Communicating with Alzheimer Patients

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Razvan Ioan Trascu, MD, MPH
rit@brainaging.ro

Prof. Luiza Spiru, MD, PhD
lsaslan@brainaging.ro

Ana Aslan International Academy of Aging
Bucharest, Romania
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:

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40 patients

17 coached
  6 corrected physician or attempted to spell WORLD backwards
  11 attempted to spell WORM backwards

23 not coached
  4 corrected physician or attempted to spell WORLD backwards
  19 attempted to spell WORM backwards
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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:

- 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:

- 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
Communicating with Alzheimer Patients. Razvan Trascu, Luiza Spiru, 2010

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
  - 2nd questionnaire about AD symptoms and course of disease
  - Corroborated with schooling, age, gender, socioeconomic status data
  - Questionnaires applied before and after AD detailed information

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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