EAPC Trondheim
session "*End of life care and quality of death*"

End of Life Care in Dutch Nursing Homes: Dying with Dignity?

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Symptoms and Signs of Terminally-ill NH Patients

Topics:

1. The Netherlands
2. Background of the study
3. Research methods
4. Results
5. Conclusions

Symptoms and Signs of Terminally-ill NH Patients

Europe

The Netherlands

NL: population and health care system

Population		16,300,000
> 65 years		14 %
> 80 years		3 %
Hospitals: 125	→	55.000 beds
Nursing Homes: 330	→	60.000 beds
Discharged from NH:	→	1 in 3

Symptoms and Signs of Terminally-ill NH Patients

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Background of the study 1 / 2

- Number of people living to an old age is rapidly increasing
- Pattern of diseases that cause most morbidity and mortality is changing
- In the near future, in the NL, NHs will increasingly be the site of terminal care
- NHs are increasingly the place of end of life care for people with dementia
- Most NH patients will enter a terminal phase and eventually will die in the NH
- Also for these NH patients good end of life care should be given

Background of the study 2 / 2

- However, PC has traditionally been focused on cancer patients
- PC needs to be available to much wider range of terminal illnesses (cfr WHO reports)
- NHs have less well been studied than hospices as setting for terminal care
- In the NL, we do not know whether NHs provide comfort for people dying in NHs
- Little is known about the symptoms and disorders that are associated with the terminal phase of NH patients

Research questions

1. What symptoms, signs, problems and diseases are causing the terminal phase in NH patients?
2. What morbidity and symptoms are present in the last two days of life of NH patients?
3. What is the quality of PC in the terminal phase in NHs?
4. How does the estimated lenght of survival accord with the actual survival?

Symptoms and Signs of Terminally-ill NH Patients

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Research Methods

- Prospective, observational cohort study in 16 Dutch nursing homes
- Selected NHs are representative for the Netherlands, according to type of NH and number of beds
- Inclusion: all long-term care patients assessed by a NH physician to have a life expectancy of 6 weeks or less
- Data collection: a 16-months period (2001-2003)

Research Methods

- Admitted on wards for somatic patients as well as psychogeriatric wards
- Questionnaires:
  - on inclusion (demographics and clinical characteristics)
  - follow-up: weekly monitoring:
    - ✓ until death, unless patient recovers
    - ✓ maximum follow-up is 12 weeks
  - after death (all patients)

Instruments

- Questionnaire for demographics and illness characteristics
- Direct causes of terminal disese phase: Classification Codes of Diseases for nursing home Medicine (CvZ-V < ICD-10)
- Symptoms:
  - Observational Minimum Data-set Palliative Care (RAI MDS-PC draft 1.8) (25 symptoms)
  - Last two days prior to death: Edmonton Symptom Assessment Scale (ESAS) (10 items)
- Stages of Dementia: Global Deterioration Scale (GDS)
- Quality of care: Palliative Outcome Scale (POS)

Palliative Care in Dutch Nursing Homes

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Results

Symptoms, Signs, Problems, and Diseases of Terminally Ill Nursing Home Patients

A Nationwide Observational Study in the Netherlands

Background: Nursing homes (NHs) are less well studied than hospices or hospitals as a setting for terminal care. For more targeted palliative care, more information is needed about the patient characteristics, symptoms, direct causes and underlying diseases, and incidence of terminally ill NH patients. These aspects are examined in this study.

Methods: Prospective observational cohort study in 16 NHs representative of the Netherlands. All long-term care patients assessed by an NH physician to have a life expectancy of 6 weeks or less were enrolled in our study.

Results: The terminal disease phase was marked with symptoms of low fluid and food intake, general weakness, and respiratory problems or dyspnea. Direct causes of these conditions were diseases of the respiratory system (mainly pneumonia) and general disorders (eg, cachexia). The 2 main underlying diseases of the terminal phase were mental and behavioral disorders and diseases of the circulatory system. Cancer was the underlying disease in only 12% of the patients. Patients with cancer showed a different pattern of symptoms than those without cancer. Per 100 beds per year, 34 NH patients entered the terminal phase. Most patients (82.9%) died within 7 days of inclusion.

Conclusions: For patients without cancer in Dutch NHs, the terminal disease phase is difficult to predict, and once diagnosed, patient survival time is short. A better identification of the symptom burden might improve the prognostication of life expectancy in elderly patients.

Arch Intern Med. 2005;165:314-320

Results: Last two days of life

Palliative Medicine 2006; **20:** 533–540

The last two days of life of nursing home patients – a nationwide study on causes of death and burdensome symptoms in the Netherlands

Objectives: The aim of this study was to identify the direct causes of death and to evaluate the presence of burdensome symptoms in the last two days of life of terminally ill nursing home (NH) patients. **Methods**: Prospective study of patients with a maximum life-expectancy of six weeks in 16 nursing homes representative for the Netherlands ($n = 463$). Symptoms were measured after death in conscious patients with the Edmonton Symptom Assessment Scale (ESAS) and the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC draft 1.8). Direct causes of death were assessed in all patients. **Results**: Most patients died from pneumonia, renal failure or dehydration. Loss of consciousness was common. The prevalence of burdensome symptom(s) at 48 and 24 hours before death was 51.3 and 28.4%, respectively. **Conclusion**: In practice, it appears that, for many patients, the last days of life are spent unconscious or conscious with one or more burdensome symptom(s), which suggests the potential for improvement of symptom management. *Palliative Medicine* 2006; **20:** 533–540

Results: Quality of end-of-life care

Palliative Medicine 2005; **19:** 334–342

The last days of life of nursing home patients with and without dementia assessed with the Palliative care Outcome Scale

The aim of this study was to assess the Palliative care Outcome Scale (POS) for terminally ill nursing home (NH) patients in the Netherlands. **Methods:** A prospective observational study of patients with a life-expectancy of six weeks or less in 16 Dutch NHs. NH staff rated the patient characteristics and measured palliative care with the POS, including items on physical, psychosocial, informational, spiritual and practical aspects. **Results:** POS non-scores (not applicable; unknown) were mainly found in the psychosocial and spiritual domains, particularly in patients with dementia. Mean scores for non-demented patients and patients with dementia were favourable for the majority of the POS items. **Conclusion:** According to the NH staff, fairly good quality care was provided, but the psychosocial and spiritual aspects of care need to be addressed more in the last days of the dying NH patient's life. The results indicate that the POS is an appropriate instrument to assess not only cancer patients, but also non-cancer and (moderately) severely demented patients. *Palliative Medicine* 2005; **19:** 334–342

Results: predicted and actual survival

Predicted Survival vs. Actual Survival in Terminally Ill Noncancer Patients in Dutch Nursing Homes

Abstract

Studies on the prediction of survival have mainly focused on hospital and hospice patients suffering from cancer. The aim of this study was to describe the predicted vs. the actual survival in terminally ill, mainly noncancer patients in Dutch nursing homes (NHs). A prospective cohort study was conducted in 16 NHs representative for The Netherlands. A total of 515 NH patients with a maximum life expectancy of 6 weeks, as assessed by an NH physician, were included. NH physicians were accurate in more than 90% of their prognoses for terminally ill—mainly noncancer—NH patients, when death occurred within 7 days. For a longer period of time, their predictions became inaccurate. In the category of patients who were expected to die within 8–21 days, predictions were accurate in 16.0%, and in the category of patients expected to die within 22–42 days, this was 13.0%. Predictions in these categories were mainly optimistic (patient died earlier) in 68.6% and 52.2%, respectively. The findings of this study suggest that accurate prediction of survival of (mainly) noncancer patients in NHs is only possible when death is imminent and seems to be dependent on an intimate knowledge of patients. Prognostication over a longer period of time tends to be less accurate, and, therefore, continues to be a challenging task for NH physicians. J Pain Symptom Manage 2006;32:560–566.

Results

All patients: n = 516

somatic wards n = 201

psychogeriatric wards n = 315

All patients:

death within 7 days: 83 %

death within 14 days: 92 %

Median duration survival: 3 days

Results : predicted and actual survival

Table 2

Data on Predicted Survival, Actual Survival, and Median Survival ($n = 515$)

Categories of predicted survival (missing = 4)	Actual Survival: Optimistic prediction (earlier death)	Actual Survival: Accurate prediction	Actual Survival: Pessimistic prediction (later death)	Median survival
	%	%	%	Days
Death within 0–7 days ($n = 267$)	Not applicable	92.9	7.1	2
Death within 8–21 days ($n = 175$)	68.6	16.0	15.4	5
Death within 22–42 days ($n = 69$)	52.2	13.0	34.8	21

Brandt HE, Ooms ME, Ribbe MW, van der Wal G, Deliens L.
Predicted Survival vs. Actual Survival in Terminally Ill Noncancer Patients in Dutch Nursing Homes.
J Pain and Symptom Management 2006 Dec;32(6):560-566

(Most) Important Symptoms and Signs as Indicative of a Limited Life Expectancy (≤ 6 weeks acc. NHP) (n = 516) 1/2

Symptom	Total (%)	Most Important (%)
(Very)little/no fluid intake	43	17
Generalized weakness	32	11
Little/no nutritional intake	25	-
Dyspnea	21	10
Somnolence	18	5
Reccurent fever	18	7
Cachexia/anorexia	15	3
Difficulty swallowing	11	4
Dehydration	10	4

Brandt HE, Deliens L, Ooms ME, van der Steen J, van der Wal G, Ribbe MW. Symptoms, Signs, Problems and Diseases of Terminally ill Nursing Home Patients. A Nation-Wide Observational Study in the Netherlands. Archives of Internal Medicine 2005 Feb;165(3):314-20

Most Important Symptoms and Signs as Indicative of a Limited Life Expectancy (≤ 6 weeks acc. NHP) (n = 516) 2/2

Symptom	Total (%)	Most Important (%)
(Extreme) tiredness	10	3
Other symptoms	10	5
Patient gives up	10	3
Severe stage of somnolence	9	5
Subcoma	9	6
(Worsening) pressure ulcer	8	2
Coma	3	3
Confusion/delirium	5	-

Brandt HE, Deliens L, Ooms ME, van der Steen J, van der Wal G, Ribbe MW. Symptoms, Signs, Problems and Diseases of Terminally ill Nursing Home Patients. A Nation-Wide Observational Study in the Netherlands. Archives of Internal Medicine 2005 Feb;165(3):314-20

Direct cause and underlying disease of the terminal phase 1 / 3

System	Direct Cause of the Terminal Phase (%)	Underlying Disease of Terminal Phase (%)
Respiratory system	**24**	**8**
Pneumonia	21	4
General disorders	**24**	**7**
Cachexia	6	-
Malaise	5	-
Coma	4	-
Fever	4	-
Septicaemia	3	-

Brandt HE, Deliens L, Ooms ME, van der Steen J, van der Wal G, Ribbe MW. Symptoms, Signs, Problems and Diseases of Terminally ill Nursing Home Patients. A Nation-Wide Observational Study in the Netherlands. Archives of Internal Medicine 2005 Feb;165(3):314-20

Direct Cause and Underlying Disease of the Terminal Phase
2 / 3

System	Direct Cause of the Terminal Phase (%)	Underlying Disease of the Terminal Phase (%)
Circulatory system	**14**	**21**
Cerebrovascular accidents	8	**9**
Heart failure	5	**2**
Endocrine, nutritional, and metabolic diseases	**10**	**3**
Dehydration	9	**-**
Digestive system	**9**	**7**

Brandt HE, Deliens L, Ooms ME, van der Steen J, van der Wal G, Ribbe MW. Symptoms, Signs, Problems and Diseases of Terminally ill Nursing Home Patients. A Nation-Wide Observational Study in the Netherlands. Archives of Internal Medicine 2005 Feb;165(3):314-20

Direct Cause and Underlying Disease of the Terminal Phase
3 / 3

System	Direct Cause of the Terminal Phase (%)	Underlying Disease of Terminal Phase (%)
Genito-urinary	7	5
Mental disorders (dementia)	4	30
Diseases of skin and subcutaneous tissue	2	-
Malignant neoplasms (incl. metastases) within all systems)	6	12

Brandt HE, Deliens L, Ooms ME, van der Steen J, van der Wal G, Ribbe MW. Symptoms, Signs, Problems and Diseases of Terminally ill Nursing Home Patients. A Nation-Wide Observational Study in the Netherlands. Archives of Internal Medicine 2005 Feb;165(3):314-20

Symptoms and Signs of the Terminal Phase by Underlying Disease 1/4

Symptom	Mental Disorders % (n=156)	Circulatory System % (n = 106)	Malignant Neoplasms % (n = 60)
Little / no fluid intake	49	45	22
Little / no nutritional intake	33	20	22
Generalized weakness	29	28	47
Recurrent fever	24	12	10
Cachexia / anorexia	17	10	27

Symptoms and Signs of the Terminal Phase by Underlying Disease 2 / 4

Symptom	Mental Disorders % (n = 156)	Circulatory System % (n = 106)	Malignant Neoplasms % (n = 60)
(Worsening) pressure ulcer	16	4	0
Dyspnea	12	31	13
Difficulty swallowing	12	18	5
Subcoma	10	9	0

Symptoms and Signs of the Terminal Phase by Underlying Disease 3 / 4

Symptom	Mental Disorders % (n = 156)	Circulatory System % (n = 106)	Malignant Neoplasms % (n = 60)
Refusal of liquid	8	1	2
Severe stage of somnolence	6	17	3
Medication not succesful	4	12	2

Symptoms and Signs of the Terminal Phase by Underlying Disease 4/4

Symptom	Mental Disorders % (n=156)	Circulatory System % (n=106)	Malignant Neoplasms % (n=60)
(Extreme) tiredness	3	10	27
Loss of apetite	1	4	10
Vomiting	1	1	12
Nausea	1	1	13
Feeling sick	1	2	10

Results : last two days of life

Table 2 Main direct causes of death in NH patients ($n = 463$)

Disease[a]	*n*	%
Pneumonia	79	17
Renal failure	60	13
Disorders of electrolyte and fluid balance, not classified elsewhere (=dehydration)	60	13
Cachexia	53	11
Heart failure	37	8
Septicaemia	17	4
Stroke, not specified as haemorrhage or infarctions	17	4
Unspecified dementia	17	4
Other and unspecified cerebrovascular diseases	11	2
Other	107	23
Missing	5	1

Brandt HE, Ooms ME, Deliens L, van der Wal G, Ribbe MW.
The last two days of life of nursing home patients - a nationwide study on causes of death and burdensome symptoms in the Netherlands. Palliative Medicine 2006 Sep;20:533-40

Results : last two days of life

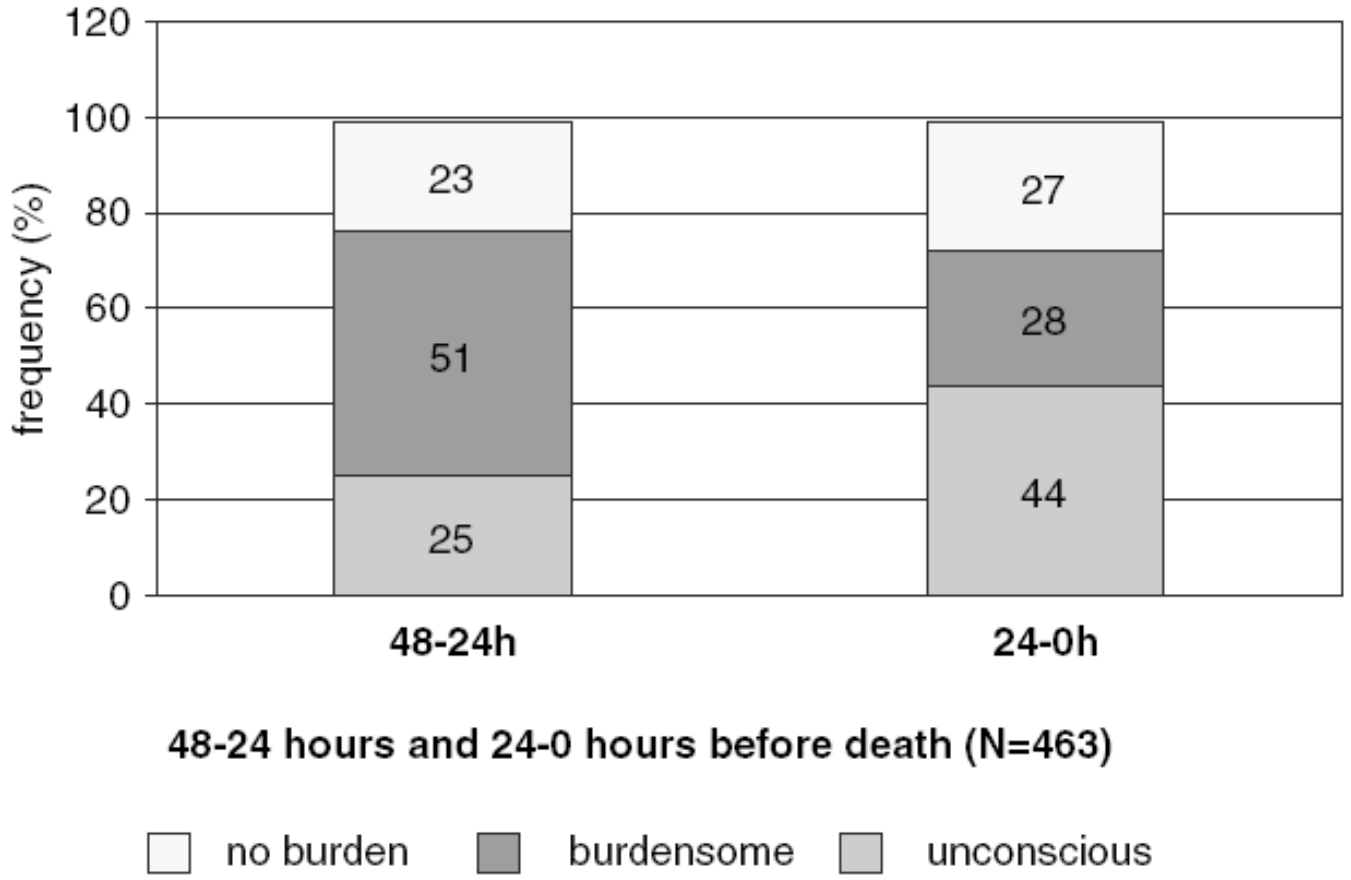

Figure 1 Prevalence of unconsciousness and burdensome symptoms.

**Brandt HE, Ooms ME, Deliens L, van der Wal G, Ribbe MW.
The last two days of life of nursing home patients - a nationwide study on causes of death and burdensome symptoms in the Netherlands. Palliative Medicine 2006 Sep;20:533-40**

Results : last two days of life

Table 3 Median severities and frequencies[a] of symptoms as assessed with the Edmonton (ESAS)[b] in the last two days of the life of conscious[c] patients ($n = 253$)

	48–24 hours before death		24–0 hours before death	
Symptoms	Median score	% (>60 on VAS)	Median score	% (>60
Pain	20.0	30	12.0	22
Decreased activity	90.0	86	95.0	91
Nausea	5.0	17	4.0	17**
Depression	10.0	30***	5.0	33***
Anxiety	13.0	25	10.0	21
Increased drowsiness	77.0	69	90.0	82
Poor appetite	95.0	92	97.0	93**
Well being	67.5	66***	52.0	61****
Shortness of breath	10.0	21	10.0	23

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Symptoms and Signs of Terminally-ill Nursing Home Patients: Conclusions 1

- Most patients (83 %) died within 7 days after inclusion, 92 % died after 14 days
- **Terminal phase** of NH patients was marked with symptoms of low fluid and food intake, general weakness, respiratory problems (dyspnea), cachexia and dehydration
- Many NH patients (4 out of 10) had **lowered consciousness**

Symptoms and Signs of Terminally-ill Nursing Home Patients: Conclusions 2

- **Direct causes of terminal phase**:
  - diseases of the respiratory system (mainly pneumonia)
  - general disorders (e.g cachexia, malaise, coma, fever, septicemia)
  - diseases of the circulatory system
  - nutritional disorders

- **2 main underlying diseases of the terminal phase:**
  - mental disorders (mainly dementia)
  - diseases of the circulatory system (e.g. stroke, heart failure)

Symptoms and Signs of Terminally-ill Nursing Home Patients: Conclusions 3

- Cancer was the underlying disease in only 12% of the NH patients
  - × with symptoms like generalized weakness, cachexia, tirdness, nausea, loss of appetite, feeling sick

- Comprehensive assessment of signs, symptoms and diseases is needed for proper care planning and treatment strategies

Symptoms and Signs of Terminally-ill Nursing Home Patients

Thank you and best regards from The Netherlands