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# Communicating with Alzheimer Patients

**20th AE Conference:  
Facing Dementia together**

**30 September-2 October 2010  
Luxembourg**

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## Background

- **Statistics suggest an Alzheimer crisis!**
  - **USA (2009 estimates):**
    - 5.3 million people have Alzheimer's
    - 148 billion dollars in annual costs
    - a new case every 70 seconds
  - **Europe (estimates, 2006, EuroCoDe / EURODEM)**
    - 7.3/6.5 million people have Alzheimer's
  - **Worldwide (2005 estimates)**
    - 29.3 million people
    - 315.4 billion dollars
  - **Romania (2005 estimates)**
    - 0.3 million people (*NB: underdiagnosed, ~10% of actual figures!*)



## Diagnostic difficulties

- **AD related challenges: symptom variability**
  - Memory problems
  - Speech difficulties
  - Behavioral changes
- **Patient related challenges: patients can be:**
  - Unaware of their problems/condition, or
  - Attempting to conceal their difficulties
- **MD-related challenges:**
  - Late referral by GPs
  - Time consuming
- **System challenges: low funding, insufficient GP training, HCS flaws**
- **Family related challenges**

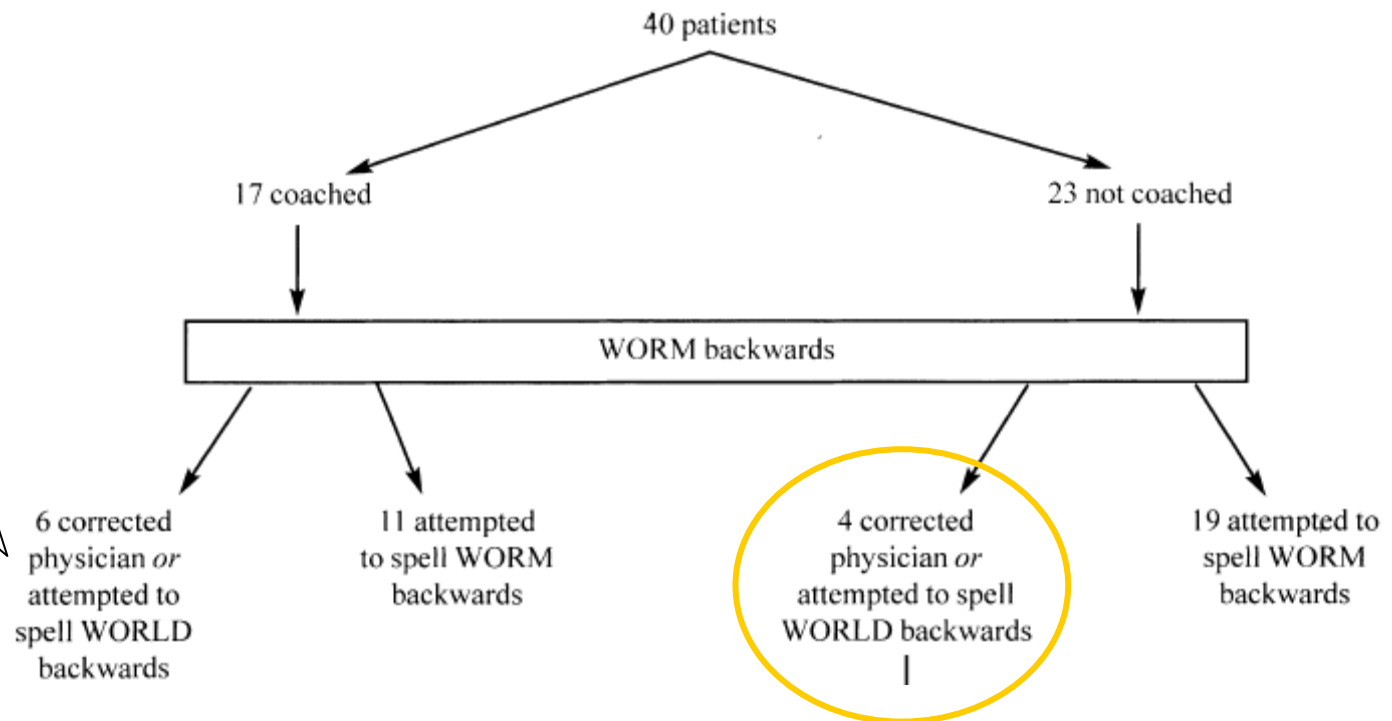


## Diagnostic difficulties

- **Family/caregiver related challenges:**

- Teneille Gofton and Donald F. Weaver. Challenges in the clinical diagnosis of Alzheimer's disease: Influence of "family coaching" on the Mini-Mental State Examination. *Am J Alzheimers Dis Other Demen* 2006; 21; 109,

Galasko D, Abramson I, Corey-Bloom J, et al.: Repeated exposure to the Mini-Mental State Examination and the Information-Memory-Concentration Test results in a practice effect in Alzheimer's disease. *Neurology*. 1993; 43: 1559-1563.





## Aims

- **To identify key messages in order to assist for a more effective communication between:**
  - **Physician and AD patients**
  - **Physician and family/caregivers/informants**
  - **AD patients and their family/caregivers**
- **To design a minimal set of communication skills and predictable courses of action**
  - **Best practices**
  - **Recommended practices**



## Method

- **Systematic overview of medical literature**
- **PubMed search:**
  - **disclos\* OR communic\* NOT communicate AND Alzheimer**
- **1181 initial results, 201 reviews, 148 free full text**
- **Further refinement:**
  - **Languages: Romanian, English, French**
  - **Aged 65+ years**
  - **Text options: links to free full text**
  - **Species: Humans**
  - **Type of articles: clinical trial, meta-analysis, practice guideline, government publication, multicenter study, patient education handout**
- **Final result: 17 papers**



## Results (1)

- **1 study investigated enhancements brought by prosthetic memory aids:**
  - M Bourgeois, Enhancing conversation skills in patients with Alzheimer's disease using a prosthetic memory aid. *Journal of Applied Behavior Analysis*. 1990(23), 29-42
- **1 study investigated effectiveness of coaching caregivers:**
  - Roque et al., Communicative strategies training effectiveness to caregivers of patients with dementia. *Pró-Fono Revista de Atualização Científica*. 2009 jul-set;21(3), 225-230
- **1 study investigated AD diagnostic disclosure:**
  - Shimizu et al., Disclosure of the diagnosis of Alzheimer's Disease. *Arq Neuropsiquiatr* 2008;66(3-B):625-630
- 14 studies were excluded (irrelevant for communication skills & abilities)



## Results (2)

- **Best practices**
  - **Defined in our review as practices used by all caregivers in all situations**
  - **May be instinctual or acquired through training**
  
- **Recommended practices**
  - **Defined for the purposes of our review as practices used by caregivers in at least half the times**
  - **Usually acquired through training**





## Results (3)

- **BEST PRACTICES**
  - **Instinctual action of caregivers:** Short, simple sentences
  - **Other helpful strategies to be used by caregivers:**
    - **Slow speech**
    - **Slow/frontal approach +/- touch**
    - **Frontal / eye contact**
    - **Avoid environmental noise**
    - **Avoid interruption of speech**
    - **Ask closed questions**
    - **Use gestures and facial expressions**
    - **Interpretation of behavior/body language**
    - **Use of objects / pictures / writing**
    - **Well-lit rooms**

Roque et al., Communicative strategies training effectiveness to caregivers of patients with dementia. Pró-Fono Revista de Atualização Científica. 2009 jul-set;21(3), 225-230



## Results (4)

- **RECOMMENDED PRACTICES**
  - **Closed vs. Open questions**
  - **Repeating what was not understood (same vs. different words)**
  - **Help in reminding words (talking about what AD patient tries to remember)**
  - **When not understanding, repeat what caregiver thinks is said and ask confirmation**
  - **Speech intonation**
  - **Use of objects, pictures, writing**

Roque et al., Communicative strategies training effectiveness to caregivers of patients with dementia. Pró-Fono Revista de Atualização Científica. 2009 jul-set;21(3), 225-230



## Results (5)

- **Study pitfalls:**
  - **Small-sized population: 7 elderly + 7 caregivers**
  - **Short-termed: 7-21 days**
  - **No quantification of actual communication effectiveness, too much focus on behavioral changes of caregivers pre- and post-briefing**
- **Conclusions:**
  - **Some strategies seem to lead to lesser frustration for caregivers and to better patient-caregiver communication (however, not quantified)**
  - **More extensive studies are required:**
    - **Larger populations**
    - **Long-termed**
    - **Assessment of communication efficacy**
    - **Practices to be avoided (!)**

Roque et al., Communicative strategies training effectiveness to caregivers of patients with dementia. Pró-Fono Revista de Atualização Científica. 2009 jul-set;21(3), 225-230



## Results (6)

- **Diagnostic disclosure:**
  - **50 patients + 50 caregivers + 50 volunteers with no AD in family**
  - **Structured questionnaire (Mimura 2003) about AD disclosure**
    - **If caregiver were to be diagnosed with AD**
    - **Would they disclose diagnostic to their own AD actual patient**
  - **2<sup>nd</sup> questionnaire about AD symptoms and course of disease**
  - **Corroborated with schooling, age, gender, socioeconomic status data**
  - **Questionnaires applied before and after AD detailed information**

Shimizu et al., Disclosure of the diagnosis of Alzheimer's Disease. Arq Neuropsiquiatr 2008;66(3-B):625-630



## Results (7)

- **73% of all caregivers agree to disclosing AD diagnostic**
  - **34 men & 66 women**
  - **Mean age 57.97 years**
  - **Median 10 years of schooling**
  - **Not influenced by age, gender and socioeconomic level**
- **No information collected about HOW to disclose the diagnostic**

Shimizu et al., Disclosure of the diagnosis of Alzheimer's Disease.

Arq Neuropsiquiatr 2008;66(3-B):625-630



## Conclusions (1)

- **Further studies are required**
- **Suggested design:**
  - **Controls vs. AD patient/caregiver pairs – (!) group size**
  - **Follow-up > 6 months**
  - **Coaching (speech language pathologist / psychologist / psychiatrist)**
    - **DOs and DON'Ts (!)**
  - **Structured questionnaires pre- and post- coaching**
    - **Quality of communication**
      - **Between MD and AD patient**
      - **Between AD patient and caregiver**
    - **Communication practices & skills**
    - **Should AD patients also be interviewed (?)**



## Conclusions (2)

- **Main study leads & aims:**
  - **Should identify communication skills which are independent of:**
    - **Age, gender**
    - **Socioeconomic status**
    - **Schooling & academic background**
    - **Cultural (regional) bias**
  - **Should identify minimal sets of communication skills & strategies to be effectively used when communicating**
  - **Should identify practices NOT to be used (!)**
  - **Such skills & strategies are probably identical for caregivers & MDs**

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***Thank you for your attention!  
- discussions -***

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