Younger people with dementia: attuning care to fit their needs

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YOD in the Netherlands

• 5,000 – 19,000 people with YOD in the Netherlands (Harvey, 1998; Ikejima, 2009; Withall, 2012; WHO 2012)

• Dutch Young-onset Dementia Knowledge Centre
  • 20 care organizations specialized in YOD services
  + the Dutch Alzheimer Society
  • National YOD Care Program
  • Educational program health care professionals
  • Collaboration with RadboudUMC and Maastricht University in the BEYOND-study and the NeedYD-Study

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The Needs in Young onset Dementia (NeedYD) study

- Investigate the course of young-onset dementia (i.e. cognitive functioning, problem behaviour, caregiver functioning)
- Explore care needs of young onset dementia patients and their caregivers
- Explore what factors are related to the use of (in)formal care, caregiver burden and the time to institutionalization in community dwelling young-onset dementia patients
- Compare these issues with late-onset dementia
Initial diagnosis

- Dementia: 55%
- Depression/burnout: 23%
- Other psychological diagnosis: 13%
- Somatic diagnosis: 4%
- No diagnosis: 5%

Final diagnosis

- Alzheimer's disease: 57%
- Frontotemporal dementia: 12%
- Vascular Dementia: 19%
- Mixed dementia: 4%
- Lewy body dementia: 3%
- Other Cause: 5%
What have we learned?

- Raising awareness among general public and health care professionals

- YOD educational program for general practitioners, elderly care physicians, occupational physicians, insurance company doctors and other health care professionals
Unmet Care Needs and Challenging Behaviours

Challenging behaviour

Unmet care needs
Person with YOD

Informal care vs. Formal care in YOD

Informal care 75%
Formal care 25%

Bakker C, de Vugt ME, van Vliet D, et al. The Use of Formal and Informal Care in Early Onset Dementia: Results From the NeedYD Study. AJGP, 2012.
Mariahoeve Centre for Specialized Care in Young-onset dementia
Where Science meets Clinical Practice
Modular care program

Someone who wants to have meaningful daytime activities and the company of others
- Support group
- Occupational therapy
- Non verbal therapies
- Individual counseling
- Adapted work

Someone who is easily agitated and might be unaware of the dementia
- Psychologist
- Group fitness
- Occupational therapy
- Psycho-education family
- Buddy

someone with apathy as a core symptom
- Recreational activities
- Outdoor activities
- Physiotherapy
- Structured program
- Psycho-education family

Someone who experiences difficulties because of medical comorbidity
- Medical care
- Individual counseling
- Physiotherapy
- Hotel service
- Diagnostic services
Supporting YOD families

Introduction course

- Transitions in care
- Informal vs formal care
- Management of behavioural symptoms
- Peer support
- Dealing with role change
- Sense of competence
- Legal and financial issues
- Relationship difficulties
- Behavioural symptoms
- Dealing with social isolation
- Dealing with other psychosocial consequences

Open support group

Individual counseling

- Mental health problems
- Grief counseling

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Conclusions I

- Casemanagement a prerequisite for integrated caregiving in YOD
- The systematic evaluation of care needs is essential for a good fit with care and support.
- Looking at challenging behaviors within the context of care needs.
- Psychotropic drug use should be reviewed regularly.
Conclusions II

• Advanced care planning helps
• Looking at challenging behaviours, especially apathy
• Enhance caregivers’ sense of competence
• Design (residential) services to fit the needs of people with YOD and their families.
Thank you!

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