Service Provision in Young-onset dementia: Towards an integrative approach in caregiving

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Introduction
• Currently an estimated 35.6 million people are affected by dementia and this number will double by 2030 and even triple by 2050 (WHO, 2012)
• An estimated 6-9% of people affected by dementia before the age of 65 (WHO, 2012)
• Increasing incidence of YOD with the increase of known risk factors for dementia such as obesity, diabetes and cardiovascular disease in developed countries (Kivipelto et al, 2005; Hayden et al, 2006; Razay et al, 2006)
• Mainstream dementia services are unlikely to be familiar with the needs and wants of these younger people and their families (Luscombe et al, 1998)

National Taskforce Young-onset Dementia
• Care organizations & Alzheimer’s Association Netherlands
• Aim:
  (1) National care program young-onset dementia
  (2) Appropriate funding
  (3) Best practice > evidence based care in YOD

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 people with young onset dementia 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 people with young-onset dementia
• Compare these issues with late-onset dementia

Unmet needs in YOD
• 24% of needs unmet!
• Most often unmet needs regarding:
  - Meaningful daytime activities (46%)
  - Social company (37%)
  - Eyesight and hearing (37%)
  - Information (23%)
  - Psychological distress (18%)
  - Etc.
Unmet care needs and health related QOL

- Increase unmet needs PWYOD
- Increase unmet care needs caregiver
- Decrease caregiver HRQoL
- Decrease caregiver HRQoL


Unmet care needs and behavioral problems

Behavioral problems

Decrease caregiver HRQoL

Increases unmet care needs

Unmet care needs

Decrease caregiver HRQoL

Behavioral problems

Unmet care needs and health related QOL

Increase unmet needs PWYOD

Increase unmet care needs caregiver

Decrease caregiver HRQoL

Decrease caregiver HRQoL


Mariahoeve Centre for Specialized Care in Young-onset dementia

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where Science meets Clinical Practice

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General practitioner

Memory clinic or mental health service

Specialized memory clinic

Dedicated YOD centre or mainstream dementia service

TIME TO DIAGNOSIS

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<tr>
<th>YOD</th>
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2.6

Years

RAISING AWARENESS

Dealing with a lack of knowledge and understanding

Raising awareness among the general public

- Periodic interviews or editorials in local newspapers
- Media coverage of events
- STIP-JD (Information and initial support through telephone or email)
- Interviews at “Alzheimer Cafe” meetings

Education of health care professionals

- YOD in the curriculum of elderly care physician education program
- YOD in the curriculum of general practitioner education program
- Training program occupational physicians and insurance company doctors
- In-company training program for those working with people with young-onset dementia
  - Base program: 8 sessions on main YOD topics
  - Advanced modules: tailored to individual needs of the professional

The need for an integrated approach in YOD caregiving

MANAGEMENT OF YOD

Florence YOD Care Program

Cluster 1
- Psychosocial support
- Occupational therapy
- Non-verbal therapies

Cluster 2
- Psychologist
- Group fitness
- Occupational therapy

Cluster 3
- Recreational activities
- Outdoor activities
- Physiotherapy

Cluster 4
- Medical care
- Individual counseling

Formal – informal care ratio

- One caregiver
- Usually a spouse
- Sometimes a child
**Predictors of informal care use**

- Increase informal care
- Severe dementia
- Decrease informal care
- Younger age

**Predictors of formal care use**

- Increase formal care
- Severe dementia & Loss of initiative
- Increase behavioral problems

**Supporting YOD families**

- Legal and financial issues
- Relationship difficulties
- Behavioral symptoms
- Dealing with social isolation
- Dealing with other psychosocial concerns

**Awareness in young-onset AD**

- Awareness over time (6 months vs. 12 months)

**Support groups**

- Meet with other people with YOD
- Share experiences
- Treatment of mild depressive symptoms
- Deal with changes as they occur
- Lower threshold for day care

**Themes**

- Loss of identity and sense of self (Horns et al., 2002)
- Social aspects (Werner et al., 2009)
- Information about the disease and care options
- Mobility
- Intimacy
- Social company
- Communication (Sokker et al., submitted)
Social events
- Meet other YOD families
- Meet YOD professionals
- Non-demanding environment

Day care centre
- Flexible operating hours
- Highly trained staff
- Program fitting the needs of people with YOD

Physical exercise
- Enhance physical health
- Improve cognitive functioning
- Reduce behavioral problems
- Retain mobility as long as possible

Art Therapy
- Non-verbal
- Reduce behavioral problems
- Improve sense of self

Musical Therapy
- Non-verbal
- Reduce behavioral problems
- Effective also in advanced dementia
Overnight and weekend stay service
- Respite
- Observation behavioral symptoms
- Acute intervention

Integrating care with diagnostic services
- Collaboration with department of neurology, HAGA Clinic
- Second opinion regarding dementia diagnosis
- Etiology of behavioral problems and treatment options
- Consults, such as psychiatrist, internist, clinical geneticist

When community care options have run out
RESIDENTIAL CARE

Predictors for institutionalization in YOD
- Increased Risk
  - Apathy

- Reduced Risk
  - Female caregiver
  - Spouse caregiver
  - High sense of competence
  - Frontotemporal dementia
  - Less severe dementia

Sheltered living
- Alternative for long term residential care
- Small scale
- Focus on creating a home
- Expert care is nearby
Long term care

- Small scale living in a large scale facility
- Mean duration of stay 3+ years
- Care program continues
- Creating a ‘home’ within an institution
- Caregiver participation
- Low usage of psychotropic drugs
- No restraints used

Thank you for your attention

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