Integrating specialist medical, psychosocial and nursing care for quality of life in Dementia:

The Dutch approach to nursing home medicine

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Key messages

- Dementia is a terminal disease, that requires specialist palliative & medical care, especially in the last stages
- A well-trained physician should be in the Nursing home team, to make sure optimal physical comfort can be assured,
- And that medical treatment is not:
  - Futile
  - Aggressive
  - Burdensome
- But patient centered, aimed at quality of life and
- In shared decision with patient/family

NCPC London 2014
Progression of Alzheimer’s disease

- **Early**
  - Symptoms
  - Diagnosis
  - Loss of independence

- **Mild**
  - Behavioural problems

- **Moderate**
  - Long term care

- **Severe**
  - Death

adapted from Feldman and Gracon 1996
Leads to shifting goals of care

Figure 1. Dementia progression and suggested prioritizing of care goals.
The Netherlands

- 17 million people
- 2.5 million elderly (65+), of whom:
  - 80% lives independently
  - 10% adjusted/sheltered houses
  - 5.5% homes for the aged, (120,000)
  - 2.5% in 325 nursing homes
  - 1 in 6 dies in nursing home
Disease trajectories for dementia and Dutch care system

- Hospital/ memory clinics
  - Diagnosis
  - Acute intervention

- Community
  - General Practitioner

- Residential home
  - Nursing home (Hospice care)

- Informal care
  - Nursing care
  - Day care

- Financial system
  - General medical insurance
  - Exceptional medical expense
  - Welfare care - municipality
Early-mild-moderate stages of dementia: at home/residential care

- Family physician/Consultation
- Social services
- Outreach mental health
- Day care
- Hospice/Terminal home nursing

NCPC London 2014
Moderate-severe stages: nursing home

- Nursing home physician
- Social services NH
- Mental health by NH psychologist
- Activities by NH
- Palliative care in NH
Physically disabled

• 29,000 beds
• 2,500 day clinic places

Dementia-patients

• 31,000 beds
• 2,500 day clinic places
• Special Units for:
  - young onset dementia,
  - Huntington,
  - Korsakov,
  - people with behavioral problems,
  - co-morbid psychiatric diagnoses
Exceptional Medical Expenses Act

- Nursing staff
- Nursing Home Physician (1 : 100)
- Physical, occupational and speech therapists (1 : 35)
- Dieticians
- Psychologists
- Social, spiritual and recreational workers
Nursing Home Medicine

• 1989: official recognition as medical specialism, start of first official training program
• problem-oriented medical care
• for chronically ill and elderly people
• suffering from chronic and intercurrent diseases
• and physical, cognitive and psychosocial problems
• who needs continuous, often long-term and multidisciplinary care

• Since 2009:
• together with social geriatrician: Elderly Care Physician
Fields of nursing home medicine

• Physically disabled patients
• Psychogeriatrics
• Rehabilitation
• Palliative care
• Consultation primary care
Specialist Training for Nursing Home Physicians

• 3 years training program
• Practical part
• Theoretical part
Structure (theoretical part)

- 1 day per week at the University Hospital (Leiden, Amsterdam, Nijmegen)
- Groups with 10-20 trainees
- 2 staff members (NHPh and Psychologist)
Main Teaching Topics

1. Acute care
2. Geriatric giants
3. Rehabilitation
4. Psychogeriatrics
5. Chronic diseases
6. Palliative care
7. Methodology of care
8. Communication skills
9. Multidisciplinary collaboration
10. Ethics and legislation
11. Professional attitude
12. Management
13. Outpatient care
14. Research
### 10 largest medical specialist fields

<table>
<thead>
<tr>
<th>10 largest medical specialist fields</th>
<th>Number of specialists</th>
</tr>
</thead>
<tbody>
<tr>
<td>General practice</td>
<td>10,500</td>
</tr>
<tr>
<td>Psychiatry</td>
<td>2,600</td>
</tr>
<tr>
<td>Occupational medicine</td>
<td>2,100</td>
</tr>
<tr>
<td>Internal medicine</td>
<td>1,850</td>
</tr>
<tr>
<td><strong>Elderly care medicine</strong></td>
<td><strong>1,500</strong></td>
</tr>
<tr>
<td>Anaesthesiology</td>
<td>1,400</td>
</tr>
<tr>
<td>Paediatrics</td>
<td>1,300</td>
</tr>
<tr>
<td>Surgery</td>
<td>1,150</td>
</tr>
<tr>
<td>Obstetrics/Gynaecology</td>
<td>950</td>
</tr>
<tr>
<td>Radiology</td>
<td>950</td>
</tr>
</tbody>
</table>

*Source: Royal Dutch Medical Association 2010*
Physical discomfort encountered in last stages

- Challenging/inappropriate/aggressive behavior
- Pain
- Shortness of breath
- Incontinence
- Pressure ulcers
- Communication with spouse and care givers
- Malnutrition
- Depression and apathy
- Muscle contractures
- Dental/mouth care
- ……etc
How is medical care different in these stage?

• Advance care planning: resuscitation? Tube feeding? Hospital admission? Medication review

• When needed: high quality medical/nursing treatment

• Comfort care:
  • - medical
  • - nursing
  • - social
  • - spiritual

• Little admissions to hospital
Avoid aggressive, burdensome or futile treatment

<table>
<thead>
<tr>
<th>Intervention</th>
<th>N (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parental therapy</td>
<td>52 (29.4%)</td>
</tr>
<tr>
<td>Hospitalisation</td>
<td>22 (12.4%)</td>
</tr>
<tr>
<td>Emergency Room visit</td>
<td>5 (2.8%)</td>
</tr>
<tr>
<td>Tube feeding</td>
<td>13 (7.3%)</td>
</tr>
<tr>
<td>Any intervention</td>
<td>72 (40.7%)</td>
</tr>
</tbody>
</table>
Permanent enteral tube feeding may not be beneficial and should as a rule be avoided in dementia

Cohort: “No increased survival in dementia patients receiving enteral tube feeding”

“Comfort feeding only through careful hand feeding as an alternative to tube feeding”
### Referral rate to hospital

<table>
<thead>
<tr>
<th></th>
<th>Mild to moderate dementia</th>
<th>Severe dementia</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>US (n=421)</td>
<td>NL (n=223)</td>
</tr>
<tr>
<td>Hospital transfer</td>
<td>29 %</td>
<td>1 %</td>
</tr>
<tr>
<td>within 30 days after diagnosis</td>
<td>2 %</td>
<td>0 %</td>
</tr>
<tr>
<td>Intensive care unit</td>
<td>84 %</td>
<td>89 %</td>
</tr>
<tr>
<td>Antibiotics</td>
<td>10 %</td>
<td>12 %</td>
</tr>
</tbody>
</table>

Figure 1. Conceptual model of influences on US physician decision-making regarding care of demented nursing home patients who develop pneumonia.
Figure 2. Conceptual model of influences on Dutch physician decision-making regarding care of demented nursing home patients who develop pneumonia.
Symptoms and treatment when death is expected in dementia patients in long-term care facilities

Maartje S Klapwijk¹,²*, Monique AA Caljouw¹, Mirjam C van Soest-Poortvliet³, Jenny T van der Steen³ and Wilco P Achterberg¹
Table 3 Medication/palliative care and cause of death ≤ 7 days before death in the study population (N = 24)

<table>
<thead>
<tr>
<th>Medication/palliative care</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Antibiotics, oral tablets</td>
<td>6</td>
<td>25.0</td>
</tr>
<tr>
<td>Morphine</td>
<td>24</td>
<td>100</td>
</tr>
<tr>
<td>Rehydration, hypodermoclyse</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Stop antibiotics, oral medication or rehydration</td>
<td>13</td>
<td>54.2</td>
</tr>
<tr>
<td>Not starting treatment with antibiotics</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Not starting treatment with surgical operation</td>
<td>2</td>
<td>8.3</td>
</tr>
<tr>
<td>Not starting further exploration in diagnosis</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Missing</td>
<td>3</td>
<td>12.5</td>
</tr>
</tbody>
</table>

Cause of death

<table>
<thead>
<tr>
<th>Cause of death</th>
<th>N</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cachexia/dehydration</td>
<td>15</td>
<td>62.5</td>
</tr>
<tr>
<td>Pneumonia (acute pulmonary disease)</td>
<td>3</td>
<td>12.5</td>
</tr>
<tr>
<td>Disease of the digestive system</td>
<td>4</td>
<td>16.7</td>
</tr>
<tr>
<td>Renal failure</td>
<td>1</td>
<td>4.2</td>
</tr>
<tr>
<td>Brain injury after a fall</td>
<td>1</td>
<td>4.2</td>
</tr>
</tbody>
</table>

Graph showing mean (SD) PAINAD until death, range 0=no pain to 10=severe pain.
## Place of death for people with dementia

<table>
<thead>
<tr>
<th>Country</th>
<th>Home</th>
<th>Hospital</th>
<th>Nursing home</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belgium</td>
<td>16</td>
<td>23</td>
<td>61</td>
</tr>
<tr>
<td>England</td>
<td>5</td>
<td>39</td>
<td>55</td>
</tr>
<tr>
<td>Wales</td>
<td>3</td>
<td>53</td>
<td>44</td>
</tr>
<tr>
<td>Scotland</td>
<td>7</td>
<td>38</td>
<td>55</td>
</tr>
<tr>
<td>Netherlands</td>
<td>5</td>
<td>3</td>
<td>91</td>
</tr>
</tbody>
</table>

Houttekier, JAGS 2010
I want to acknowledge Prof Zuidema & Prof Koopmans
Thank you very much for your attention

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