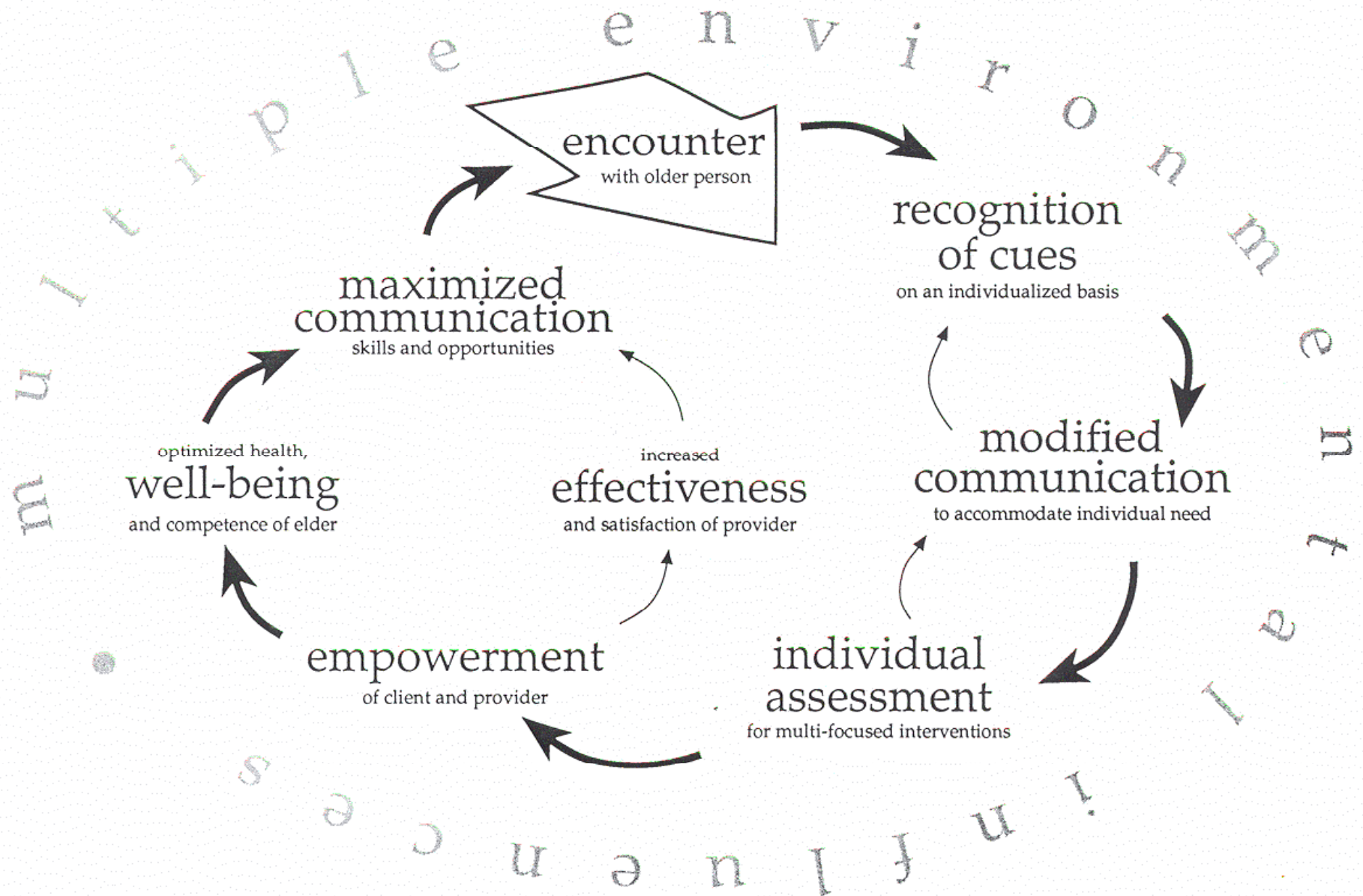
# Selected Examples of Elder-Speak, Patronizing Speech, Secondary Baby Talk

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- Increased loudness
- Exaggerated intonation
- Higher pitch
- Slow speaking rate
- Simplified syntax
- Simplified content
- Tag question
- Closed-end questions
- Short directives
- Short utterances
- Higher # utterances per conversational turn
- Presumptions of poor memory
- Nonverbal behaviours
- Terms of endearment, pet names, nick names
- Use of first name

# Communication Enhancement Model

(Orange et al., 1995; Ryan et al., 1995)



# Video

*“Real Stories – Good Morning Mrs. Vickers”*

# The 'Self' and Personhood

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## Sabat's (2001) Concept of 'Self'

1. The self of personal identity – “I”, “Me”, ‘My”, “Mine”, etc. used by persons with dementia
2. Self attributes – descriptions of past and present characteristics, beliefs, abilities, and talents
3. Self as public personae – profile of self in society
  - profession, volunteer, public figure, award winner, etc.

# Kitwood's (1997) Positive Care Interactions - Personhood

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1. Recognition – person known by unique characteristics or name(s)
2. Negotiation – person is consulted about preferences, choices, and needs
3. Validation – acceptance of reality, and acknowledging feelings, connectedness and person
4. Collaboration – align with the person with dementia to engage together in tasks; work together to achieve goals
5. Facilitation – enable person to accomplish what he/she would otherwise be unable to do by providing missing parts of intended actions

# Video

Mealtime Conversation – “The Polish  
Soldier”

# Movie Clip

*“Iris”*

Emphasis on the need to connect with Iris’s own language and communication