Palliative care in Dutch nursing homes

VRIJE UNIVERSITEIT

Palliative care in Dutch nursing homes

ACADEMISCH PROEFSCHRIFT

ter verkrijging van de graad Doctor aan
de Vrije Universiteit Amsterdam,
op gezag van de rector magnificus
prof.dr. L.M. Bouter,
in het openbaar te verdedigen
ten overstaan van de promotiecommissie
van de faculteit der Geneeskunde
op woensdag 17 januari 2007 om 15.45 uur
in de aula van de universiteit,
De Boelelaan 1105

door

Hella Elisabeth Brandt

geboren te Zeven, Duitsland

promotoren: prof.dr. M.W. Ribbe
prof.dr. G. van der Wal
prof.dr. L.H.J. Deliens

Contents

1

General Introduction

Introduction

The objective of this study was to investigate the incidence and quality of palliative care in the terminal phase of patients in Dutch nursing homes (NHs).

Background

Palliative care has its origin in the modern hospice movement and palliative medicine was born as a new strategy of management for those patients whose illness is chronic and who are in the last stages of life, that is the terminally ill.(1) Palliative care is concerned with the physical, psychological and spiritual care of patients with a life-threatening disease and their families, with both the quality of the remaining life of the patient and with support of the family. In the year 1967, Cicely Saunders founded the first professional hospice, the St. Christopher's hospice in Sydenham, London.(2)

What is palliative care?

Palliative care has been defined by the World Health Organization in 2002(3) as: 'An approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.

Palliative care
- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.(4)

Palliative care in nursing homes

Populations in European and other developed countries are ageing and most deaths occur in people aged over 65, and increasingly also over 80. Almost 25% of Americans die in NHs.(5) These numbers indicate that in the near future, the nursing home (NH) will increasingly be the site of terminal care and the place of death for many of the elderly and those with dementia, because this group

accounts for a significant majority of decedents.(6-8) From comparative studies between the US and the Netherlands the conclusion can be drawn that (most) NHs in the Netherlands are comparable with (most) in the US. One salient difference is the short-stay rehabilitation, which is much less known in NHs in the US (except for a few specialised NHs).(9) Another difference between the two countries is that the staff in Dutch NHs include specially trained NH physicians (in general one full-time physician per 100 patients), who provide medical care and are employed by the NH.(10)

With an ageing population, the pattern of disease also changes. Traditionally, palliative care has focused on patients with cancer, but this type of care is needed for a much wider range of terminal illnesses and should be integrated more broadly across the health care services, as was stated by the World Health Organization (WHO).(11) Most elderly people do not die from cancer and the available data suggest that the pattern of their symptoms in the terminal phase differs from that of cancer patients. Older people very clearly have special needs, because their problems are different from and often more complex than those of younger people.(12) They mostly die from 'old age' and/or complications in the end-stage of chronic disease rather than from acute illnesses. Dementia, cardiac disease and respiratory disease, in particular, are frequent causes of death,(13) but the nature and burden of symptoms associated with the terminal phase of these diseases is still unclear. Nevertheless, they also need palliative care, a type of care which should be based on patient and family need, rather than on prognosis.(12) In the last 48 hours of the life of NH patients, pain and respiratory symptoms have been found to be the most prevalent symptoms, but the pattern of symptoms may be determined by the underlying disease.(14) There has been growing recognition that comparatively little research has been carried out on older people's needs for palliative care, because they do not represent the traditional palliative care population. Despite the prevalence and importance of the elderly in NHs, health care policies in general have little concern with regard to the quality of care that is provided for them. This could be cause or consequence of the fact that NHs are less well studied than hospices or hospitals as a setting for terminal care.(15) Therefore, more research is needed on patients admitted to NHs, with common serious illnesses other than cancer.

Development of palliative care in the Netherlands
In the Netherlands, there has always been concern about appropriate care for the dying. The first efforts to improve care for the dying date back to the 1970s and 1980s(16) with the Antonius Ysselmonde in Rotterdam, which started in 1977 (informal source: Marinus van den Berg, Antonius Ysselmonde. Rotterdam, June 2006) as the first NH in the Netherlands to offer professional terminal care. The Netherlands is also the only country in the world with a systematic review of end of life decisions. From 1990 on, the government commissioned every five years a large scale study on medical end-of-life decisions, namely alleviation of pain and symptoms, non treatment decisions and physician assisted death (euthanasia and physician assisted suicide).(17;18) In the late sixties/early seventies terminal care

received growing attention and became the subject of research.(19) Until then medical developments, including advanced medical technologies prevented or postponed death in patients who formerly would have died.(20;21)

The rapid development of palliative care in the Netherlands started in the beginning of 1990 and was inspired by the work of Dame Cicely Saunders. Improving care for the terminally ill was the mainspring of the Dutch hospice pioneers. Dying should be no longer disturbed by medical-technical domination, but regarded as a normal phase of life. The first hospice in the Netherlands was situated in Nieuwkoop. One of the first independent hospices was the hospice Kuria in Amsterdam, founded in 1992. In 1994 the hospice Rozenheuvel followed. All these hospices stemmed from religious commitment. In a number of NHs a special unit for palliative care was established; a pioneer in this field was the Antonius Ysselmonde, which opened its first units in 1993.(22)

During the nineteen-nineties the social and political priority given to the palliative care of terminally ill patients increased substantially. The Minister of Health, Welfare and Sport initiated in 1998 a stimulation programme during this period, based on the expectation that the need for palliative care will increase further in the coming decades and intended to support initiatives in the sector. This stimulation programme encompassed three specific separate programmes:
- encouragement of research and innovative projects under a programme of the Health Research and Development Council/Medical Sciences (ZonMw)
- promotion and guidance of palliative care by six university centres: the Centres for the Development of Palliative Care (COPZs)
- stimulation of the integration of hospice facilities in regular health care by the Hospice Care Integration Project group (PIH)(23)

As a result of reports of the examination commission COPZ and the Hospice Care Integration Project group, the Minister of Health, Welfare and Sport formulated a governmental framework regarding palliative care. One basic principle was that palliative care should be a general, and not a separate, part of Dutch regular health care system (generalist approach).(24)

The COPZs played a crucial role in the further development of palliative care in the Netherlands. These centres initiated many research projects e.g. on epidemiology, ethics and informal care.(23)

One of these research projects concerned nursing homes, and resulted in this PhD thesis.

In the near future the need for palliative care will increase due to the growing number of people living to an old age. The Netherlands currently has a population of approximately 16.2 million. The number of people aged over 65 in the Netherlands is presently 13.3% of the population, but will rise to 25% in 2040.(22)

Currently, a wide range of palliative care services is available in the Netherlands. The principle behind these is that good quality palliative care has to be accessible and available to every terminally ill patient and his or her family. In the intramural care services, various specialised locations for palliative care can be distinguished.

Probably the largest, location of palliative care services are the Dutch NHs, because a large number of people die in these institutions: in 2000 this was approximately 18% (n=25.568)(25;26), in 2004 21.9% (n=29.890), and in 2005 22.2% (n=30.264) of all deaths (informal source: Statistics Netherlands [CBS], June 2006). This indicates that terminal care is provided for a large number of dying people, whether or not according to the principles of palliative care, a subject which is investigated in this study.

A special palliative care service within the Dutch NHs is the unit for short-term palliative care (PCU's) for patients who can no longer be cared for at home, because of high demands of care and/or lack of family support. In April 2006 approximately 63 NHs with a total of 255 beds comprised PCU's.(22) and it is likely that in these units care is provided according to the principles formulated by the World Health Organization (WHO).(3) In 2004 the number of deaths in 30 units was n=1858 (informal source: Netherlands Institute for Health Services [NIVEL], June 2006). Other numbers of deaths in palliative care units are not available yet, since deaths in NHs are not separately specified by the CBS (Statistics Netherlands). However, these units were not subject of this study, because patients admitted to PCU's do not represent the general NH population. They are non-residents of the NH they are admitted to, mostly diagnosed with cancer and of a lower mean age.(27)

Background of this thesis
Most of the patients admitted to a NH will enter a terminal phase and eventually will die in the NH. There were no representative data available about the incidence of palliative terminal care and quality of care for the terminally ill in Dutch NHs. Therefore, the COPZ initiated a research project to investigate these aspects. This thesis is the first epidemiological study in the Netherlands to gain insight into the end of life care of a non-cancer population, namely palliative care for the long-term care NH patients. However, to measure a concept of quality of (palliative) care is complicated. In this study it is done indirectly by observation by proxy in daily practice, and therefore relies on observational instruments rather than self-reports.

The major emphasis of this thesis has been placed on the provision of palliative care with regard to patients' physical, psychosocial and spiritual needs. A description is given of diseases in and prognosis of the terminal phase, of symptoms (without symptom management), psychosocial and spiritual problems, and end-of-life decisions. To our knowledge this has not been investigated earlier on a national level. The aspects discussed (symptoms, psychosocial and spiritual problems, end-of-life decisions) represent four of the ten care domains of palliative (and terminal) care(28), as originally formulated by the American Geriatrics Society.

The results of this thesis may be a starting point for a comprehensive discussion regarding the palliative care of those dying in nursing homes in the Netherlands.

Aims and research questions

This thesis addresses a variety of aspects of the terminal phase, the quality of palliative care, and is aimed at improving the quality of dying in NHs.

The main questions addressed in this thesis are:

Part 1   Identification and prognostication of the terminal phase

> Research question 1 (chapter 2)
> What symptoms, signs, problems and diseases are the direct causes of the terminal phase and what is the incidence of terminal care in nursing homes?

> Research question 2 (chapter 3)
> How does the estimated length of survival accord with the actual survival period?

Part 2   Problems, symptoms and quality of palliative care

> Research question 3 (chapter 4)
> What are the psychosocial and spiritual problems found in the terminal phase?

> Research question 4 (chapter 5)
> What is the quality of palliative care in the terminal phase in a nursing home?

> Research question 5 (chapter 6)
> What morbidity and symptoms are present in the last two days of life of nursing home patients?

Part 3   End-of-life decisions

> Research question 6 (chapter 7)
> What is the frequency and character of end-of-life decisions in terminally ill nursing home patients?

Method
The methodology related to each research question is addressed in greater detail in the separate chapters.

Design and population
To answer the research questions, a prospective observational cohort study was conducted during a 16-month period from November 2001 until March 2003 in 16 NHs, representative of the Netherlands.
All long-term care patients, assessed by a NH physician to have a maximum life-expectancy of 6 weeks or less, were included in the study with a subsequent follow-up until death. Patients who were admitted for rehabilitation and patients who died a sudden and unexpected death were excluded from the study.

Sampling of nursing homes
In the Netherlands three types of NHs can be distinguished: those exclusively for physically ill patients, those for psychogeriatric patients, and NHs for both categories with separate wards for physically ill and for psychogeriatric patients. In 2004, there were approximately 345 NHs, with around 27,400 beds for physically ill patients and 35, 650 beds for psychogeriatric patients.(29) All patients benefit from the different NH functions, mainly rehabilitation and long-term care. Most of the psychogeriatric patients have dementia (96%) and will stay in a NH until they die.(30) The care in NHs is provided by a multidisciplinary team that comprises specially trained NH physicians (in general one full-time physician per 100 patients), who provide medical care and are employed by the NH,(10) nurses, physiotherapists and occupational therapists, among others. Other disciplines are available on demand to assist with the care.
The NHs in the present study were deliberately sampled to be representative of all Dutch NHs. Firstly, the proportion of the three types of NHs was calculated.(31) This proportion was 3:1:1 (combined versus physically versus psychogeriatric). Therefore, the aim was to include nine combined NHs, three NHs for physically ill patients, and three NHs for psychogeriatric patients. Secondly, the mean number of beds for physically ill and psychogeriatric patients per NH was calculated, and the NHs were arranged in order of this calculated mean. Finally, the nearest NHs above and below the mean were invited to participate in the study. During the course of the data collection, due to organisational and capacity problems, one nursing home for physically ill patients stopped collecting the data. For the remaining time of the data collection, another one from the same stratum replaced this NH. Hence, the total number of participating homes was 16. In this study the average number of NH beds was 103 for physically ill patients, 156 for psychogeriatric patients, and 157 for combined care.

Instruments
On inclusion, the regular NH physician and one attending nurse both completed a questionnaire for each patient, on basic demographics, clinical characteristics

(e.g., stage of dementia, direct cause and underlying disease of terminal phase, main direct cause of death). The patients were monitored weekly, until death or exclusion, with an identical questionnaire.

At the time of patient death, the NH physician completed a questionnaire for all long-term care patients. For patients who had not been included in the study a shorter version of this questionnaire was completed. NH-physicians and nurses made their assessments by reporting information they collected as part of their usual care observations. Therefore, informed consent was not required. Neither the patients nor members of their family were interviewed. The stage of dementia was assessed by the NH physician according to the validated Global Deterioration Scale (GDS).(32) The validated Classification Codes of Diseases for Nursing Home Medicine (CvZ-V)(33) was used by the NH physician to classify diseases of the terminal status on inclusion and at the time of death.

Quality of care was assessed by the nurses and measured with the validated Palliative care Outcome Scale (POS).(34) Symptoms were measured with the validated Edmonton Symptom Assessment Scale (ESAS)(35) and the observational Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC draft 1.8).(36) This instrument has recently been developed for inclusion in the RAI instruments. Draft 1.8 was prior to the final validation of this instrument, but changes were negligible. Spiritual needs were also measured with this instrument.

Structure of this thesis

Following this Introduction, the chapters 2-7 of this thesis are based on articles of which four have been published or are in press and two have been submitted. This implies that in particular the methods sections overlap, so each chapter can be read independently.

Chapter 2 describes the symptoms, signs, problems, and diseases and, diseases that are associated with the terminal disease phase. In the same chapter the incidence of patients who require palliative terminal care is closely described. Chapter 3 examines the prognostication ability of NH physicians with regard to survival time. The estimated survival, assessed by the NH physician, was compared to the actual survival. Information about psychological and spiritual needs in the last days of life is discussed in chapter 4. In chapter 5, the assessment of key domains in the provision of palliative care with the Palliative care Outcome Scale (POS) is addressed. The outcomes of the POS are evaluated including patients with dementia. In chapter 6 the last two days of life are studied with respect to cause and symptom burden. Furthermore, in chapter 7, medical end-of-life decisions are discussed. Finally, in chapter 8 the results are summarised and discussed. Also the implications of these results for health policy and practice and for further research are described.

References

1.	Dame Cicely Saunders Summers DH, Teller N, ed. Hospice: the living idea. Edward Arnold, 1981.
2.	Janssens R. Palliative care. Concepts and Ethics. University Press, Nijmegen, 2001.
3.	World Health Organization. National cancer control programme: policies and managerial guidelines. Geneva: WHO, 2002 (2nd edition).
4.	World Health Organization. http://www.who.int/cancer/palliative/en/. 2006.
5.	Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L et al. Advance care planning and end-of-life care for hospitalized nursing home residents. J Am Geriatr Soc 2002; 50(5):829-835.
6.	Froggatt KA. Palliative care and nursing homes: where next? Palliat Med 2001; 15(1):42-48.
7.	Zerzan J, Stearns S, Hanson L. Access to palliative care and hospice in nursing homes. JAMA 2000; 284(19):2489-2494.
8.	Zimmerman S, Sloane PD, Hanson L, Mitchell CM, Shy A. Staff perceptions of end-of-life care in long-term care. J Am Med Dir Assoc 2003; 4(1):23-26.
9.	Ribbe MW, Ljunggren G, Steel K, Topinkova E, Hawes C, Ikegami N et al. Nursing homes in 10 nations: a comparison between countries and settings. Age Ageing 1997; 26 Suppl 2:3-12.
10.	Hoek JF, Ribbe MW, Hertogh CM, van der Vleuten CP. The role of the specialist physician in nursing homes: the Netherlands' experience. Int J Geriatr Psychiatry 2003; 18(3):244-249.
11.	World Health Organization. Palliative Care: The Solid Facts. Copenhagen, Denmark: World Health Organization; 2004.
12.	World Health Organization. Better Palliative Care for Older People. Copenhagen, Denmark: World Health Organization, 2004.
13.	Hall P, Schroder C, Weaver L. The last 48 hours of life in long-term care: a focused chart audit. J Am Geriatr Soc 2002; 50(3):501-506.
14.	Klinkenberg M, Willems DL, van der Wal G, Deeg DJ. Symptom burden in the last week of life. J Pain Symptom Manage 2004; 27(1):5-13.
15.	Hanson LC, Henderson M, Menon M. As individual as death itself: a focus group study of terminal care in nursing homes. J Palliat Med 2002; 5(1): 117-125.
16.	de Jong-Vekemans M. Netherlands: development of terminal care in the Netherlands. In Dame Cicely Saunders, Summers DH, Teller N, ed. Hospice: the living idea, pp 180-182. Edward Arnold, 1981.
17.	Quill TE, Kimsma G. End-of-life care in The Netherlands and the United States: a comparison of values, justifications, and practices. Camb Q Healthc Ethics 1997; 6(2):189-204.
18.	van der Maas PJ, van der Wal G, Haverkate I, de Graaff CL, Kester JG, Onwuteaka-Philipsen BD et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. N Engl J Med 1996; 335(22):1699-1705.

19. van der Wal G. Euthanasie en hulp bij zelfdoding door huisartsen. PhD Thesis. Vrije Universiteit Amsterdam, 1992

20. Buskes JJ. Waarheid en leugen aan het ziekbed. Amsterdam, the Netherlands: ten Have; 1964.

21. van den Berg JH. Medische macht en medische ethiek. 1969.

22. RIVM. http://palliatief.nl. 2006.

23. Francke AL. Palliative care for terminally ill patients in the Netherlands. The Hague, the Netherlands: Ministry of Health, Welfare and Sport, 2003.

24. Mistiaen P, Francke AL. Monitor Palliatieve Zorg: Rapport 2004. Utrecht, the Netherlands: NIVEL, 2004.

25. Prismant/Arcares. Verpleeghuizen in Cijfers 2000 [Statistical Data on Dutch Nursing Homes 2000]. Utrecht, the Netherlands: Prismant/Arcares; 2002.

26. Statistics Netherlands (CBS). Vademecum Health Statistics Netherlands. Voorburg/Heerlen, the Netherlands: Statistics Netherlands (CBS); 2001.

27. Echteld MA, Deliens L, van der Wal G, Ooms ME, Ribbe MW. Palliative care units in the Netherlands: changes in patients' functional status and symptoms. J Pain Symptom Manage. 2004 Sep;28(3):233-43.

28. VU medisch centrum: afdeling Verpleeghuisgeneeskunde, afdeling Inwendige Geneeskunde. Syllabus Palliatieve zorg en medische beslissingen rond het levenseinde, Stage overstijgend Onderwijs (SOO) co-assistentschappen VUmc 2005-2006. VU medical center, Amsterdam, 2000.

29. RIVM.Bilthoven. http://www.nationaalkompas.nl.

30. van der Steen JT, Ooms ME, Ader HJ, Ribbe MW, van der Wal G. Withholding antibiotic treatment in pneumonia patients with dementia: a quantitative observational study. Arch Intern Med 2002; 162(15):1753-1760.

31. Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Jaarboek Verpleeghuizen 1997 [SIG Nursing Home Information System Annual Report Nursing Homes 1997].Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG), 1998.

32. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139(9):1136-1139.

33. Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Classificatie van ziekten voor de verpleeghuisgeneeskunde [Classification Codes of Diseases for Nursing Home Medicine]. Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1994.

34. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. Qual Health Care 1999; 8(4):219-227.

35. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000; 88(9):2164-2171.

36. Steel K, Ljunggren G, Topinkova E, Morris JN, Vitale C, Parzuchowski J et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003; 20(3):211-219.

Part 1

Identification and prognostication of the terminal phase

2

Symptoms, signs, problems, and diseases of terminally ill nursing home patients

Abstract

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 terminal 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.

Conclusion
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.

Introduction

The number of people living to an old age in Western countries is rapidly increasing. Consequently, the pattern of diseases that cause the most morbidity and mortality is also changing.(1) In the near future, the nursing home (NH) will increasingly be the site of terminal care and the place of death for many elderly people and people with dementia.(2-5) Before death, NH patients enter a terminal phase in which optimal palliative care should be provided. Traditionally, palliative care has focused on patients with cancer, but this type of care is needed for a much wider range of terminal illnesses, and should be integrated more broadly across the health care services, as was recently stated by the World Health Organization.(1)

Nursing homes have been less well studied than hospices or hospitals as a setting for terminal care.(6) We do not know whether NHs provide good care for the dying, or how comfortably people die in a NH. Moreover, little is known about the symptoms and disorders that are associated with the terminal phase of these patients' lives. To our knowledge, there are no reports on the incidence of NH patients who require palliative terminal care. Knowledge about the number of patients who will enter the terminal phase is required for the planning and organization of palliative terminal care. As the role of NHs in providing end-of-life care continues to expand, these facilities will be challenged to meet residents' and families' expectations and to achieve adequate outcomes of care.(7) Knowledge of the symptoms and disorders that are associated with the terminal phase in NH patients' lives will help to improve the quality of dying. Physicians who, for example, do not realize how little time is left for the patient may miss the chance to devote more efforts to improve the quality of the patient's life in the remaining period.(8) This study examined patient characteristics, symptoms, direct causes and underlying diseases, and incidence of the terminal phase in terminally ill patients in the Netherlands.

In Dutch NHs, curative, supportive, or palliative care is provided for all patients according to the course of their illness.

Methods

Setting and Design
A prospective observational study was conducted in 16 Dutch NHs during a 16-month period from November 2001 until March 2003. Unlike most other countries, the Netherlands employs specially trained physicians to provide medical care in NHs.(9) Three types of NHs can be distinguished: those for physically ill patients, those for psychogeriatric patients, and combined types with separate wards for each category. Both the physically ill and the psychogeriatric patients benefit from the different nursing home functions, mainly rehabilitation and long-term care. This type of care can be characterized as continuous, long-term, systematic, and multidisciplinary.(10) Most (96%) of the psychogeriatric patients have dementia and will stay in the NH until they die.(11) In 2000, there were 334 NHs in the

Netherlands with a total of 58778 beds, which accounted for approximately 18% of the total mortality of Dutch inhabitants.(12,13)

The NHs in the present study were purposefully sampled to be representative of all Dutch NHs. First, the proportion of the 3 types of NHs was calculated.(14) This proportion was 3:1:1 in order of combined, those for solely physically ill patients, and those for solely psychogeriatric patients. Therefore, the aim was to include (9) combined NHs, 3 NHs for physically ill patients, and 3 NHs for psychogeriatric patients. Second, the mean number of beds for physically ill and psychogeriatric patients per NH was calculated, and the NHs were arranged in order of this calculated mean. Finally, the NHs closest above and below the mean were invited to participate in the study.

The beginning and end dates of the data-collection varied per NH. Each participating NH included all patients as soon as the estimated life expectancy became 6 weeks or less; follow-up was until death, with a maximum of 12 weeks. Each patient included was given a unique identification number by the local research coordinator, who supervised the data-collection.

Patients

The treating physician was responsible for the inclusion of patients in the study if they met the following criteria: (1) remaining life expectancy of 6 weeks or less; (2) admitted for long-term care; and (3) admitted for rehabilitation, but during their admittance it became obvious that the patient would not leave the NH. The exclusion criteria were (1) admitted for rehabilitation and expected to be discharged from the NH and (2) sudden and unexpected death (ie, with no clear terminal palliative phase).

The period of 6 weeks is based on prior consultation with NH physicians who participated in our study. Admittance to NHs for terminal care is handled differently in different countries. In the Netherlands, it is set at 3 months because of administrative reasons, such as refunding by health care insurance companies. For practical reasons, the NH physicians perceived a weekly follow-up registration of 3 months with a maximum follow-up of 6 months as not feasible. We agreed on a weekly follow-up registration of 6 weeks with a maximum follow-up of 12 weeks (3 months). On the basis of their clinical experience, NH physicians decided whether a patient had a life expectancy of 6 weeks or less.

Measurements

On inclusion, the nursing home physician completed a questionnaire on basic demographics, illness characteristics (eg, stage of dementia), symptoms, direct cause and underlying disease of the terminal phase. The stage of dementia was assessed according to the validated Global Deterioration Scale.(15) This instrument identifies 3 major clinical phases: a forgetfulness phase, a confusional phase, and a late dementia phase. These phases are further sub-divided into 7 clinically identifiable stages, ranging from stage 1 (no cognitive decline) to stage 7 (very severe cognitive decline). Stage 5 represents the phase of early dementia, and patients in this stage can no longer survive without some assistance.

Symptoms were measured according to a list of 25 symptoms (with 1 additional open question). This list was developed in cooperation with experienced NH physicians, who on the basis of their clinical practice included the main common symptoms present in NH patients. On inclusion, the NH physicians were also asked to give a maximum of 3 symptoms in order of magnitude, on which they based their estimated life expectancy of 6 weeks or less for that particular patient (1 indicates most important; 2, second most important; 3, third most important). The validated Dutch Classification Codes of Diseases for Nursing Home Medicine (CvZ-V) (16) were used for registration of the direct cause of the terminal phase (disorder that directly caused the symptoms on which the NH physician based an estimated life expectancy of 6 weeks or less) and the underlying disease (disease that was the underlying cause of the disorder on which the NH physician based the limited life expectancy). The CvZ-V is a Dutch standard, based on the International Classification of Diseases, 10th Edition (ICD-10),(17) which gives a classification of diseases, intercurrent diseases, disorders, injuries, other problems and causes of death in NH patients. However, unlike the ICD-10, it contains a general section with codes for diseases, disorders, and problems which supersede one particular organ system.

We aimed to check all eligible patients by screening all deaths that occurred in the participating NHs. At the time of patient death, the NH physicians completed a questionnaire for all long-term care patients, including patients who had not been included in the study, for whom a short questionnaire was completed. In this short questionnaire, we checked the reason for noninclusion. (1) "a sudden and unexpected death (no or very short terminal phase)"; (2) "the patient should have been included earlier"; or (3) "other, namely….". The patients included under point 2 were "missed" patients who were identified afterwards. For these patients, the NH physician was asked in a separate question why these patients were not included earlier. The alternatives could be (1) "forgotten (to be included),"
(2) "pressure of work," (3) "organizational reasons (eg, should have been included during the weekend)," 4. "family had objections for inclusion in our study," and (5) "other, namely .…"

We went to great lengths to ensure that all eligible patients were included or at least identified. A check was made per NH to ensure that all deaths of long-term care patients were registered. At the end of the data-collection, the local research coordinator of each NH was asked in a personal interview for a number or estimate of patients incorrectly omitted. This number included the missed patients who were identified afterward.

Statistical analysis
All analyses were performed with SPSS statistical software, version 10.1 (SAS Institute Inc, NC) for Windows. The Pearson χ2 and Fisher exact tests were used to detect statistically significant differences (P<.05) in categorical data between groups.
The Fisher exact test was chosen when the number in the cells was small or zero. The incidence was calculated from 16 selected NHs, most of which participated from January 2002 to March 2003. For the numerator, we counted all patients who

entered the terminal phase, whether included or missed and irrespective of outcome (ie, died or survived within the maximum duration of follow-up of 12 weeks, including second inclusions). The denominator was calculated separately for each participating NH, and the results were added together. The total number of beds was multiplied by the mean bed occupancy of the home in 2002 (if the number of beds changed during the inclusion period, the average was calculated) and the inclusion period. The lengths of the inclusion period varied among the NHs. Because of this, we corrected data to the 1-year period.

Ethical review
The study was approved by the Medical Ethics Committee of the VU University Medical Center. Confidentiality of the data was guaranteed by providing coded information only to the researcher. Informed consent was not necessary, because the physicians and nurses were simply reporting information collected as part of the usual care provided. As required by Dutch law, the patients and their families were informed about the study through an informational flyer and were given the option of refusing the transfer of data.

Results

A total of 544 patients were included. For 516 of these patients, NH physicians completed questionnaires on inclusion, which were used for analysis. An additional 272 patients were found to have been incorrectly omitted from the study. These patients were considered to be missed patients who were identified afterwards. The main reasons for noninclusion, given in the questionnaire in order of sequence by the NH physicians, were pressure of work, organizational reasons (eg, should have been included during the weekend), forgotten (to be included), other reasons, and family had objections for inclusion in our study.
Representative sampling in this study was checked against 2 parameters; the distribution of physically ill and psychogeriatric patients and sex. No significant differences were found between the national NH population and the study population for either parameter.
The incidence was calculated as follows:

Included Patients + Missed Patients (Identified Afterward) / Beds X Mean Bed Occupancy X Mean Inclusion Period.

Taking into account the duration of follow-up during the 1-year period, we identified 544 patients (474 first inclusions, 12 second inclusions, 57 exclusions, 1 at end of follow-up) plus 272 missed patients, which divided by the number of beds (2429.6) equaled 0.34 long-term care patients who met the inclusion criteria. This is equivalent to 34 patients per year in an NH with 100 beds. After inclusion, most patients (82.9%) died within 7 days, and 92.3% died within 14 days.
The median duration of survival was 3 days, with a 10th and 90th percentiles of 0 (death within 24 hours) and 12 days, respectively. Fifty-seven (11.0%) of the 516 patients recovered and were excluded. Of these patients, 26 (46%) of 57 died later

during our study (21.0% after the second inclusion and 24.6% between 5 and 228 days after exclusion).

Table 1   Demographics and disease characteristics in 516 patients*

	Frequency, %
Variable	
Male	29.1
Female	70.9
Age on inclusion, mean ± SD (range), y	83.5 (45 – 100; 8.1)
Marital status	
Never married	9.2
Married	27.6
Widowed	59.6
Divorced	3.5
No. of months in nursing home, median (range)	14 (0 - 215)
Reason for admission to nursing home	
Chronic care	75.6
Rehabilitation	15.7
Terminal care	5.7
Other (eg, special care)	2.9
Ward on inclusion	
Physically ill	37.7
Psychogeriatric	56.4
Others	5.8
Stage of dementia (Global Deterioration Scale15)	
Stage 1, no cognitive decline	33.5
Stage 2 – 4, very mild to moderate cognitive decline	5.2
Stage 5, moderately severe cognitive decline	8.1
Stage 6, severe cognitive decline	27.0
Stage 7, very severe cognitive decline	26.0

* Data are presented as percentage unless otherwise indicated

Table 1 presents the demographics and disease characteristics of patients on inclusion in the study. Most of the patients were female (70.9%) and mostly widowed (59.6%), with a mean ± SD age of 83.5 years ± 8.1 years. Patients were predominantly admitted to the NH for chronic care (75.6%), and most (56.4%) stayed in a psychogeriatric ward. Of all the patients included, 33.5% had no cognitive decline, 5.2% had very mild to moderate cognitive decline, 8.1% had moderately severe cognitive decline, 27.0% had severe cognitive decline, and 26.0% had very severe cognitive decline. Possible selection bias was evaluated by testing differences between included patients and patients who were found to be incorrectly omitted from the study for 3 parameters: age, sex, and ward. No significant differences were found for sex and ward between the included and

omitted patients. For age, a significant difference was found (mean age, 83.5 years for included patients vs 81.9 years for the omitted ones; P=.04). Since the mean age of both groups differed by 1.6 years, we considered this difference acceptable.

Table 2 Most important symptoms, signs, or problems perceived by nursing home physicians as indicative of a life expectancy of 6 weeks or less*

Symptoms	Total, %†	Most important, %‡	Second most important, %	Third most important, %
(Very) little/no fluid intake	42.6	17.2	17.2	8.1
Generalized weakness	31.8	10.7	10.3	10.9
(Very) little/no nutritional intake	24.8		13.6	9.9
Respiratory problems/dyspnea	21.3	9.9	6.6	4.8
Somnolence	17.8	5.2	4.3	8.3
Recurrent fever	17.6	6.6	5.8	5.2
Cachexia/anorexia	14.5	2.9	5.2	6.2
Difficulty swallowing	11.4	3.5	5.0	2.9
Dehydration	10.3	3.7	3.3	3.3
(Extreme) tiredness	9.7	3.1	4.5	2.1
Other symptoms§	9.7	5.2		2.7
Patient gives up	9.5	3.3		4.8
Severe stage of somnolence	9.1	5.4		2.1
Sub-coma	8.5	5.8		2.1
(Worsening) pressure ulcer	7.8	2.3		4.1
Medication not successful	7.4		2.7	2.7
Confusion/delirium	5.4			2.5
Refusal of liquid	3.9			
Loss of appetite	3.7		2.3	
Refusal of medication	3.7			
Coma	3.3	2.5		
Refusal of food	3.1			
Feeling sick	2.9			
Vomiting	2.5			
Nausea	2.1			
Rare symptoms	1.9	1.0	0.4	0.6

* Nursing home physicians were asked to list at maximum 3 of the most important symptoms, signs, or problems in order of magnitude that are reasons for the physician to discuss limited life expectancy (6 weeks or less) with this particular patient

† Only symptoms with a frequency higher than 2% are presented

‡ Nursing home physicians were asked to give a maximum of 3 problems in order of magnitude: 1 indicates most important; 2, second most important; and 3, third most important

§ Symptoms reported by nursing home physician that were not listed in the questionnaire (eg, diarrhea, pain, or constipation)

Table 2 gives the most important symptoms, signs or problems on study inclusion, in order of magnitude, perceived by the NH physician as indicative of a limited life expectancy. In 42.6% of all cases, the problem of "(very) little/no fluid intake" was reported as a reason for the NH physician to estimate the life expectancy to be 6 weeks or less. "Generalized weakness" was reported in 31.8% of the cases, "(very) little/no nutritional intake" in 24.8%, and "respiratory problems/dyspnea" in 21.3% of the cases. The percentages of other symptoms, signs or problems were less than 20%. "(Very) little/no fluid intake" (17.2%) and "generalized weakness" (10.7%) were the symptoms that were most frequently reported as most important. "(Very) little/no fluid intake" (17.2%) and "(very) little/no nutritional intake" (13.6%) were most frequently reported as the second most important symptoms or problems. The third most important symptoms were "generalized weakness" (10.9%) and "(very) little/no nutritional intake" (9.9%).

Table 3 Direct cause and underlying disease of the terminal phase in 516 patients according to the nursing home physician*

Variable	Direct cause of the terminal phase, No.	(%)†	Underlying disease of the terminal phase, No.	(%)‡
Diseases of the respiratory system	126	(24.4)	42	(8.1)
Pneumonia	106	(20.5)	21	(4.1)
Malignant neoplasms	7	(1.4)	7	(1.4)
General disorders	123	(23.8)	36	(7.0)
Cachexia	29	(5.6)		
Malaise	24	(4.7)		
Coma	18	(3.5)		
Fever	18	(3.5)		
Septicaemia	14	(2.7)		
Malignant neoplasms	2	(0.4)	10	(2.0)
Diseases of the circulatory system	72	(14.0)	106	(20.5)
Cerebrovascular accidents	40	(7.8)	48	(9.3)
Heart failure	27	(5.2)	11	(2.1)
Malignant neoplasms				
Endocrine, nutritional and metabolic diseases	50	(9.7)	14	(2.7)
Disorders of electrolyte and fluid balance, not elsewhere classified (dehydration)	48	(9.3)		
Malignant neoplasms				
Diseases of the digestive system	44	(8.5)	34	(6.6)
Dysphagia	14	(2.7)		
Malignant neoplasms	8	(1.6)	20	(4.0)
Diseases of the genitourinary system	34	(6.6)	24	(4.7)
Renal failure	19	(3.7)		
Malignant neoplasms	1	(0.2)	2	(0.4)
Mental and behavioral disorders	18	(3.5)	156	(30.2)
Dementia	12	(2.3)	151	(29.3)
Diseases of the skin and subcutaneous tissue	11	(2.1)		
Malignant neoplasms				
Remaining systems	23	(4.6)	48	(9.4)
Malignant neoplasms	12	(2.4)	21	(4.1)
Missing	15	(2.9)	55	(10.7)
Malignant neoplasms (including secondary malignant neoplasms) within all systems	30	(6.0)	60	(12.0)

As given in **Table 3**, the terminal phase was directly caused by a disease of the respiratory system, predominantly pneumonia, in 24.4% of the study population, "general" disorders (disorders that supersede one particular organ system) in 23.8% of the patients, and diseases of the circulatory system (such as cerebrovascular accidents and heart failure) in 14.0% of the patients. "Endocrine, nutritional, and metabolic disorders" (such as dehydration) were reported in only 9.3% of the cases. With regard to the underlying disease of the terminal phase, the 2 main categories were mental and behavioral disorders (30.2%), almost exclusively dementia, and diseases of the circulatory system (20.5%). The third category was cancer (12%).

Table 4 Symptoms, signs and problems for the 2 main underlying diseases of the terminal phase and malignant neoplasms*

Symptom	Group 1 (Mental and behavioural disorders), % (n=156)	Group 2 (Diseases of the circulatory system), % (n=106)	Group 3 (Malignant neoplasms including Metastases), %..(n=60)	Group 1 vs 2, χ2 P Value	Group 1 vs 3, Fisher exact test P Value	Group 2 vs 3, Fisher exact test P Value
(Very) little/no fluid intake	49.4	45.3	21.7	.52	<.001	.003
(Very) little/no nutritional intake	32.7	19.8	21.7	.02	.14	.84
Generalized weakness	28.8	28.3	46.7	.92	.02	.03
Recurrent fever	23.7	12.3	10.0	.02	.02	.80
Cachexia/ anorexia	17.3	10.4	26.7	.12	.13	.009
(Worsening) pressure ulcer	16.0	3.8	0.0	.002	<.001	.30
Respiratory problems/ dyspnea	12.2	31.1	13.3	<.000	.82	.01
Difficulty swallowing	12.2	17.9	5.0	.20	.14	.02
Sub-coma	10.3	9.4	0.0	.83	.007	.01
Refusal of liquid	7.7	0.9	1.7	.01	.12	>.99
Severe stage of somnolence	6.4	17.0	3.3	.007	.52	.01
Medication not successful	3.8	12.3	1.7	.01	.68	.02
Other symptoms†	3.2	9.4	20.0	.03	<.001	.06
(Extreme) tiredness	3.2	10.4	26.7	.02	<.001	.007
Loss of appetite	1.3	3.8	10.0	.19	.006	.17
Vomiting	1.3	0.9	11.7	.80	.002	.004
Nausea	1.3	0.9	13.3	.80	.001	.001
Feeling sick	0.6	1.9	10.0	.35	.002	.03

* Including secondary neoplasms

† Symptoms reported by NH physicians that were not listed in our questionnaire

Table 4 gives reported symptoms on inclusion for the 2 main underlying diseases of the terminal phase (mental and behavioral disorders and diseases of the circulatory system) and malignant neoplasms (including secondary malignant neoplasms). For 9 of the 26 symptoms, significant differences were found between the 2 main underlying diseases. Most frequently reported symptoms in the group of patients with mental disorders (mostly dementia) were problems regarding "fluid intake" (49.4%), "nutritional intake" (32.7%), "generalized weakness" (28.8%), "recurrent fever" (23.7%), "cachexia/anorexia" (17.3%) and "(worsening) pressure ulcer" (16.0%). Patients with diseases of the circulatory system more often had "respiratory problems/dyspnea" (31.1% vs 12.2%). They more often experienced "(extreme) tiredness" (10.4% vs 3.2%), severe stage of somnolence (17.0% vs 6.4%), and "other symptoms" (9.4% vs 3.2%). Included in this group was "medication not successful" (12.3% vs 3.8%), but there were fewer problems with "nutritional intake," "recurrent fever," "(worsening) pressure ulcer," and "refusal of liquid."

The frequencies of reported symptoms for patients with cancer show a different pattern when compared with the 2 main underlying diseases (Table 4). Significant differences between patients with cancer and those with mental and behavioral disorders and diseases of the circulatory system were found for 11 and 12 (of 26) symptoms, respectively.

Compared with patients with mental and behavioral disorders, those with cancer more often experienced "generalized weakness" (46.7% vs 28.8%), "other symptoms" (20.0% vs 3.2%), "(extreme) tiredness" (26.7% vs 3.2%), "loss of appetite" (10.0% vs 1.3%), "vomiting" (11.7% vs 1.3%), "nausea" (13.3% vs 1.3%), and "feeling sick" (10.0% vs 0.6%). They less frequently had "(very) little/no fluid intake" (21.7% vs 49.4%), "reccurent fever" (10% vs 23.7%), "(worsening) pressure ulcer" (0.0% vs 16.0%) and "sub-coma" (0.0% vs 10.3%).

When compared with patients who had diseases of the circulatory system, patients with cancer more often experienced "generalized weakness" (46.7% vs 28.3%), "cachexia/anorexia" (26.7% vs 10.4%), "(extreme) tiredness" (26.7% vs 10.4%), "vomiting" (11.7% vs 0.9%), "nausea" (13.3% vs 0.9%), and "feeling sick" (10.0% vs 1.9%). They less frequently had "(very) little/no fluid intake" (21.7% vs 45.3%), "respiratory problems/dyspnea" (13.3% vs 31.1%), "difficulty swallowing" (5.0% vs 17.9%), "sub-coma" (0.0% vs 9.4%), '' severe stage of somnolence" (3.3% vs 17.0%), and "medication not successful" (1.7% vs 12.3%).

Discussion

To our knowledge, this is the first nationwide study to provide insight into the symptoms, the direct causes, and underlying diseases of the terminal disease phase in NH patients. Furthermore this study estimated the incidence of NH patients who entered the terminal phase. The strengths of this study are the large-scale design, the representativeness of the NHs, and the prospective character, which enhances the validity and reliability of the findings.

However, the study has some limitations. The underlying disease of the terminal phase was assessed with a question analogue to the cause-of-death question on

Dutch death certificates.(13) The NH physicians who participated in the study might have had difficulties in reporting the underlying disease of the terminal phase and therefore may have incorrectly registered the cause of death on the death certificates.(18) Problems occur mainly with regard to the sequence of the primary and secondary causes of death, and the primary cause (underlying disease) cannot always be determined.

There was also missing information about a large number of terminally ill patients. These patients should have been included. Although we did not find substantial differences between the study sample and the omitted group in the demographic variables (age, sex, and ward), we cannot, in case physicians selectively missed patients, exclude a possible bias on the outcome variables of this study. Also, no separate incidence of patients (eg, with and without cognitive impairment) who would enter a terminal disease phase could be calculated.

In addition, although sudden and unexpected death was an exclusion criterion, different physicians may differently read the signs in the phase before death and may miss signs of nearing death. It is possible that physicians missed the signs of nearing death and mistakenly described patients as having died suddenly. However, we believe that physicians did not deliberately misclassify patients. Furthermore, individual interpretation was possible regarding the data on having a limited life expectancy of 6 weeks or less; however, this factor was decided on the basis of clinical daily practice.

The 4 most frequently reported symptoms, signs or problems in the terminal disease phase of NH patients, which physicians identified as related to terminal illness, were problems with fluid and nutritional intake, generalized weakness, and respiratory problems or dyspnea. The patients were frequently in a state of somnolence and experienced recurrent fever. These symptoms alone might be highly predictive of approaching death and could be an indication for the physician and all others involved that the patient is dying. However, this must be confirmed in future research on predictive models. Since the identified period of terminal illness is limited, the question is whether palliative care is sufficiently addressed.

Direct causes of the terminal phase, according to the NH physicians, were diseases of the respiratory system, mostly pneumonia, and disorders of a general nature, such as cachexia, malaise, coma, fever, and septicemia. Diseases of the circulatory system were less frequently reported by the NH physicians. Hanson et al6 found that NH deaths are preceded by a slow trajectory punctuated by acute and reversible illnesses, such as pneumonia, sepsis, or dehydration. The results of the present study are in line with this observation. Health care professionals are therefore challenged with providing care for patients with diseases that have trajectories of slow decline with periodic crises and a less well-defined terminal phase.(19)

Diseases of the circulatory system and mental or behavioral disorders dominate as the underlying diseases in the terminal phase of NH patients. However, regardless of the underlying disease, symptoms of "(very) little/no fluid intake," "generalized weakness," "somnolence" and "cachexia/anorexia" were common in both groups. For other symptoms, different patterns could be determined between these 2 main groups. For patients with mental disorders, mainly dementia, the beginning of the

terminal phase was marked with problems of nutritional intake, and they experienced recurrent fever. This group was most likely to refuse liquid and to develop a (worsening) pressure ulcer. In these NH patients, it appeared that low food and fluid intake, together with episodes of fever, led to a deterioration in their overall condition, which may have caused (worsening of) pressure ulcers. In patients with disorders of the circulatory system, mainly caused by poor heart function, the presence of respiratory problems or dyspnea can be expected. Extreme tiredness and severe stage of somnolence can be the consequences of a circulatory disease. A low level of oxygen in the blood, due to insufficient heart function, causes tiredness, and the mental state of patients in the severe stage of somnolence can probably be explained by the high prevalence of cerebrovascular accidents (9.3%) in the study population. In this group of patients, medication was significantly less successful than in the group of patients with mental disorders. The findings of the present study reflect a (mainly) noncancer population. Only 12% of the patients had cancer as the underlying disease. Those patients showed a different pattern of symptom prevalence with regard to the noncancer population. These characteristics are in line with the findings of Addington-Hall et al,[20] who reported a difference in the prevalence of symptoms between patients with and without cancer.

It is estimated that in an NH with 100 beds, 34 patients will enter the terminal phase of life each year. In other words, for every 3 beds, an NH can expect 1 patient per year to reach a terminal disease phase that requires palliative care. This information is useful for policy making and assessment of the required terminal care. Although the estimated incidence of the terminal phase is high, the duration of this phase, as noticed by the physicians, is most often limited to a couple of days.

The study demonstrates that most of the patients were considered to be terminally ill only when death was actually already very near. After inclusion most patients died within 7 days, and after 14 days almost all patients were dead. This finding highlights the late identification of terminally ill patients by NH physicians. On the other hand, 1 of 10 patients recovered. Nevertheless, almost half of these patients died later during the inclusion period. Even the advantage that the physicians are employed by the NH and therefore know their patients very well is no guarantee of an accurate prediction of life expectancy. The difficulty of defining patients without cancer as terminally ill or predicting their life expectancy has been recognized in several studies.[21-23] An estimation of the possible survival period is importance for the patients, their families, and the NH physicians and nurses and also has implications for the planning of appropriate medical care. Therefore, improving prognostication of life expectancy for patients without cancer is needed.

In conclusion, it is perhaps even more difficult to provide appropriate palliative care for elderly patients with chronic diseases than for patients with cancer. The course of chronic diseases is more difficult to predict because it shows a more gradual decline when compared with patients dying of cancer.[24]

As our study shows, when patients were identified as entering a terminal disease phase, death was only a few days off. This indicates that the traditional focus of palliative terminal care on patients with cancer needs to be extended and adopted

to the specific needs of elderly patients without cancer. This public health challenge was recently adopted by the World Health Organization.(1)

Our study also highlights how ineffective NH physicians are at determining prognosis with regard to life expectancy and poses the question of whether this limited time is adequate for the implementation of palliative terminal care, if this has not already been provided. High-quality symptom control and organization of palliative care in NHs is needed owing to the apparent speed of deterioration and therefore a steep increase in symptoms.

The findings of this study stress the difficulty of estimating incidence of palliative care needs of the terminally ill patients in NHs. Further research to estimate these needs is desirable.

References

1.   World Health Organization. Palliative Care: The Solid Facts. Copenhagen, Denmark: World Health Organization; 2004.
2.   Zerzan J, Stearns S, Hanson L. Access to palliative care and hospice in nursing homes. JAMA. 2000; 284:2489-2494.
3.   Happ MB, Capezuti E, Strumpf NE, et al. Advance care planning and end-of-life care for hospitalized nursing home residents. J Am Geriatr Soc. 2002; 50:829-835.
4.   Zimmerman S, Sloane PD, Hanson L, Mitchell CM, Shy A. Staff perceptions of end-of-life care in long-term care. J Am Med Dir Assoc. 2003; 4:23-26.
5.   Froggatt KA. Palliative care and nursing homes: where next? Palliat Med. 2001; 15: 42-48.
6.   Hanson LC, Henderson M, Menon M, Menon M. As individual as death itself: a focus group study of terminal care in nursing homes. J Palliat Med. 2002; 5: 117-125.
7.   Ersek M, Wilson SA. The challenges and opportunities in providing end-of-life care in nursing homes. J Palliat Med. 2003; 6: 45-57.
8.   Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ. 2000; 320: 469-472.
9.   Ribbe MW, Ljunggren G, Steel K et al. Nursing homes in 10 nations: a comparison between countries and settings. Age Ageing. 1997; 26 (suppl2): 3-12.
10.   Ribbe MW. Care for the elderly: the role of the nursing home in the Dutch health care system. Int Psychogeriatr. 1993; 5:213-222.
11.   Van der Steen JT, Ooms ME, Adér HJ, Ribbe MW, van der Wal G. Withholding antibiotic treatment in pneumonia patients with dementia: a quantitative observational study. Arch Intern Med. 2002; 162: 1753-1760.
12.   Prismant/Arcares. Verpleeghuizen in Cijfers 2000. [Statistical Data on Dutch Nursing Homes 2000]. Utrecht, the Netherlands: Prismant/Arcares; 2002.
13.   Statistics Netherlands (CBS). Vademecum Health Statistics Netherlands. Voorburg/Heerlen, the Netherlands: Statistics Netherlands; 2001.
14.   Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Jaarboek Verpleeghuizen 1997 [SIG Nursing Home Information System Annual Report Nursing Homes 1997]. Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1998.
15.   Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry. 1982; 139: 1136-1139.
16.   Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Classificatie van ziekten voor de verpleeghuisgeneeskunde. [Classification Codes of Diseases for Nursing Home Medicine]. Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1994.
17.   World Health Organization. International Classification of Diseases, 10th Revision (ICD-10). Geneva, Switzerland: World Health Organization; 1992.

18. Bouter LM, Rosendaal RF. Wrong Tracks in Methodology [In Dutch]. Ned Tijdschr Geneeskd. 2002; 146: 57-60.

19. Hall P, Schroder C, Weaver L. The last 48 hours of life in long-term care: a focused chart audit. J Am Geriatr Soc. 2002; 50: 501-506.

20. Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in nonmalignant disease. Palliat Med. 1998; 12: 417-427.

21. Field D. Special not different: general practitioners' accounts of their care of dying people. Soc Sci Med. 1998; 46: 1111-1120.

22. Teno JM, Coppola KM. For every numerator, you need a denominator: a simple statement but key to measuring the quality of care of the "dying". J Pain Symptom Manage. 1999; 17: 109-113.

23. Hanson LC, Henderson M. Care of the dying in long-term care settings. Clin Geriatr Med. 2000; 16: 225-237.

24. Teno JM, Weitzen S, Fennell M, Mor V. Dying trajectory in the last year of life: Does cancer trajectory fit other diseases? J Palliat Med. 2001; 4: 457-464.

3

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.

Introduction

The prediction of survival is one of the most important, but also one of the most difficult issues in daily clinical practice for the terminally ill. Nevertheless, the issue of length of survival remains important both for patients and their families when they are confronted with end-of-life issues, like deciding about further burdensome treatment options, joint decision making with regard to starting or forgoing supportive care, preparing for death, ending a relationship with loved ones, etc. The physician is expected to provide patients and their families with accurate information about future expectations.

Studies on the prediction of survival have mainly focused on hospital and hospice patients suffering from cancer.(1-5) Their results suggest that it is very difficult to make an accurate prognosis for terminally ill cancer patients, that the predictions remain controversial, and that physicians are often, but not always, too optimistic. Nevertheless, many, mainly elderly, dependent people die from the end-stages of a chronic disease, such as a vascular disease or dementia, and it is well known that the nursing home (NH) population consists of more patients with chronic diseases than patients with cancer. The course of an illness due to cancer can often be predicted, but there is uncertainty for other common chronic diseases.(6)

Prognostic errors have detrimental effects on patient care, and predicting and staging the end of life continues to be difficult, especially for NH residents with diseases other than cancer.(7)

The purpose of this study is to evaluate the prediction of survival at the beginning of the terminal phase in a general NH population.

Methods

Setting and design

A prospective observational study was carried out in 16 Dutch NHs from November 2001 to March 2003.(8)

In the Netherlands, three types of NHs can be distinguished as follows: NHs solely for physically ill patients, NHs solely for psychogeriatric patients, and combined NHs with separate wards for each of these categories. All patients benefit from the different NH functions, mainly rehabilitation and long-term care (admitted to the NH permanently). The NHs in the present study were purposefully sampled to be representative of all NHs in the Netherlands. First, the proportion of the three types of NHs was calculated: nine combined NHs, three for physically ill patients, and three for psychogeriatric patients. Secondly, the mean number of beds for physically ill and psychogeriatric patients per NH was calculated, and the NHs were arranged in order of this calculated mean. Finally, the nearest NHs above and below the mean were invited to participate in the study. During the course of the data collection, due to organizational and capacity problems, one NH for physically ill patients stopped collecting the data. For the remaining time of the data collection, another one from the same stratum replaced this NH. Hence, the total number of participating homes was 16. In this study, the average number of NH beds was 103 for physically ill patients, 156 for psychogeriatric patients, and 157

for combined care. The physically ill patients and the psychogeriatric patients all benefit from the various different NH functions, mainly rehabilitation and long-term care. Dutch NH care is organized differently than in most other countries. However, differences concern mainly structural aspects, and are limited concerning characteristics of patient populations. An important difference between Dutch NHs and NHs in other countries is the patient population admitted for rehabilitation.(9) As the majority of these patients are usually discharged after 4-8 weeks of treatment, these patients were not included in our study. Most salient difference in Dutch NHs compared to other countries is the presence of specially-trained NH physicians (in general one full-time physician per 100 patients), who provide medical care and are employed by these homes.(10)

Selection of patients
This study was introduced in each NH by the authors (HB, MEO). Written and verbal instructions were given to the NH physicians in how to fill in the questionnaires. They were asked to include on daily basis all consecutive (physically ill and psychogeriatric) patients who met the following criteria:
(1) maximum life expectancy of 6 weeks, according to clinical assessment by the NH physician, and (2) admitted for long-term care; or (3) previously admitted for rehabilitation, but transferred to long-term care during their stay (i.e. it became obvious that the patient would not leave the NH).
Based on their clinical experience, NH physicians decided whether a patient had a maximum life expectancy of 6 weeks. Patients who died suddenly, that is, with no clear terminal palliative phase, who recovered unexpectedly, or who survived the maximum follow-up period of 12 weeks (84 days), were excluded from the study. The maximum life expectancy of 6 weeks is based on prior consultation with the NH physicians who participated in the study. After the pilot study, the NH physicians considered that a weekly follow-up registration of 6 weeks with a maximum follow-up of 12 weeks, was the longest possible period over which any meaningful prediction could be made.

Measurements
On inclusion, the NH physician completed a questionnaire for each patient concerning basic demographics, clinical characteristics (e.g., stage of dementia, underlying disease on inclusion), and prediction of survival. The patients were monitored weekly, with an identical questionnaire on inclusion (except basic demographics), until death or exclusion.
The stage of dementia was assessed by the NH physician according to the validated Global Deterioration Scale (GDS), on the basis of their clinical experience.(11) This instrument identifies three major clinical phases: forgetfulness, confusion, and a late phase of dementia. These phases are further subdivided into seven clinically identifiable stages, ranging from Stage 1 (no cognitive decline) to Stage 7 (very severe cognitive decline). Stage 5 represents the phase of early dementia, and patients in this stage can no longer survive without some assistance.

The validated Classification of Diseases for Nursing Home Medicine (CvZ-V)(12) was used by the NH physician to classify the underlying disease on inclusion (disease which was the underlying cause of the disorder on which the NH physician based the limited life expectancy). The CvZ-V is a Dutch standard assessment, based on the International Classification of Diseases, 10th Edition (ICD-10),(13) with codes for the classification of diseases, intercurrent diseases, disorders, injuries, other problems, and causes of death in NH patients. However, unlike the ICD-10, the CvZ-V contains a "general" section with codes for diseases, disorders, and problems that supersede one particular organ system, because this situation is common in NH patients. The strength of this instrument is that the Classification of Diseases is tailored to the average NH population.

The NH physicians were asked to predict survival in a separate question on inclusion, with the following possible answers: death within 1 week (0-7 days), death within one to three 1-3 (8-21 days), and death within 4-6 weeks (22-42 days). This question on expected survival periods was analogous to a question in the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC draft 1.8)(14) and was fit to our study purpose. The original RAI MDS-PC question was "estimated length of life": (0) death imminent (within days); (1) less than 6 months to live; (2) 6 months or longer to live. The rationale behind the three intervals in this study was as follows: firstly, whether the included patient met the maximum life expectancy of six weeks, and secondly, were the NH physicians able to distinguish sub-categories among included patients. The NH physicians were given no assessment aid for prediction, which makes their assessment subjective and not replicable. However, accurate prognostic tools have not been developed,(15) and, therefore, the NH physicians had to rely on their clinical experience.

After inclusion there was a weekly follow-up registration for a period of 6 weeks, with a maximum follow-up of 12 weeks (84 days). The occurrence and date of death was registered by the NH physician. An optimistic prediction indicates earlier death than predicted, and a pessimistic prediction indicates death later than predicted.

Statistics
The analyses were performed in SPSS for Windows, version 11.0, and descriptive statistics were used to characterize the patients. Eligible patients were those for whom the date of inclusion, the date of death, or the date of exclusion was confirmed. Survival curves were calculated according to the Kaplan-Meier method. Proportional hazard analysis was applied to investigate the potential modifying influence of diseases and the stage of dementia.

Ethical review
The Medical Ethics Committee of the VU University Medical Center approved the study protocol. Confidentiality of the data was guaranteed by providing only coded information to the researchers. No patients or members of their family were interviewed. Because the NH physicians were simply reporting information that was collected as part of their usual care observations, no informed consent was

required, according to the VU Medical Ethics Committee. As required by Dutch law, the patients and their families were informed about the study through an information flyer, and were given the option to refuse the transfer of data.

Results

A total of 515 patients were included, for whom data on inclusion were confirmed. Of these patients, 467 died within 6 weeks (data on death confirmed) and 48 patients survived until the end of follow-up at 6 weeks. Patients and their families were informed about the study, which required no informed consent (see Ethical review). To the knowledge of the researchers, no patients refused data transfer.

Table 1 Demographic and clinical characteristics of patients on inclusion (n=515)

Demographics	n	%
Gender (missing=1)		
Male	150	29.2
Female	364	70.8
Age on inclusion (years) (missing=6)		
Mean age (min-max; SD)	83.5 (45-100; 8.1)	
Median survival of deceased patients (days) (N=467)		3.0
Marital status (missing=2)		
Never married	46	9.0
Married	141	27.7
Widowed	304	59.7
Divorced	18	3.5
Clinical characteristics		
Stage of dementia (Global Deterioration Scale[a]) (missing=26)		
Stage 1 no cognitive decline	165	33.7
Stage 2 – 4 very mild to moderate cognitive decline	24	4.8
Stage 5 moderately severe cognitive decline	38	7.8
Stage 6 severe cognitive decline	134	27.4
Stage 7 very severe cognitive decline	128	26.2

continue **Table 1**

Main underlying disease on inclusion[b] (CvZ-V codes)		
Mental and behavioral disorder	155	30.1
malignant neoplasms	0	0.0
Diseases of the circulatory system	106	20.6
malignant neoplasms	0	0.0
Diseases of the respiratory system	42	8.2
malignant neoplasms	7	1.4
General disorders	36	7.0
malignant neoplasms	10	2.0
Diseases of the digestive system	34	6.6
malignant neoplasms	20	4.0
Diseases of the nervous system	21	4.1
malignant neoplasms	2	0.4
Remaining systems	66	12.9
malignant neoplasms	21	4.2
Missing	55	10.7
Main direct cause of death[c] (CvZ-V codes) (n=467)		
General disorders	106	22.7
(mainly cachexia)	(55)	(11.8)
Diseases of the respiratory system	102	21.8
(mainly pneumonia)	(78)	(16.7)
Diseases circulatory system	82	17.6
(mainly heart failure)	(37)	(7.9)
(mainly stroke)	(17)	(3.6)
Diseases genitourinary system	71	15.2
(mainly renal failure)	(59)	(12.6)
Endocrine, nutritional and metabolic diseases	62	13.3
(mainly dehydration)	(61)	(13.1)
Remaining systems	39	8.3
Missing	5	1.1

SD = standard deviation

[a] GDS[11] was used to determine the stage of dementia

[b] Only diseases with a minimum prevalence of 4% are presented

[c] Only diseases with a minimum prevalence of 4% are presented. The total of patients (n=467) does not correspond with the total on inclusion (n=515), because all survivors are excluded

Table 1 presents the demographics and clinical characteristics of the patients on inclusion. Most of the patients were female (70.8%), and widowed (59.7%), with a mean age of 83.5 years (SD 8.1). Of all the patients who were included, 33.7% had no cognitive decline, 4.8% had very mild to moderate cognitive decline, 7.8% had

moderately severe cognitive decline, 27.4% had severe cognitive decline, and 26.2% had very severe cognitive decline. The main underlying diseases on inclusion were mental and behavioral disorders (30.1%) and diseases of the circulatory system (20.6%). Malignant neoplasms (12.0%) occurred most frequently in the digestive system (4.0%). The most prevalent causes of death were general disorders (22.7%, mainly cachexia 11.8%), and diseases of the respiratory system (21.8%, mainly pneumonia 16.7%) and circulatory system (17.6%, mainly heart failure 7.9% and strokes 3.6%).

Figure 1 Survival function of predicted and actual survival (n=515)
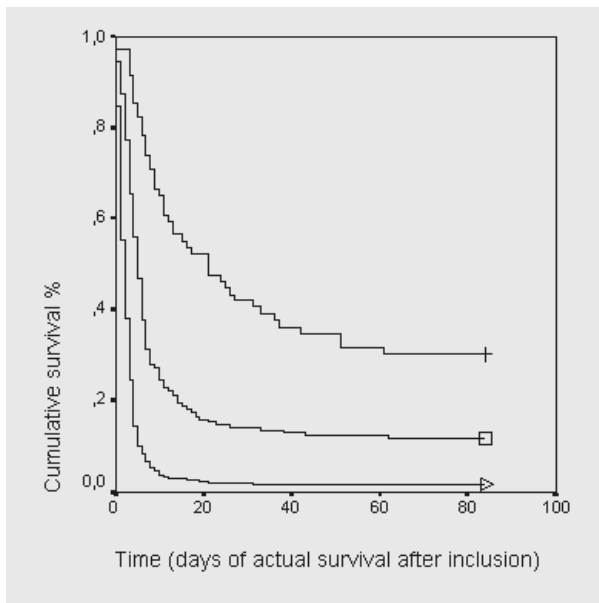
+ 4-6 weeks (22-42 days)
□ 1-3 weeks (8-21 days)
▷ 1 week (0-7 days).

Figure 1 shows the actual survival in Kaplan-Meier curves for the three categories of predicted survival. According to the logrank test, the three curves are significantly different (P < 0.0001). The median duration of survival of all the included patients was 3.0 days (data not shown). The predicted survival was most accurate for patients who died shortly after inclusion (0-7 days).

Table 2 Data on predicted survival, actual survival and median survival (n=515)

Categories of predicted survival (Missing=4)	Actual survival			Median survival
	Optimistic prediction (Earlier death)	Accurate prediction	Pessimistic prediction (Later death)	
	%	%	%	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

Table 2 presents data on categories of predicted vs. actual survival. Prediction was accurate in 92.9% of the patients who were expected to die within 0-7 days (median survival 2 days). In the category of patients who were expected to die within 8-21days or within 22-42 days, the prediction was accurate in 16.0% and 13.0%, respectively. But the overall predictions in these categories were mainly optimistic (patient died earlier) in 68.6% and 52.2%, respectively. In proportional hazard analysis, it appeared that the main underlying disease was not related to predicted and actual survival. The stage of dementia was of no importance with regard to the assessment of the NH physician (was neither a confounder nor a modifier for prognosis).

Discussion

To our knowledge, this is the first study that provides insight into prognostic assessment in the terminal stage of NH patients. It shows, that the survival of patients (with mainly noncancer diseases) is inaccurately predicted by NH physicians, except when death is imminent.

One limitation of this study is that the patients were included if the NH physician expected that they were likely to die within 6 weeks. Although no substantial differences were found between the study sample and the patients who were not included with regard to demographic variables (age, gender and ward), if NH physicians selectively missed patients, we cannot exclude a possible bias on the outcome variables of this study. However, the strengths of this study are the large-scale design, the representativeness of the NHs, and the prospective nature of the

research, which enhances the validity and reliability of the findings. It also provides data on a population that is relatively underinvestigated in end-of-life research, namely noncancer patients.

The findings of this study show that NH physicians predicted the death of patients with mainly chronic diseases with an accuracy of more than 90% when death occurred within 7 days (imminent death). These findings are, despite a different group of patients, consistent with the findings of Oxenham and Cornbleet, who reported, in their study of survival in a hospice, that members of the clinical staff were able to predict imminent death of patients with diagnosis of advanced malignant disease, with significant accuracy, either based on increased knowledge of individual patients or based on increasing illness.(16) Christakis and Lamont in their prospective cohort study of hospice outpatients, concluded that prognostic inaccuracy was associated with a stronger doctor-patient relationship and that the majority of predictions were over-estimated (63%).(2) In Dutch NHs, where specially-trained physicians provide medical care, profound knowledge of the patient's condition can be assumed, as well as a strong doctor-patient relationship. This study cannot support the assumption that the latter aspect is an "obstacle" to accurate prediction. Nonetheless, predicted and actual survival became substantially less accurate over a period longer than 7 days, when death was not imminent. Accurate prediction decreased to 16%-13% (categories of 1-3 weeks and 3-6 weeks, respectively), and survival prediction was over-optimistic in these categories (68.6%-52.2%), which is consistent with the findings of Christakis and Lamont(2) and Morita et al.(17) One might expect a better prognostication of long-term survival by the NH physician because of the profound knowledge of the patient. Nevertheless, the reason for the poor prognostication may be due to the fact that NH patients get frail and die from complex multifactorial causes (comorbidity and intercurrent diseases). Deterioration in one health domain influences other health domains, resulting in a cumulative negative effect on patients overall health condition and thus making prognostication difficult. Two-thirds of the studied patients had dementia (stage 5-7 GDS),(11) a complicated disease with unpredictable course.
Uncertainty of prognosis does not mean that the needs of these patients and their families are any less important. The application of the principles of palliative care should not be influenced by the estimate of survival. However, as a consequence of a more accurate survival prediction, a more frequent assessment and addressing of needs and demands of the patient is possible. Giving the apparent speed of deterioration, physical, psychosocial, and spiritual needs could be addressed better, all resulting in improved end-of-life care and improved quality of life for the remaining life time, how ever short it is.

In conclusion, 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 the patients. Prognostication over a longer period of time tends to be less accurate, and, therefore, continues to be a challenging task for physicians.

References

1. Bruera E, Miller MJ, Kuehn N, MacEachern T, Hanson J. Estimate of survival of patients admitted to a palliative care unit: a prospective study. J Pain Symptom Manage 1992; 7(2):82-86.
2. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ 2000; 320(7233):469-472.
3. den Daas N. Estimating length of survival in end-stage cancer: a review of the literature. J Pain Symptom Manage 1995; 10(7):548-555.
4. Faris M. Clinical estimation of survival and impact of other prognostic factors on terminally ill cancer patients in Oman. Support Care Cancer 2003; 11(1): 30-34.
5. Vigano A, Dorgan M, Buckingham J, Bruera E, Suarez-Almazor ME. Survival prediction in terminal cancer patients: a systematic review of the medical literature. Palliat Med 2000; 14(5):363-374.
6. World Health Organization. Better palliative care for older people. Copenhagen: World Health Organization, 2004.
7. Travis SS, Loving G, McClanahan L, Bernard M. Hospitalization patterns and palliation in the last year of life among residents in long-term care. Gerontologist 2001; 41(2):153-160.
8. Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients: a nationwide observational study in the Netherlands. Arch Intern Med 2005; 165(3):314-320.
9. Ribbe MW, Ljunggren G, Steel K, et al. Nursing homes in 10 nations: a comparison between countries and settings. Age Ageing 1997; 26 Suppl 2:3-12.
10. Hoek JF, Ribbe MW, Hertogh CM, van der Vleuten CP. The role of the specialist physician in nursing homes: the Netherlands' experience. Int J Geriatr Psychiatry 2003; 18(3):244-249.
11. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139(9):1136-1139.
12. Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Classificatie van ziekten voor de verpleeghuisgeneeskunde [Classification Codes of Diseases for Nursing Home Medicine]. Utrecht, The Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1994.
13. World Health Organization. International classification of diseases, 10th Revision (ICD-10). Geneva, Switzerland: World Health Organization; 1992.
14. Steel K, Ljunggren G, Topinkova E, et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003; 20(3):211-219.
15. Mitchell SL, Kiely DK, Hamel MB, Park PS, Morris JN, Fries BE. Estimating prognosis for nursing home residents with advanced dementia. JAMA 2004; 291(22):2734-2740.

16. Oxenham D, Cornbleet MA. Accuracy of prediction of survival by different professional groups in a hospice. Palliat Med 1998; 12(2):117-118.

17. Morita T, Tsunoda J, Inoue S, Chihara S. Improved accuracy of physicians' survival prediction for terminally ill cancer patients using the Palliative Prognostic Index. Palliat Med 2001; 15(5):419-424.

Part 2

Problems, symptoms and quality

of palliative care

4

Assessment of psychological and spiritual needs in terminally ill Dutch nursing home patients

Abstract

The aim of this study was to assess psychological and spiritual needs in terminally ill nursing home (NH) patients. A prospective observational study was carried out in 16 Dutch NHs among patients with a maximum life-expectancy of 6 weeks (N=426). These needs were assessed with the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC) and the Edmonton Symptom Assessment Scale (ESAS). The majority of NH patients showed psychological and spiritual needs in the last three days of life. However, healthcare providers had insufficient knowledge about these needs because they were unable to assess a significant portion of them.

Introduction

Terminally ill elderly people often spend the last days of their life in a nursing home (NH).(1) It is therefore important that the long-term care physicians and the NH staff provide appropriate palliative care in this setting.(2) Only a few empirical studies have focused on end-of-life care for long-term patients in NHs (3-5) and research on the experience of dying is limited.(6) It has been acknowledged that good end-of-life care pays attention to psychological and spiritual issues.(7) However, it is suggested that physical pain continues to dominate the focus of care in dying residents,(8) whereby patients and their families are isolated from social and spiritual support.(9) Holtkamp et al. (2000) described in their study that about 40% of the residents who needed help with family problems, feelings of sadness or depression did not receive care for these problems.(10)

Palliative care is holistic care, and therefore attention must also be paid to psychosocial and spiritual issues. The National Council for Hospice and Specialist Palliative Care Services (1997) has defined psychosocial care as: being concerned with the psychological and emotional well-being of patients and their families/carers, including issues of self-esteem, insight into adaptation to the illness and its consequences, communication, social functioning and relationships.(11) Given the rather broad spectrum of these psychosocial needs, the present study will focuses on indicators for psychological needs such as mood, depression, anxiety, well-being. These indicators lend themselves well to specific psychological interventions during the care process.(12)

Spirituality is an aspect of palliative care, that has been even less frequently investigated and defined differently by different authors.(13) At least in the recent literature, spirituality has been defined as a concept that is broader than religiosity alone.(14;15) One of these definitions describes spirituality as the quest for understanding life's ultimate questions and the meaning and purpose of life; it emphasizes individual experience, and may or may not lead to participation in a community.(16) In this study, we aim to investigate both the religious and the non-religious dimension of spirituality at the end of life.

This study forms part of a large-scale palliative care study of mainly non-cancer, terminally ill patients in Dutch NHs.(17) At the end of the life of long-term care patients, their needs and the focus of the care that is provided may change, and psychological and spiritual issues may become more important.(18) Therefore, the aim of this study was to investigate the psychological and spiritual needs of terminally ill long-term care patients admitted to NHs in the Netherlands.

Methods

Setting and design
A prospective observational study was carried out in 16 Dutch nursing homes (NHs) from November 2001 to March 2003, with an average inclusion period of 0.9 years and 2429.5 bed-years.

In 2003, there were about 330 NHs in The Netherlands. Three types of NHs can be distinguished: those solely for physically ill patients, those solely for psychogeriatric patients, and combined types with separate wards for each of these categories. Most of the psychogeriatric patients have dementia (96%) and will stay in a NH until they die.(19) All patients benefit from the different NH functions, mainly rehabilitation and long-term care. The staff includes specially trained nursing home physicians: (in general one full-time physician per 100 patients), who provide the medical care and are employed by these homes.(20)

The NHs in the present study were purposefully sampled to be representative of all NHs in the Netherlands. First, the proportion of the three types of NHs was calculated: nine combined NHs, three for physically ill patients, and three for psychogeriatric patients. Secondly, the mean number of beds for physically ill and psychogeriatric patients per NH was calculated, and the NHs were arranged in order of this calculated mean. Finally, the nearest NHs above and below the mean were invited to participate in the study. During the course of the data collection, due to organizational and capacity problems, one nursing home for physically ill patients stopped collecting the data. For the remaining time of the data collection, another one from the same stratum replaced this NH. Hence, the total number of participating homes was 16. In this study the average number of NH beds was 103 for physically ill patients, 156 for psychogeriatric patients, and 157 for combined care.

We included all patients (physically ill and psychogeriatric) who were admitted for long-term care with a maximum life-expectancy of 6 weeks, as assessed by the NH physician.

Selection of patients
This study was introduced during instruction sessions in each NH by the authors (HB, MEO), and written instructions were also provided. The NH physicians were asked to include all consecutive patients who met the following criteria:
(1) maximum life-expectancy of 6 weeks, according to the NH physicians' own clinical assessment; and (2) admitted for long-term care (admitted to the NH permanently), or (3) previously admitted for rehabilitation, but transferred to long-term care during their stay (i.e. it became obvious that the patient would not leave the nursing home). Patients who died suddenly and unexpectedly (i.e., with no clear terminal palliative phase), who unexpectedly recovered, or survived the maximum follow-up period of 12 weeks, were excluded from the study.

The maximum life-expectancy of six weeks is based on prior consultation with the NH physicians who participated in the study. Admittance to an NH for terminal care is handled differently in different countries. In the Netherlands the limit is set at three months, due to reimbursement by health care insurance companies. In the pilot study, the NH physicians considered that a weekly follow-up registration of three months with a maximum follow-up of six months was not feasible. After the pilot study, based on a maximum life-expectancy of six weeks, the participating (experienced) NH physicians agreed that this criterion was the longest possible period over which any meaningful prediction could be made.

54

Measurements
On inclusion, the regularly attending NH physician and one attending nurse both completed a separate questionnaire for each patient. The patients were monitored weekly, until death or exclusion, with an identical questionnaire. At the time of patient death, the NH physician completed a questionnaire for all long-term care patients. NH-physicians and nurses did make their assessments by reporting information they collected as part of their usual care observations. Neither the patients nor members of their family were interviewed, regarding psychological or spiritual needs.

Measurements by the NH physician
The NH physician completed a questionnaire on the basic patient demographics, disease characteristics (e.g. stage of dementia, main underlying disease of terminal status), and psychological needs. The stage of dementia was assessed by the NH physician according to the validated Global Deterioration Scale (GDS).(21) This instrument identifies three major clinical phases: forgetfulness, confusion, and a late phase of dementia. These phases are further sub-divided into seven clinically identifiable stages, ranging from stage 1 (no cognitive decline) to stage 7 (very severe cognitive decline). Stage 5 represents the phase of early dementia, and patients in this stage can no longer survive without some assistance.
The validated Classification Codes of Diseases for Nursing Home Medicine (CvZ-V)(22) was used by the NH physician to classify the main underlying disease of the terminal status on inclusion (disease which was the underlying cause of the disorder on which the NH physician based the limited life-expectancy). The CvZ-V is a Dutch standard, based on the International Classification of Diseases, 10th Edition (ICD-10)(23), with codes for the classification of diseases, intercurrent diseases, disorders, injuries, other problems, and causes of death in NH patients. However, unlike the ICD-10, the CvZ-V contains a 'General' section with codes for diseases, disorders and problems that supersede one particular organ system, because this situation is common in NH patients. The strength of this instrument is that the Classification of Diseases is tailored to the average NH population.

In this study psychological needs were measured by the NH physician in the domains of (A) mood disturbance, and (B) depression, anxiety and well-being. Assessment of other, more psycho-pathological disorders, such as personality disorders, was beyond the scope of this study.
(A) Mood disturbance was assessed with the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC Draft 1.8.).(24) Draft 1.8 was prior to the final validation of this instrument, but subsequent changes were negligible. This psychological aspect was measured on inclusion and was weekly monitored (if patient was still alive). The mood questions consisted of 11 items and considered the previous three days. The alternatives for each item were:
(1) "Indicator in the last three days not exhibited",
(2) "Indicator 1-2 times in the last three days exhibited",
(3) "Indicator exhibited on each of last three days",
(4) "Unknown/not assessed".

The concepts of (B) depression, anxiety and well-being were measured with items of the Edmonton Symptom Assessment Scale (ESAS),(25) in the questionnaire which was completed by the NH physician at the time of death. In this questionnaire, the NH physician assessed retrospectively in all conscious patients, for the period 48-24 hours and 24-0 hours before death, a number of physical and psychosocial symptoms. The validated ESAS consists of nine 100 mm visual analogue scales (VASs) for pain, activity, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. The scores range from 0-100 (higher scores reflect greater symptom severity.(25) Therefore, a score nearing 100 indicates very depressed, very anxious, and poor well-being.

Before every assessment of the psychological needs the NH physician could indicate in the questionnaire whether or not a patient was conscious. RAI MDS-PC items were assessed in conscious as well as unconscious patients, but ESAS items were only assessed in conscious patients.

RAI MDS-PC scores of the last assessment before death of conscious patients with stage 1–5 dementia (GDS)(21) were included for analysis. Stage 5 was included, although reflecting the phase of early dementia, for these patients are still able to express their wishes. Patients with stage 6 and 7 dementia (GDS) were excluded, because of their severe cognitive impairment, which makes only non-verbal communication possible. To prevent bias in the scoring of variables by the NH physician, the extra response category 'unknown/not assessed' was added to all RAI MDS-PC and ESAS items. Assigned non-scores (unknown/not assessed) are an indication for quality of palliative care.

For deceased patients who had not been included in the study, the NH physician completed a shorter questionnaire at the time of death. In this short questionnaire, we checked the reason for non-inclusion: (1) sudden and unexpected death; (2) should have been included earlier; (3) other, namely. The patients included under point 2 were 'missed' patients of whom the NH physician was asked in a separate question why these patients were not included earlier (alternatives: 1. forgotten [to be included], 2. pressure of work, 3. organizational reasons [e.g. should have been included during the weekend], 4. family had objections to inclusion in the study, 5. other reasons).

Measurements by the nurses
Spiritual needs were assessed by nurses on inclusion and monitored weekly (if patient was still alive), according to the RAI MDS-PC.(24) Alternative response categories were added, such as 'unknown' if the nurse did not have enough knowledge to assign a score and, 'not applicable', e.g. for unconscious patients.

Statistics
All analyses were performed in SPSS for Windows, version 11.0, and descriptive statistics were used to characterize the patients. Data of the last assessment before death of conscious patients with stage 1-5 dementia (GDS)(21) were included for analysis. Because most data were missing for the unconscious patients, the analyses were limited to the conscious patients.

The outcome variables of the ESAS were derived from the questionnaire completed at the time of death by the NH physician (Table 3), therefore the number of cases is not consistent with the other tables. The items depression, anxiety and well-being were screened for normality . Standard transformations were made, if necessary. Symptom development of the ESAS was analyzed in patients who were conscious on both time points, 48-24 hours and 24-0 hours before death (N=235). Differences in mean score were determined with the paired-samples t-test. Patients with no data on consciousness and/or cognitive decline were excluded from the analysis.

Ethical review
The Medical Ethics Committee of the VU University Medical Center approved the study. Confidentiality of the data was guaranteed by providing only coded information to the researchers. Neither the patients nor members of their family were interviewed. Because the NH-physicians and nurses were simply reporting information that was collected as part of their usual care observations, no informed consent was required, according to the VU Medical Ethics Committee. As required by Dutch law, the patients and their families were informed about the study through an information flyer, and were given the option to refuse the transfer of data.

Results

A total of 426 patients were included. For these patients we received a questionnaire on inclusion, a weekly questionnaire (dependently on survival time after inclusion), and a final questionnaire after death. Most patients died within the first week of inclusion (86.6%), therefore, most data were gathered from the questionnaire on inclusion.
In the same period, an additional 272 deceased patients were found to have been incorrectly not included in the study. Those patients were considered as 'missed' patients. The main reasons for non-inclusion, given in the shorter questionnaire at the time of death, in order of sequence by the NH physicians, were pressure of work, organizational reasons (e.g. should have been included during the weekend), forgotten (to be included), other reasons (e.g. death not foreseen).

Demographics
Table 1 presents the demographics and disease characteristics of three groups of patients on inclusion: conscious patients with stage 1-5 dementia, patients with stages 6 and 7 dementia according to the GDS, and unconscious patients. In all categories, most of the patients were female (66% to 77%), and mostly not married (72% to 75%), with a mean age of 82.9 to 85.0 years. One fifth to a quarter had no children. The main religion was Catholic or Protestant. The median duration of residence in the NH was 7 to 21 months. On inclusion, unconscious patients were predominately admitted to a psychogeriatric ward (66%). A quarter of the unconscious patients had no cognitive decline (26%), whereas more than two third (65%) had severe or very severe cognitive decline. The main underlying cause of terminal status on inclusion for patients with stage 1-5 dementia were diseases of

the circulatory system (29%). For patients with stage 6 and stage 7 dementia, as well as for unconscious patients, the main underlying disease of terminal status were mental and behavioural disorders (53% and 37%). Malignant neoplasms were predominantly in conscious, not demented patients (18.0%). In the total population 10% had cancer (data not shown).

Psychological needs
Table 2 shows the assessment by the NH physician of mood disturbance in conscious patients in the last three days of life. The most salient indicators in this last assessment, which were exhibited at least 1-2 time(s) and on each of the last 3 days, were 'sad, pained, worried facial expressions' (52%), 'at peace with life' (45%), 'expressions of fear' (36%), 'feeling of sadness or being depressed' (29%), 'insomnia/change in usual sleep pattern' (21%), 'anhedonia' (19%), and 'repetitive, anxious complaints and concerns' (11%). The score for the indicator 'not exhibited in the last three days' was > 60% for 7 of the 11 items of mood disturbance. The score for 'unknown' was highest for the items 'at peace with life' (33%), 'feeling sad or depressed' (25%), and 'anhedonia' (19%).

Table 1 Demographics and disease characteristics of patients on inclusion, according to the stage of dementia and consciousness (N=426)

	Conscious		Unconscious*
Stage of dementia (Global Deterioration Scale[21])†	1-5 (n=157)	6 and 7 (n=165)	Stages 1-7 (n=82)
	%	%	%
Demographics			
Gender			
Male	31.8	23.5	34.1
Female	68.2	76.5	65.9
Age on inclusion			
Mean age	82.9	85.0	84.0
(min-max; SD‡)	(45-98; 9.0)	(65-100; 6.5)	(53-100; 8.2)
Marital status			
Married	27.7		33.3
Not married	72.3		66.7
Number of children			
Children	81.7		75.6
No children	18.3		24.4
Religion			
Catholic	42.2	37.1	50.0
Protestant	35.9	37.9	30.3
Other (e.g. Jehovah, Humanist, Muslim)	4.7	9.5	7.6
None	17.2	15.5	12.1

continue **Table 1**

	Conscious		Unconscious*
Stage of dementia (Global Deterioration Scale[21])†	1-5 (n=157) %	6 and 7 (n=165) %	Stages 1-7 (n=82) %
Disease characteristics			
Number of months in nursing home			
Median (min–max)	7.1(0-199)	21.3(0-215)	14.8(0-164)
Ward on inclusion			
Physically ill	73.2	1.8	29.3
Psychogeriatric	17.8	94.5	65.9
Others	8.9	3.6	4.9
Stage of dementia (Global Deterioration Scale[21])			
Stage 1 No cognitive decline	71.3	-.-	25.9
Stage 2 – 4 Very mild to moderate cognitive decline	12.7	-.-	2.5
Stage 5 Moderately severe cognitive decline	15.9	-.-	6.2
Stage 6 Severe cognitive decline	-.-	53.6	28.4
Stage 7 Very severe cognitive decline	-.-	45.8	37.0
Main underlying disease of terminal status on inclusion § (Classification of Diseases for Nursing Home Medicine[22])			
Diseases of the circulatory system	29.3	10.8	20.7
General disorders	10.8	4.8	4.9
Diseases of the digestive system	8.9	5.4	-.-
Mental and behavioural disorders	7.6	53.0	36.6
Others	43.4	26.0	37.8
Malignant neoplasms (including secondary malignant neoplasms) within all systems	18.0	3.0	4.8

* Missing=5

† Missing=17

‡ Standard deviation

§ Only diseases with a prevalence above 4% are presented

Table 2 Mood disturbance* in the last three days of the life of conscious patients with stage 1-5 dementia Global Deterioration Scale (GDS)[21], assessed by the nursing home physicians (N=153)†

Indicator	Exhibited 1-2 times in last three days	Exhibited on each of last 3 days	Not exhibited in last three days	Unknown
	%	%	%	%
Sad, pained, worried facial expressions	29.1	22.5	41.7	6.6
At peace with life	20.0	24.7	22.0	33.3
Expressions of fear	23.2	13.2	51.7	11.9
Feelings of sadness or being depressed	13.9	15.2	45.7	25.2
Insomnia/change in usual sleep pattern	11.3	9.9	68.9	9.9
Anhedonia	11.3	7.3	62.9	18.5
Repetitive, anxious complaints and concerns	6.0	4.6	79.5	9.9
Frustrated	7.3	2.7	78.0	12.0
Repetitive health complaints	6.0	3.3	80.8	9.9
Recurrent crying, tearfulness	6.6	2.6	82.1	8.6
Persistent anger with self or others	4.0	4.6	80.1	11.3

* Mood disturbance measured with the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC Draft 1.8)[24]

† 4 missing. At the last assessment, the total of all conscious patients with stage 1-5 dementia (GDS)[21] no longer corresponds with the total on inclusion (N=157), due to 4 additional unconscious patients

Figure 1 Number of mood disturbances* observed in conscious patients in the last three days of life (n=153)
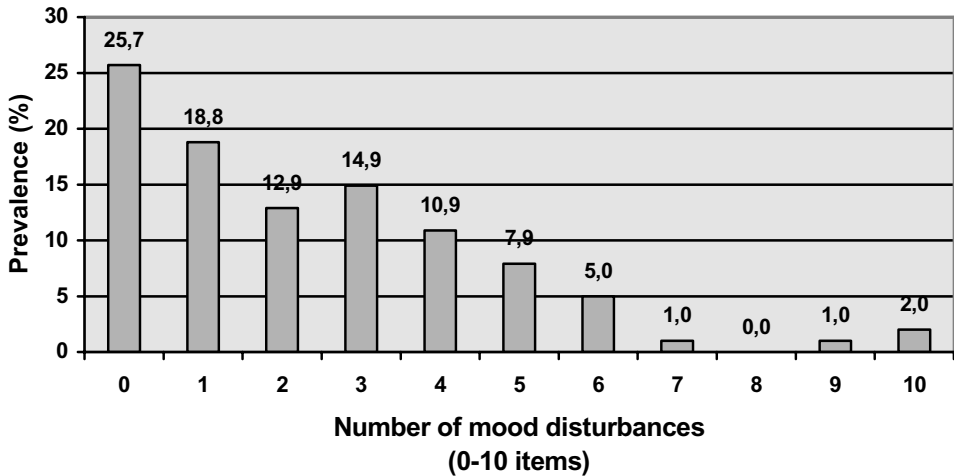
* Mood disturbances include all indicators presented in Table 2, with the exception of 'at peace with life'

Figure 1 shows the number of mood disturbances observed in conscious patients in the last three days of life. For all indicators listed in Table 2, with the exception of 'at peace with life', we counted how many times the nurses assessed the response categories 'exhibited 1-2 times in the last three days' or 'exhibited on each of last three days'. A quarter of the patients (25.7%) showed no mood disturbance at all, one-fifth (18.8%) showed one mood disturbance, and less than 15.0% showed 2-10 mood disturbances.

Table 3 Median score for depression, anxiety and well-being* 48-24 hours and 24-0 hours before death in conscious†, non-demented‡ patients, retrospectively assessed by the nursing home physician (N=113)§

	48-24 hours before death		24-0 hours before death		
	Median score	Unknown %	Median score	Unknown %	P-value¶
Depression	12	18.6	8.0	28.3	0.000
Anxiety	21	8.0	10	8.0	0.001
Well - being	70	19.5	52	28.3	0.007

* Assessed according to the Edmonton Symptom Assessment Scale (ESAS)[25]. A score nearing 100 indicates very depressed, very anxious, and poor well-being

† Conscious on both time points: 48-24 hours and 24-0 hours before death

‡ Stage 1-5 Global Deterioration Scale[21]

§ Occurrence and date of death was registered by the NH physician in a separate questionnaire, other than on inclusion. Therefore the number of cases is not consistent with the other tables

¶ Differences in mean scores 48-24 hours and 24-0 hours before death

Table 3 shows the median score for depression, anxiety and well-being two days before death in conscious, non-demented patients. The median scores for depression, anxiety and well-being decreased towards death (less depressed, less, anxious, and more well-being). The frequency of the score for 'unknown' increased towards death. Analysis for all patients (N=253, stage 1-7 GDS) showed the same results (data not shown).

Spiritual needs

Table 4 presents the spiritual needs in the last days before death of conscious, non-demented patients, as assessed by the nurses. More than one-third (44.8%) of all patients wished ' religious or spiritual guidance or support'. More than one-eight (15.8%) was 'struggling with the meaning of life'. In half of the cases it was 'unknown' to the nurses whether or not the patient was 'struggling with the meaning of life' (54.0%) or felt 'anger toward God, religion or fate' (52.1%). When spiritual needs were analyzed according to demographics (gender, marital status, actual living status before NH admittance, number of children, religion), the results showed that patients belonging to a religious denomination asked significantly more often for religious or spiritual guidance or support than non-religious patients (data not shown).

Table 4 Spiritual needs in the last assessment before death by nurses of conscious, non-demented patients (N=153)*

	No	Yes	Unknown
Question	%	%	%
Patient wishes religious or spiritual guidance or support	22.8	44.8	32.4
Patient is struggling with the meaning of life	30.2	15.8	54.0
Patient feels anger toward God, religion or fate	46.5	1.4	52.1

* 4 missing. At the last assessment, the total of all conscious patients with stage 1-5 dementia (GDS)[21] no longer corresponds with the total on inclusion (N=157), due to 4 additional unconscious patients

Discussion

To the knowledge of the investigators, this is the first nationwide study that gives insight into psychological and spiritual issues in the terminal phase of NH patients. Furthermore, an assessment was made of the prevalence of psychological and spiritual needs in terminally ill NH patients in the Netherlands.

The findings of the present study reflect a (mainly) non-cancer population. Only 10% had cancer as the underlying disease. In general, psychosocial and spiritual needs were present at high frequencies, but simultaneously NH physicians and nurses showed a lack of assessment of these needs, expressed in high assigned non-scores.
Half of the patients showed sad, pained, worried facial expressions, one-third exhibited expressions of fear and expressed feelings of sadness or depression. One-fifth suffered from insomnia or change in the usual sleep pattern. At the same time , almost half of the conscious, non-demented (stage 1-5 GDS) patients was at peace with life in the last three days of their life and NH physicians reported significant improvement of depression, anxiety and well-being towards death. More than two-fifth (44.8%) of the patients wished religious or spiritual guidance or support, but 15.8% was struggling with the meaning of life. The results showed that aspects of spiritual needs like struggling with the meaning of life and anger towards God, religion or fate, were unknown to a majority of the attending nurses, which suggests potential for improvement of assessment of spiritual needs in end-of-life care.

The study provides detailed information about various aspects of the terminal phase of elderly people with a chronic disease. The large-scale design of this study, its prospective character, and the representativeness of the participating NHs, all enhance the validity and reliability of the findings.
However, the study has some limitations. Firstly, the data were obtained from the reports of proxies, namely professionals. These proxies may have under-reported or over-reported the psychological and spiritual issues. Hence, the patient's

experiences can be biased. Several studies have evaluated the reliability of proxy reports on the quality of life, respectively the quality of care, in elderly patients with and without dementia.(26-30) In general, these studies evaluating the reliability of proxy ratings show different outcomes. Assessments made by significant others and health care providers are reasonably accurate, and nurses may even be the most suitable source of proxy information. Fairly good agreements between patient and proxy reports have been found with regard to physical functioning and cognitive status, but agreement is poorest for subjective aspects of the patient's experience, such as pain, anxiety and depression. In patients with dementia, agreement decreased with increasing severity of the dementia, and therefore proxy assessments should be interpreted with caution.(28)

Secondly, the main underlying disease of terminal status on inclusion was assessed with a question analogous to the cause of death question on the Dutch death certificates.(31) The NH physicians who participated in the study might have had difficulties in reporting the underlying disease and therefore may have incorrectly registered the cause of death on the death certificates.(32) Problems occur mainly with regard to the sequence of the primary and secondary causes of death, and the primary cause (underlying disease) cannot always be determined. Thirdly, when death is approaching, the assessment of consciousness is difficult. It is possible that physicians did misclassify the state of consciousness, which could have influenced the reliability of the data. Furthermore, there is missing information about a large number of terminal patients (n=272), who should have been included. Although no substantial differences were found between the study sample and the omitted group with regard to gender and type of ward, we cannot, in case physicians selectively missed patients, exclude a possible bias on the outcome variables of this study.(17) Finally, the retrospective assessment of depression, anxiety and well-being of the period 48-24 hours and 24-0 hours before death by the ESAS, cannot exclude recall-bias. Because the NH physicians were instructed to fill in the questionnaire soon after death, this has possibly been limited. The retrospective approach and the use of proxies is a solution to overcome the obstacles when evaluating care of the dying.(26) Again, when death is approaching assessments are difficult and could have influenced the reliability of the data.

In this study feelings of sadness or depression were assessed in (29%) of the patients. These results contradict with the findings by Reynolds et al. (2002) In their study, family members and nursing home staff reported that 44% of the decedents were very sad or depressed during their final three months of life.(33) Our findings suggest that these feelings were either absent (indicator not exhibited) in almost half (46%) of the patients in the last three days of their life, or they were unknown to the carers. There are reasons to think that the latter suggestion is correct, since in 33% of the cases the NH physicians had no knowledge about whether or not patients were at peace with life and in 25% if they expressed feelings of sadness or depression.

In the light of these results, it is not surprising that a quarter (26%) of the patients exhibited no mood disturbance in the last three days of their life. Approximately one-fifth of these patients (19%) had only one mood disturbance, and with the

increasing number of disturbances the number of patients with those disturbances decreased rapidly. Again, the question remains as to whether mood disturbances were absent or whether the NH physicians did not recognize them. A surprising result was that, regardless of their stage of dementia, the well-being of conscious patients increased significantly towards death. This may be due to intensification of the alleviation of pain and/or symptoms, but further investigation of the cause of this phenomenon was beyond the scope of this study.

In half of the cases the spiritual needs as struggling with the meaning of life (54%) or anger towards God, religion or fate (52%) were unknown to the nurses. Not surprisingly, they had more knowledge of the more concrete wishes of the patient with regard to religious or spiritual guidance or support (45%). Very often spirituality is equated to religiosity, because variables such as religious practice seem easier to measure.(15) The findings of this study are supported by DeSilva et al. (2001), who found in their study from bereaved family members about quality of care in the last month of life of their loved one, that in only 15% of the cases referral to a spiritual leader by health care providers occurred, and a health care provider spoke to only 44% of family members about their religious or spiritual concerns.(34) Demographic parameters were not important for the spiritual needs of the patient, with one exception: patients belonging to a religious denomination asked significantly more often for religious or spiritual guidance or support than non-religious patients.

The major finding of this study is that staff were not able to include all the valid cases, and when they did include them, they were unable to assess a significant portion of them. The majority of NH patients showed psychological and spiritual needs in the last three days of life. However, healthcare providers had insufficient knowledge about these needs, which was expressed in the high frequency of assigned non-scores (unknown/not assessed). As an evaluation of palliative care these results give an indication of the quality of the provided care. The question remains, whether this was due to unawareness or the absence of feasible assessment instruments. This isn't clear. Evaluation of palliative care relies on adequate tools, to develop high-quality end-of-life care. Also psychosocial and spiritual aspects of care should be more integrated in the continuing professional education of health professionals. Developing effective methods to assess the psychological and spiritual needs of patients very near the end of life is an important task. To judge from this study, it is also a difficult task. More research is needed to shed more light on why it is so difficult or how these challenges could be met.

References

1   Miller SC, Mor VN. The role of hospice care in the nursing home setting.
        J Palliat Med 2002; 5(2):271-277.
2.   World Health Organization. Better Palliative Care for Older People.
        Copenhagen, Denmark; World Health Organization; 2004.
3.   Oliver DP, Porock D, Zweig S. End-of-life care in U.S. nursing homes: a
        review of the evidence. J Am Med Dir Assoc 2004; 5(3):147-155.
4.   Forbes S. This is Heaven's waiting room: end of life in one nursing home.
        J Gerontol Nurs 2001; 27(11):37-45.
5.   Keay TJ, Taler GA, Fredman L, Levenson SA. Assessing medical care of
        dying residents in nursing homes. Am J Med Qual 1997; 12(3):151-156.
6.   Kayser-Jones J. The experience of dying: an ethnographic nursing home
        study. Gerontologist 2002; 42 Spec No 3:11-19.
7.   Pantilat SZ. End-of-life care for the hospitalized patient. Med Clin North Am
        2002; 86(4):749-70.
8.   Orchard H, Clark D. Tending the soul as well as the body: spiritual care in
        nursing and residential homes. Int J Palliat Nurs 2001; 7(11):541-546.
9.   Zerzan J, Stearns S, Hanson L. Access to palliative care and hospice in
        nursing homes. JAMA 2000; 284(19):2489-2494.
10.   Holtkamp CC, Kerkstra A, Ribbe MW, Van Campen C, Ooms ME. The
        relation between quality of co-ordination of nursing care and quality of life in
        Dutch nursing homes. J Adv Nurs 2000; 32(6):1364-1373.
11.   Jeffry D. What do we mean by psychosocial care in palliative care? In Lloyd-
        Williams M, ed. Psychosocial issues in palliative care, pp 1-12. Oxford:
        Oxford University Press, 2003.
12.   MacLeod R. Psychosocial care for non-malignant disease. In Lloyd-Williams
        M, ed. Psychosocial issues in palliative care, pp 119-133. Oxford: Oxford
        University Press, 2003.
13.   Brady MJ, Peterman AH, Fitchett G, Mo M, Cella D. A case for including
        spirituality in quality of life measurement in oncology. Psychooncology 1999;
        8(5):417-428.
14.   Lickiss JN, Hacker NF. Care of the patient close to death. Best Pract Res
        Clin Obstet Gynaecol 2001; 15(2):333-340.
15.   Speck P, Higginson I, Addington-Hall J. Spiritual needs in health care. BMJ
        2004; 329(7458):123-124.
16.   Koenig HG, George LK, Titus P, Meador KG. Religion, spirituality, and acute
        care hospitalization and long-term care use by older patients. Arch Intern
        Med 2004; 164(14):1579-1585.
17.   Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe
        MW. Symptoms, signs, problems, and diseases of terminally ill nursing home
        patients: a nationwide observational study in the Netherlands. Arch Intern
        Med 2005; 165(3):314-320.
18.   Shannon SE, Tatum P. Spirituality and end-of-life care. Mo Med 2002;
        99(10):571-576.

19. van der Steen JT, Ooms ME, Ader HJ, Ribbe MW, van der Wal G. Withholding antibiotic treatment in pneumonia patients with dementia: a quantitative observational study. Arch Intern Med 2002; 162(15):1753-1760.

20. Hoek JF, Ribbe MW, Hertogh CM, van der Vleuten CP. The role of the specialist physician in nursing homes: the Netherlands' experience. Int J Geriatr Psychiatry 2003; 18(3):244-249.

21. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139(9):1136-1139.

22. Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Classificatie van ziekten voor de verpleeghuisgeneeskunde [Classification Codes of Diseases for Nursing Home Medicine]. Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1994.

23. World Health Organization. International Classification of Diseases, 10th Revision (ICD-10). Geneva, Switzerland: World Health Organization; 1992.

24. Steel K, Ljunggren G, Topinkova E, Morris JN, Vitale C, Parzuchowski J et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003; 20(3):211-219.

25. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000; 88(9):2164-2171.

26. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Soc Sci Med 2003; 56(1):95-109.

27. Sneeuw KC, Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. J Clin Epidemiol 2002; 55(11):1130-1143.

28. Novella JL, Jochum C, Jolly D, Morrone I, Ankri J, Bureau F et al. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. Qual Life Res 2001; 10(5):443-452.

29. Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. J Am Geriatr Soc 2000; 48(12):1646-1654.

30. Sneeuw KC, Aaronson NK, Sprangers MA, Detmar SB, Wever LD, Schornagel JH. Evaluating the quality of life of cancer patients: assessments by patients, significant others, physicians and nurses. Br J Cancer 1999; 81(1):87-94.

31. Statistics Netherlands (CBS). Vademecum Health Statistics Netherlands. Voorburg/Heerlen, the Netherlands: Statistics Netherlands (CBS); 2001.

32. Bouter LM, Rosendaal RF. Wrong tracks in methodology [in Dutch]. Ned Tijdschr Geneeskd. 2002; 146: 57-60.

33. Reynolds K, Henderson M, Schulman A, Hanson LC. Needs of the dying in nursing homes. J Palliat Med 2002; 5(6):895-901.

34. DeSilva DL, Dillon JE, Teno JM. The quality of care in the last month of life among Rhode Island nursing home residents. Med Health R I 2001; 84(6):195-198.

5

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

Abstract

The aim of this study was to assess the palliative care for terminally ill (NH) patients in the Netherlands with the Palliative care Outcome Scale (POS).

Methods
A prospective observational study of patients with a life-expectancy of 6 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, particular 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, the assessed outcome of palliative care was fairly good, 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.

Introduction

Most deaths in Western countries concern people who are over 65 years of age. Almost 25% of Americans die in nursing homes (NHs),(1) and in the Netherlands almost 20%.(2,3) NHs provide a supportive environment for their residents and many of these patients receive palliative care until they die. Despite the magnitude and importance of elderly dying in NHs, health policies in general have little concern with regard to the quality of care that is provided for older people.(4) Much research has been focused on younger patients with specific diseases (especially cancer), but very little attention has been paid to 'typical' NH patients, who usually die from the more common complications that are associated with the final stages of a chronic disease, such as pneumonia.(5-12) Little is known about the quality of care at the end-of-life of the elderly and a dearth of research is published on end-of-life care in the NH setting.(13-18) A Pubmed search on ('terminal care' [MeSH terms] or 'life support care' [MeSH terms] or 'palliative care' [MeSH terms]) and 'nursing homes' [MeSH terms] and 'quality of health care' [MeSH terms] for patients aged 65+ years provides only 12 reviews, two RCTs and three editorials in the last ten years.

To gain insight into the various aspects of palliative care for terminally ill NH patients, a prospective observational study was carried out among NH patients with a life-expectancy of six weeks or less. The Palliative care Outcome Scale (POS) was used to evaluate palliative care, since it not only focuses on physical symptoms, but also pays ample attention to the psychosocial aspects of the dying patient.(19) The POS was developed as an outcome measure for patients with advanced cancer and their families, but has not been used in the assessment of patients with non-cancer diseases or dementia. As proxy instrument, caregivers can also assess the POS. The latter can be measured with a slightly adapted version to be completed by the staff. An acceptable agreement between staff and patient ratings has been found.(20)

As communication with the patient and the family is hampered by the presence of cognitive disorders, it could be expected that differences will exist in the POS-scores between patients with and without dementia. Patients with dementia are frequently non-communicative in the later stages and therefore certain items, such as being able to share feelings, may not apply.

As in most countries, about half of the NH population in the Netherlands is principally physically disabled and the other half suffer from a psychogeriatric illness (mostly dementia).(21) The aim of this study was to assess the palliative care that is provided for terminally ill NH patients in the Netherlands, with and without dementia, with the Palliative care Outcome Scale (POS).

Methods

Setting and Design
A prospective nationwide observational study was conducted in 16 Dutch nursing homes (NHs) from November 2001 until March 2003.

Selection of nursing homes
The NHs in the present study were deliberately sampled to be representative of all Dutch NHs. First, the proportion of the three types of NHs was calculated.(22) This proportion was 3:1:1 in the order of combined, those for solely somatic patients, and those for solely psychogeriatric patients. Therefore, the aim was to include nine combined NHs, three NHs for somatic patients and three NHs for psychogeriatric patients. Secondly, the mean number of beds for somatic and psychogeriatric patients per NH was calculated and the NHs were arranged in order of this calculated mean. Finally, the NHs closest above and below the mean were invited to participate in the study.

Selection of patients
In each NH, verbal and written instructions were given to all the NH physicians and they were asked to include all patients (physically disabled and psychogeriatric) who met the following criteria: 1) remaining life-expectancy of six weeks or less, according to their own judgment; and 2) admitted to long-term care or admitted for rehabilitation, but previously transferred to long-term care (during the course of the admittance it became obvious that the patient would not leave the nursing home). Patients who died suddenly and unexpectedly (i.e., with no clear terminal palliative phase) were not included. Patients could be included in the study if a questionnaire was completed on inclusion and the death was registered.

Measurements
On inclusion, the regularly attending NH physician and one attending nurse both completed a questionnaire. The NH physicians registered basic demographics and clinical characteristics. If the patient lived longer than one week, the nurses completed a weekly questionnaire assessing the palliative care.

The stage of dementia was assessed according to the Global Deterioration Scale.(23) This instrument identifies three major clinical phases: forgetfulness, confusion and late dementia. These phases are then further sub-divided into seven clinically identifiable stages, ranging from stage 1 (no cognitive decline) to stage 7 (very severe cognitive decline). Stage 5 represents the phase of early dementia and patients in this stage need some assistance. This stage was defined as the cut-off point between non-demented and demented patients in the present study (stage 1-4: non-demented; stage 5-7: demented).
The validated Dutch Classification Codes of Diseases for Nursing Home Medicine (CvZ-V) was used for the classification of underlying diseases on inclusion.(24) The CvZ-V is a Dutch standard, based on the International Statistical Classification of Diseases and Related Health Problems (ICD-10).(25) However, in addition to the ICD-10, it also contains a 'General' section that allows coding for diseases, disorders and problems that supersede a particular organ system.
The outcome of care was measured with the validated Palliative care Outcome Scale (POS). This scale consists of two almost identical measures, one completed by the staff, and the other by the patient. Agreement between the two measures has proven acceptable.(20) On inclusion, and subsequently on a weekly basis,

nurses completed the POS-Staff version. These questionnaires on inclusion (completed by NH physicians and nurses) and the weekly questionnaire (only completed by nurses), including the POS, were piloted among the NH physicians and nurses over a two-month training period. The main finding of this pilot study was that it was difficult for nurses to give an answer to the POS-Staff questions for severely demented and comatose patients. To prevent bias, two extra response categories, 'unknown' and 'not applicable (e.g., coma or severely demented)', were added to questions 1-9 and the response category 'unknown' was added to question 10.

Both versions (staff and patient) incorporate ten questions concerning the physical, psychological and spiritual domains of life within the field of palliative care. It assesses these domains over the previous three days of care. An eleventh question in both versions invites participants to describe their main problems in free text. Participants score each of the first eight POS-questions on a 5-point Likert scale, ranging from 0 (no problem) to 4 (overwhelming problem).(26) POS-questions 9 and 10 are scored on a 3-point scale (0-2-4) from 0 (good) to 4 (bad). A mean score of 2.0 or below was considered as favourable. The main problems reported in free text (POS-question 11) were categorized by the authors.

Information from the POS can be used to assess improvement or deterioration in a patient's condition or circumstances in one single domain. The total score at the end of the assessment can help to assess and monitor overall well-being and care. The POS can be used to assess the palliative care provided.(27) The POS-Staff version was used in the present study (translated and translated back into Dutch by M. Echteld, psychologist and H. Brandt, social gerontologist) because it was not feasible to interview patients due to (rapid decline in) their physical or mental status.

We made some adaptations in the presentation of the POS, namely we added the labels, e.g., pain, other symptoms, patient anxiety, to improve the readability of the text. The selection of the labels was based on labels previously presented by the authors of the POS.(20)

The occurrence and date of death was registered by the NH physician.

Statistical analysis
SPSS 10.1 for Windows was used for the statistical analyses and descriptive statistics were used to characterise the patients. Non-parametric Mann-Whitney U-tests were used to test the differences between groups in the mean POS scores of patients with and without dementia because it appeared that several POS items were not normally distributed.

The valid POS questionnaire data differed across the respective variables, with the number of variables marked as 'not applicable (e.g., coma or severely demented)' or 'unknown', if the staff did not feel confident in assigning a POS score (0 – 4). POS scores of the latest assessment before death of non-comatose patients, distinguishing between non-demented and demented patients, were included in the analysis. Comatose patients were excluded from the analysis because this group could consist of non-demented and demented patients, but also because it was unclear whether the POS scores referred to the comatose status or to the days

before the patient had become comatose. Patients with no data regarding the stage of cognitive decline and/or state of consciousness were also excluded. A mean total POS score was calculated if data on at least six out of a total of ten items were valid.

Ethical review
The Medical Ethics Committee of the VU University Medical Center approved the study. Confidentiality of the data was guaranteed by providing only coded information to the researchers. Patients or their families were interviewed. Because the NH physicians and nurses were simply reporting information collected as part of the usual care observations, including those needed to score the POS, informed consent was not required by the Medical Ethics Committee of the VU. The patients and their families were informed about the study through an information flyer and were given the possibility to refuse the transfer of data.

Results

In the inclusion period, we received a questionnaire at death from 471 included patients. In the same period, an additional deceased 272 patients were found to have been incorrectly not included in the study. The main reasons for non-inclusion, as reported in a short non-inclusion questionnaire completed by the NH physicians, were in order of frequency: pressure of work, organisational reasons (e.g., should have been included during the weekend), forgotten (to be included), family had objections for inclusion in our study, and other reasons.(28) From 448 patients a complete set of data (questionnaire on inclusion, the weekly questionnaire and the questionnaire at the time of death) was available for analysis.

Table 1 Demographic and clinical characteristics of patients on inclusion (n=448)

Demographic characteristics	n	%
Age on inclusion (in years)		
≤ 60	4	0.9
61 – 69	26	5.8
69 - 80	98	21.9
80 - 90	227	50.7
90 - 100	88	19.6
100 >	5	1.1
Mean age (min-max; SD[a])	83.7 (45 – 100; 8.0)	
Gender		
Male	133	29.7
Female	315	70.3

continue **Tabel 1**

Marital status		
Never married	38	8.6
Married	124	27.9
Widowed	268	60.4
Divorced	14	3.2
Actual living status before admittance to nursing home		
Single	304	68.2
Together, with partner	142	31.8
Number of children		
Children	346	80.5
No children	84	19.5
Clinical characteristics		
Number of days from inclusion until death		
Median (min–max)	3.0 (0 - 62)	
Comatose	89	20.5
Stage of dementia (Global Deterioration Scale[b])		
Stage 1 No cognitive decline	146	34.1
Stage 2 – 4 Very mild to moderate cognitive decline	23	5.4
Stage 5 Moderately severe cognitive decline	29	6.8
Stage 6 Severe cognitive decline	119	27.8
Stage 7 Very severe cognitive decline	111	25.9
Underlying diseases on inclusion (CvZ-V codes[c])	n	%
Mental and behavioral disorders	137	30.6
Diseases of the circulatory system	92	20.5
Diseases of the respiratory system	33	7.4
General disorders	34	7.6
Diseases of the digestive system	27	6.0
Diseases of the nervous system	19	4.2
Diseases of the genitourinary system	17	3.8
Endocrine, nutritional and metabolic diseases	12	2.7
Breast and female genital organs disorders	8	1.8
Remaining systems	17	3.7
Missing	52	11.6
Malignant neoplasms within underlying diseases	47	10.2

[a] SD = standard deviation

[b] The Global Deterioration Scale (GDS) was used to determine the stage of dementia (Reisberg et al. 1982: translation: Verhey F 1986)

[c] Classificatie van Ziekten voor de Verpleeghuisgeneeskunde [Classification Codes of Diseases for Nursing Home Medicine]

The average age on inclusion was 83.7 years, ranging from 45 to 100 years **(Table 1)**. Over two thirds (70.3%) of the decedents were female. Many patients were widowed (60.4%) or single (68.2%) before admittance to the NH. The majority, 80.5%, had children. The median time from inclusion until death was three days. Seven days after inclusion, 83.7% of the patients had died, increasing to 93.5% after fourteen days (data not shown). Most patients (60.5%) had dementia (stage 5-7). The main underlying diseases on inclusion were mental and behavioral disorders (30.6%) and diseases of the circulatory system (20.5%). A malignant neoplasm was known to be an underlying disease in only 10.2% of the study population.

The assessment of the POS varied considerably per POS-item from 29.4% to 92.0% of patients **(Table 2)**. Patients were rated least in the items patient anxiety (Q3), support (Q6), life worthwhile (Q7), self-worth (Q8) and personal affairs (Q10). Non-scores were more frequently 'not applicable' than 'unknown', except for family anxiety (Q4), self-worth (Q8) and personal affairs, which were more frequently 'unknown'. The number of missing for POS assessment was very low in all ten items, the highest of which was 2.2%.

The assessed POS items of non-demented patients ranged from 45.5% to 96.2% and from 18.3% to 89.2% in patients with dementia. In addition, in patients with dementia the items were more frequently rated as 'not applicable'. For all ten POS items non-demented patients had higher percentages of assessment. The assessment of POS items patient anxiety (Q3), support (Q6), life worthwhile (Q7) and self-worth (Q8) was for patients with dementia 50% lower than for non-demented patients.

Within the group of patients with dementia (stage 5, 6 and 7 of the Global Deterioration Scale) non-scores were, in order of sequence of the stage of dementia, for seven out of ten items highest in patients with stage 7 dementia. In patients with stage 5 dementia, the nurses were less knowledgeable about whether the patient's illness-related personal affairs (Q10) had been adequately addressed, compared to patients with stage 6 or 7 dementia. However, in patients with stage 6 dementia, compared to patients with stage 5 or 7 dementia, non-scores were higher for family anxiety (Q4) and the given information (Q5) (data not shown).

Very little difference was found between the mean POS scores of non-demented and demented patients **(Table 3)**. In only one of the ten items was there a statistically significant difference between these groups: patients with dementia scored half a point less favourable on 'support' (P=0.030). For 'life worthwhile' half a point higher (less favourable) for patients with dementia, but this difference was not statistically significant (P=0.069).

Mean scores for non-demented and demented patients, equal to 2.0 and more favourable, were found for pain (Q1), other symptoms (Q2), patient anxiety (Q3), information Q5), support (Q6), wasted time (Q9) and personal affairs (Q10). Unfavourable mean scores were found for non-demented and demented patients for family anxiety (Q4), life worthwhile (Q7) and self-worth (Q8).

Nurses rarely described problems of patients in the free text area. They reported most frequently 'medical problems' (without specification), followed by pain, problems with the intake of fluid and nutrition and shortness of breath.

The mean total POS score for non-demented patients was 1.53 (SD 0.57) and for patients with dementia it was 1.48 (SD 0.57) (P=0.575). When analysed for patients with dementia separately, i.e., stage 5, 6 and 7 of the Global Deterioration Scale, the mean total scores were 1.74 (SD 0.50), 1.43 (SD 0.52), 1.44 (SD 0.69), respectively (data not shown).

Table 2 Assessment of the Palliative care Outcome Scale (POS) of non-demented and demented patients in a nursing home population (n = 328)[20]

Over the past three days:	Total population (n = 328)				Non-demented (n=133)			Demented (n = 195)		
	POS score[a] 0-4 (%)	Non-scores[b] Not applicable (%)	Unknown (%)	Missing (%)	POS score[a] 0-4 (%)	Non-scores[b] Not applicable (%)	Unknown (%)	POS score[a] 0-4 (%)	Non-scores[b] Not applicable (%)	Unknown (%)
Q1 Has the patient been affected by pain? (Item1: pain)	83.6	11.4	4.9	1.3	91.7	2.3	6.1	78.1	17.7	4.2
Q2 Have other symptoms e.g., nausea, coughing or constipation seemed to be affecting how well they feel? (Item2: other symptoms)	83.4	13.8	2.8	1.1	95.5	3.8	0.8	75.0	20.8	4.2
Q3 Have they been feeling anxious or worried about their illness or treatment? (Item3: patient anxiety)	54.1	26.6	19.3	0.7	74.4	6.8	18.8	40.2	40.2	19.6
Q4 Have any of their family or friends been anxious or worried about the patient? (Item4: family anxiety)	92.0	2.1	5.8	0.9	96.2	0.0	3.8	89.2	3.6	7.2
Q5 How much information has been given to the patient and their family or friends (Item5: information)	87.9	11.1	0.9	2.2	95.5	3.0	1.5	82.7	16.8	0.5
Q6 Has the patient been able to share how they are feeling with their family or friends (Item6: support)	57.2	35.3	7.5	2.2	81.1	10.6	8.3	40.4	52.7	6.9
Q7 Do you think they have felt life was worth living? (Item7: life worthwhile)	33.4	34.4	32.2	1.3	48.1	9.0	42.9	23.2	52.1	24.7
Q8 Do you think they have felt good about themselves? (Item8: self-worth)	29.4	33.4	37.2	1.8	45.5	8.3	46.2	18.3	50.8	30.9
Q9 How much time do you feel has been wasted on appointments relating to healthcare of this patient, e.g., waiting around for transport or repeating tests? (Item9: wasted time)	73.8	19.1	7.1	0.9	83.2	9.9	6.9	67.5	25.3	7.2
Q10 Have any practical matters resulting from their illness, either financial or personal, been addressed? (Item10: personal affairs)	55.2	--.-	44.8	0.2	62.4	--.-	37.6	50.3	--.-	49.7

[a] Questions 1–8: range 0 (no problems) to 4 (overwhelming problems). Questions 9 and 10: scores 0, 2 or 4, with higher scores indicating more practical problems

[b] Not present in original POS scale

Table 3 Mean Palliative care Outcome scores[a] for non-demented and demented patients[20] (n=328)

	Mean (SD[b]) Non-demented[d] (n=range 60–128)	Mean (SD[b]) Demented[e] (n=range 35–173)	P-value[c]
Over the past 3 days:			
Q1 Has the patient been affected by pain? (Item1: pain)	1.8 (1.3)	1.9 (1.2)	.565
Q2 Have other symptoms e.g. nausea, coughing or constipation seemed to be affecting how well they feel? (Item2: other symptoms)	1.6 (1.3)	1.4 (1.2)	.221
Q3 Have they been feeling anxious or worried about their illness or treatment? (Item3: patient anxiety)	2.0 (1.3)	1.6 (1.4)	.113
Q4 Have any of their family or friends been anxious or worried about the patient? (Item4: family anxiety)	2.9 (1.2)	2.9 (1.2)	.431
Q5 How much information has been given to the patient and their family or friends? (Item5: information)	0.1 (0.3)	0.2 (0.6)	.670
Q6 Has the patient been able to share how they are feeling with their family or friends? (Item6: support)	1.5 (1.5)	2.0 (1.5)	.030
Q7 Do you think they have felt life was worth living? (Item7: life worthwhile)	2.3 (1.6)	2.8 (1.6)	.069
Q8 Do you think they have felt good about themselves? (Item8: self worth)	2.7 (1.4)	2.9 (1.4)	.523
Q9 How much time do you feel has been wasted on appointments relating to the healthcare of this patient, e.g. waiting around for transport or repeating tests? (Item9: wasted time)	0.3 (0.9)	0.3 (0.8)	.822
Q10 Have any practical matters resulting from their illness, either financial or personal, been addressed? (Item10: personal affairs)	0.4 (0.9)	0.2 (0.7)	.195

Table 4 Palliative care Outcome Scale: mean total scores according to sociodemographic characteristics for non-demented and demented patients (n=266)[20]

	Mean[a] Non-demented[c] (n=115)	Mean[a] Demented[d] (n=99)	P-value[b]
Age (years)			
< 80	1.6	1.4	.128
> 80	1.5	1.5	.474
Gender			
Male	1.6	1.6	.969
Female	1.5	1.4	.775
Marital status			
Married	1.6	1.7	.717
Not married	1.5	1.4	.631
Actual living status before admittance to nursing home			
Together, with partner	1.7	1.7	.921
Single	1.5	1.4	.678
Number of children			
Children	1.5	1.5	.566
No children	1.5	1.7	.405

No significant difference in sociodemographic characteristics was found between non-demented and demented patients **(Table 4)**. In both groups all mean total scores were favourable, and below 2.0. The mean total scores for sociodemographic characteristics in non-demented patients varied only from 15 to 17, and in demented patients from 14 to 17.

Discussion

This is the first study that describes the provided palliative care in the last days of the life of nursing home (NH) residents, who were mainly non-cancer patients. The Palliative care Outcome Scale (POS) was used to assess the key domains in the provision of palliative care.(20) Furthermore, the usefulness of the POS was evaluated in a NH population including patients with dementia. For this specific study population, two extra options were added to the POS items, i.e., 'not applicable' and 'unknown'. These 'non-scores' were often found in the POS-items patient anxiety, support, life worthwhile and self-worth, but it was also frequently unknown whether the patient's illness-related personal affairs had been addressed. The assessment of the POS for demented patients was lower than that for non-demented patients, especially for items as patient anxiety, support, life worthwhile and self-worth. The POS was originally developed to assess patients in the stages of advanced cancer. In spite of the opportunity to rate an item with two extra options (non-scores), the results of this study show that the POS can also be used to assess at least a considerable subgroup of demented patients. Further research is needed to determine to what stages of dementia can be assessed with the POS. The present data suggest that stage 7 of the Global Deterioration Scale (GDS) is questionable. For seven out of the ten POS items non-scores were higher for stage 7 dementia than for stages 5 and 6.

Specific mean POS scores were favourable for both non-demented and demented patients.
Pain (Q1) and other symptoms (Q2) seemed to be under control, the given information was sufficient (Q5), little time was wasted on health care (Q9) and personal affairs (Q10) were adequately addressed. Differences in mean POS scores between the two groups were small and most of the differences were observed in the items subjective aspects support, life worthwhile and self-worth. Regarding these items the nurses on average more often assigned a negative score to demented patients than to non-demented patients. An important statistically significant difference concerned the POS-item support (Q6): demented patients were less able to share their feelings with family and friends. This can be expected because of the inability of demented patients to communicate their needs and level of distress verbally. Volicer et al. remarked that evaluation of the care that is provided for cognitively impaired patients relies on non-verbal communication.(29) Equally unfavourable POS scores for both groups were found for family anxiety (Q4). When the mean total POS score was analysed according to sociodemographic characteristics for non-demented and demented patients, no significant differences were found between these two groups.
This study has some limitations. The main limitation was that the study relied on the reports of proxies, namely care-givers. These proxies may have under-reported or over-reported the patient's symptoms and preferences for palliative care and knowledge of the patient's experiences relies on the reports made by these care-givers. Several studies have evaluated the use of proxy reports on the quality of life, respectively the quality of care, in elderly patients with and without

dementia.(30-34) In general, these studies focusing on the reliability of proxy ratings show different outcomes. Assessments made by significant others and health care providers are reasonably accurate and nurses may be the most suitable source of proxy information. Fairly good agreements between patient and proxy are reported with regard to physical functioning and cognitive status, but agreement is poorest for subjective aspects of the patient's experience, such as pain, anxiety and depression. In patients with dementia, agreement decreased with increasing severity of the dementia and therefore proxy assessments should be interpreted with caution.(32) However, the strengths of this study are its large-scale design and its prospective character, which both enhance the validity and reliability of the findings.

The results of this study indicate that fairly good palliative care is provided in the last days of life of patients in Dutch NHs, irrespective of their cognitive status and other characteristics, such as gender and age. Symptom control, a key point of attention in palliative care, seemed to receive sufficient attention. This appears to contradict with the results from other studies concluding that nursing home residents do not receive optimal palliative care.(16) We acknowledge that there is a possibility that in our study staff may have over estimated the outcome of the care they provided and that older people tend to underreport their symptoms.(4) Whereas the physical aspects (pain and other symptoms) of palliative care were adequately addressed, most shortcomings occurred in the more subjective, less observable psychosocial (patient anxiety) and spiritual domains (support, life worthwhile and self-worth). Especially in the spiritual domain, there is known to be an unmet need among patients during the dying process. The low score on 'life worthwhile' can be expected. The view is probably subjective of a carer's view of the deterioration of the patient and not necessarily the view of the patient. Reynolds et al. found in their study that 30% of dying NH residents needed more care for their emotional and spiritual needs.(17)

This study underscores again the fact that greater attention must be paid to psychosocial and spiritual aspects in the dying process of NH patients. Policy- and decision-makers should pay more attention to these psychosocial and spiritual aspects of palliative care. In order to develop high-quality care towards the end of life, psychosocial and spiritual care should be more integrated in the continuing professional education of health professionals working with the dying patient.

References

1.   Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L et al. Advance care planning and end-of-life care for hospitalized nursing home residents. J Am Geriatr Soc 2002; 50(5): 829-835.
2.   Prismant/Arcares. Verpleeghuizen in Cijfers 2000. [Statistical Data on Dutch Nursing Homes 2000]. Utrecht, the Netherlands: Prismant/Arcares; 2002.
3   Statistics Netherlands (CBS). Vademecum Health Statistics Netherlands. Voorburg/Heerlen, the Netherlands: Statistics Netherlands (CBS); 2001.
4.   World Health Organization. Better Palliative Care for Older People. Denmark: World Health Organization; Copenhagen 2004.
5.   Aangenendt-Siegers IP, Cools HJ. [Cause of death in nursing homes]. Ned Tijdschr Geneeskd 1992; 136(41): 2015-2017.
6.   Beard CM, Kokmen E, Sigler C, Smith GE, Petterson T, O'Brien PC. Cause of death in Alzheimer's disease. Ann Epidemiol 1996; 6(3): 195-200.
7.   Boersma F, Van Den Brink W, Deeg DJ, Eefsting JA, Van Tilburg W. Survival in a population-based cohort of dementia patients: predictors and causes of mortality. Int J Geriatr Psychiatry 1999; 14(9): 748-753.
8.   Burns A, Jacoby R, Luthert P, Levy R. Cause of death in Alzheimer's disease. Age Ageing 1990; 19(5):341-344.
9.   Koopmans RT, van Hell ME, de Jongh F, Froeling PG, van den Hoogen HJ, van Weel C. [The course of Alzheimer's disease in a group of nursing home patients: epidemiology, (co)morbidity and mortality]. Ned Tijdschr Geneeskd 1991; 135(19): 845-850.
10. Molsa PK, Marttila RJ, Rinne UK. Survival and cause of death in Alzheimer's disease and multi-infarct dementia. Acta Neurol Scand 1986; 74(2): 103-107.
11. Muder RR. Pneumonia in residents of long-term care facilities: epidemiology, etiology, management, and prevention. Am J Med 1998; 105(4): 319-330.
12. Thomas BM, Starr JM, Whalley LJ. Death certification in treated cases of presenile Alzheimer's disease and vascular dementia in Scotland. Age Ageing 1997; 26(5): 401-406.
13. Baer WM, Hanson LC. Families' perception of the added value of hospice in the nursing home. J Am Geriatr Soc 2000; 48(8): 879-882.
14. Kayser-Jones J. The experience of dying: an ethnographic nursing home study. Gerontologist 2002; 42 Spec No 3: 11-19.
15. Lynn J, Teno JM, Phillips RS, Wu AW, Desbiens N, Harrold J et al. Perceptions by family members of the dying experience of older and seriously ill patients. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. Ann Intern Med 1997; 126(2): 97-106.
16. Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. Arch Intern Med 2004; 164(3): 321-326.
17. Reynolds K, Henderson M, Schulman A, Hanson LC. Needs of the dying in nursing homes. J Palliat Med 2002; 5(6): 895-901.
18. Singer PA, Bowman KW. Quality care at the end of life. BMJ 2002; 324(7349): 1291-1292.

19. Stromgren AS, Groenvold M, Pedersen L, Olsen AK, Sjogren P. Symptomatology of cancer patients in palliative care: content validation of self-assessment questionnaires against medical records. Eur J Cancer 2002; 38(6):788-794.
20. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. Qual Health Care 1999; 8(4): 219-227.
21. Ribbe MW, Ljunggren G, Steel K, Topinkova E, Hawes C, Ikegami N et al. Nursing homes in 10 nations: a comparison between countries and settings. Age Ageing 1997; 26 Suppl 2: 3-12.
22. Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Jaarboek Verpleeghuizen 1997 [SIG Nursing Home Information System Annual Report Nursing Homes 1997]. Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1998.
23. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139(9): 1136-1139.
24. Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Classificatie van ziekten voor de verpleeghuisgeneeskunde [Classification Codes of Diseases for Nursing Home Medicine]. Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1994.
25. World Health Organization. International Classification of Diseases, Tenth Revision (ICD-10). Geneva, Switzerland: World Health Organization; 1992.
26. Horton R. Differences in assessment of symptoms and quality of life between patients with advanced cancer and their specialist palliative care nurses in a home care setting. Palliat Med 2002; 16(6): 488-494.
27. Hughes R, Aspinal F, Addington-Hall J, Chidgey J, Drescher U, Dunckley M et al. Professionals' views and experiences of using outcome measures in palliative care. Int J Palliat Nurs 2003; 9(6): 234-238.
28. Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients. Arch Intern Med 2005; 165: 314-320.
29. Volicer L, Hurley AC, Blasi ZV. Scales for evaluation of end-of-life care in dementia. Alzheimer Dis Assoc Disord 2001; 15(4):194-200.
30. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Soc Sci Med 2003; 56(1):95-109.
31. Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. J Am Geriatr Soc 2000; 48(12):1646-1654.
32. Novella JL, Jochum C, Jolly D, Morrone I, Ankri J, Bureau F et al. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. Qual Life Res 2001; 10(5): 443-452.
33. Sneeuw KC, Aaronson NK, Sprangers MA, Detmar SB, Wever LD, Schornagel JH. Evaluating the quality of life of cancer patients: assessments by patients, significant others, physicians and nurses. Br J Cancer 1999; 81(1): 87-94.

34.   Sneeuw KC, Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. J Clin Epidemiol 2002; 55(11): 1130-1143.

6

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

Abstract

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.

Introduction

The last days of life have been the subject of many studies, almost all concerning patients with cancer.(1;2) However, the majority of elderly people do not die from cancer, but from 'old age' and/or complications in the end-stage of chronic disease. Dementia, cardiac disease and respiratory disease, in particular, are frequent causes of death,(3) but the nature and burden of symptoms associated with the terminal phase of these diseases is still unclear.(4) Many non-cancer patients are cared for in long-term care facilities, such as nursing homes (NHs), but the available data suggest that the pattern of their symptoms in the terminal phase differs from that of cancer patients. In the last 48 hours of life of NH patients, pain and respiratory symptoms have been found to be the most prevalent symptoms, but the pattern of symptoms may be determined by the underlying disease.(5) For example, in demented patients, pneumonia, cachexia and dehydration are often the direct cause of death.(6-8) Unconsciousness may be the result of metabolic and physiological disturbances, directly or indirectly related to the underlying disease, or the intended or unintended result of medication.(9) Remarkably, there is very little literature on the prevalence of loss of consciousness in the terminal phase.

The objective of this paper 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 NH patients. Symptom management as such was not the scope of this paper. However, knowledge of the symptoms associated with the terminal phase in NH patients may help to improve the quality of dying.(10;11) In addition, attention was paid to the state of consciousness.

Methods

Setting and design
A prospective, observational study was conducted from November 2001 to March 2003. In 2000, there were 334 nursing homes (NHs) in the Netherlands, with a total of 58 778 beds.(12) Three types of NHs exist: physically ill, psychogeriatric patients, and combined types with separate wards for each category. The vast majority (96%) of psychogeriatric patients suffer from dementia, and will stay in an NH until they die.(13) All patients benefit from the different NH functions, mainly rehabilitation and long-term care (admitted to the NH permanently,[14]). The staff includes specially trained NH physicians (in general one full-time physician per 100 patients), who provide medical care and are employed by the NH.(15)

The NHs in the present study were purposefully sampled to be representative of all NHs in the Netherlands. First, the proportion of the three types of NHs was calculated: nine combined NHs, three for physically ill patients, and three for psychogeriatric patients. Second, the mean number of beds for physically ill and psychogeriatric patients per NH was calculated, and the NHs were arranged in order of this calculated mean. Finally, the nearest NHs above and below the mean

were invited to participate in the study. In order to obtain the participation of nine combined NHs, three NHs for physically ill and three NHs for psychogeriatric patients, the following numbers of NHs had to be approached: 30 combined NHs, eight for physically ill patients and seven for psychogeriatric patients.

During the course of the data collection, due to organizational and capacity problems, one NH for physically ill patients stopped collecting the data. For the remaining time of the data collection, another NH from the same stratum replaced this NH. Hence, the total number of participating NHs was 16. In this study, the average number of NH beds was 103 for physically ill patients, 156 for psychogeriatric patients and 157 for combined care. The beginning and end dates of the data collection varied per NH, with an average inclusion period of 0.9 years and 2430 bed years.

Selection of patients

This study was introduced during instruction sessions in each NH by the first two authors (HB, MEO), written instructions were also provided. The NH physicians were asked to include all consecutive patients who met the following criteria: (1) Maximum life-expectancy of six weeks, according to the NH physician's own clinical assessment; (2) Admitted for long-term care (admitted to the NH permanently[14]), or (3) Previously admitted for rehabilitation but, transferred to long-term care during their stay (ie, it became obvious that the patient would not leave the NH). Patients who died suddenly and unexpectedly (ie, with no clear terminal palliative phase) were not included.

Admittance to a NH for terminal care is handled differently in different countries. In the Netherlands, the limit is set at three months, due to reimbursement by health care insurance companies. In the pilot study, the NH physicians considered that a weekly follow-up registration of three months with a maximum follow-up of six months, was not feasible. After the pilot study, based on a maximum life-expectancy of six weeks, the participating (experienced) NH physicians agreed that this criterion was the longest possible period over which any meaningful prediction could be made.

Measurements

The occurrence and date of death was registered by the NH physician for all long-term care patients, including patients who had not been included in the study, for whom a shorter questionnaire was completed. In this short questionnaire, we checked the reason for non-inclusion: (1) sudden and unexpected death; (2) should have been included earlier; (3) other, namely. The patients included under (2) were 'missed' patients of whom the NH physician was asked in a separate question why these patients were not included earlier. The main direct cause of death was assessed with a question analogous to the cause-of-death question on Dutch death certificates.(16) When a patient was included, the NH physician completed a questionnaire on the basic demographics and clinical characteristics of the patient. The stage of dementia was assessed according to the validated Global Deterioration Scale (GDS).(17) This instrument identifies three major clinical phases: forgetfulness, confusion, and a late dementia phase. These phases are

further sub-divided into seven clinically identifiable stages, ranging from stage 1 (no cognitive decline) to stage 7 (very severe cognitive decline). Stage 5 represents the phase of early dementia, and patients in this stage can no longer survive without some assistance. Written information about the characteristics of these seven stages was provided to the NH physician for adequate assessment.

The validated Classification of Diseases for Nursing Home Medicine (CvZ-V),(18) was used to classify the main underlying cause of the terminal status on inclusion and the main direct cause of death. The CvZ-V is a Dutch standard, based on the International Classification of Diseases, tenth edition (ICD-10).(19) However, unlike the ICD-10, the CvZ-V contains a general section with codes for diseases, disorders, and problems that supersede one particular organ system, as this situation is common in NH patients.

After the death of each patient, the NH physician assessed retrospectively, over two time-periods (48-24 and 24-0 hours before death), a number of physical and psychosocial symptoms according to the Edmonton Symptom Assessment Scale (ESAS) and the observational Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC draft 1.8). This instrument has recently been developed for inclusion in the RAI instruments.(20) Draft 1.8 was prior to the final validation of this instrument, but changes were negligible. Before every assessment, the NH physicians could indicate in the questionnaire whether or not a patient was conscious. RAI MDS-PC items were assessed in conscious as well as unconscious patients, but ESAS items were only assessed in conscious patients. The validated ESAS consists of nine 100 mm visual analogue scales (VASs), which include pain, activity, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. Scores can range from 0-100 (higher scores reflect greater symptom severity).(21) A symptom was considered to be burdensome at a cut-off point of 60 or more on this scale.

There are 19 physical symptoms/conditions listed in the RAI MDS-PC. From these, 15 were selected because the other four symptoms corresponded with the ESAS (shortness of breath at rest, shortness of breath with exertion, impaired endurance and loss of appetite). Four symptoms were added (death rattle, fatigue, confusion and pressure ulcer), and these were assessed in a similar manner as the RAI MDS-PC items. To prevent bias in the scoring of variables by the NH physician, the extra response category 'unknown/not assessed' was added to all ESAS and RAI MDS PC items.

NH physicians and family members rated the quality of death on a VAS, ranging from 0 (no gentle death) to 100 (gentle death). After death of their loved one, family members received a questionnaire (sent by mail or handed over during an aftercare conversation with the NH physician) about the quality of care, in which they could among others assess the quality of death.

Statistical analysis
All analyses were performed in SPSS for Windows version 11.0, and descriptive statistics were used to characterize the patients. As most symptom data were

missing for the unconscious patients, the analyses were limited on symptom development in patients who were conscious at both time points, 48-24 and 24-0 hours before death (n=253).

The outcome variables of the ESAS items and the VAS concerning the quality of death were screened for normality. Standard transformations were made, if necessary. Two selection criteria were applied for the symptoms in both instruments. First, a selection of symptoms was made, which were considered to be burdensome in the last 48 hours of life: six out of nine items of the ESAS - pain, nausea, depression, anxiety, well-being and shortness of breath; and the RAI MDS-PC item - difficulty coughing, constipation, diarrhea, dry mouth, nausea/vomiting, end-stage restlessness, offensive odor to patient/family, pruritus, urinary retention and fatigue.

Second, ESAS items were considered to be burdensome at a cut-off point of 60 or more on the VAS, range 0-100 (eg, 0 = no pain; 100 = extreme pain). This dichotomization is an analytical classification, in order to provide data on frequencies on burdensome symptoms, since higher scores reflect greater symptom severity. Differences between VAS scores were determined with paired-samples t-test or Wilcoxon signed ranks test, if necessary. RAI MDS-PC response categories (0=not present; 1=present, not distressed; 2=present, distressed) were dichotomized: 0 and 1 were combined to category 1, and 2 was category 2. Since the patient was distressed by the symptoms in the latter category, they were considered burdensome. Differences between dichotomized items were tested with the McNemar test for two related samples.

Ethical review

The Medical Ethics Committee of the VU University Medical Center approved the study. Confidentiality of the data was guaranteed by providing only coded information to the researchers. Neither the patients nor members of their family were interviewed. Because the NH physicians were simply reporting information that was collected as part of their usual care observations, informed consent was not required. As required by Dutch law, the patients and their families were informed about the study through an information flyer, and were given the option to refuse the transfer of data.

Results

A total of 463 patients were included. Patients who died suddenly (n=263), who recovered unexpectedly (n=57) and those who survived the maximum follow-up period of 12 weeks (n=1) were excluded from the study. Representative sampling in this study was checked against two parameters: the distribution of physically ill and psychogeriatric patients and sex. No significant differences were found between the national NH population and the study population for either parameter.(22) An additional 272 patients were found to have been incorrectly not included in the study and were considered as 'missed' patients. The main reasons for non-inclusion, given in the shorter questionnaire in order of sequence by the NH physicians, were pressure of work, organizational reasons (eg, should have been

included during the weekend), forgotten (to be included), other reasons, family had objections to inclusion in our study.(22)

Table 1 presents the demographic and clinical characteristics of the patients on inclusion. The average age on inclusion was 83.4 years, with a range from 45 to 100 years and over two thirds (70.8%) of the patients were female. Most of the patients were single (67.6%) on admittance to the NH. On inclusion, 34.4% had no cognitive decline (normal clinical appearance), 13.3% had very mild (phase of forgetfulness) to moderately severe (phase of early dementia) cognitive decline, 26.5% had severe cognitive decline (middle phase of dementia) and 25.8% had very severe cognitive decline (late dementia). The main underlying causes of terminal status on inclusion were mental and behavioural disorders (30.5%) and diseases of the circulatory system (20.1%). Malignant neoplasms (11.1%) occurred most frequently in the digestive system (3.1%), breast and female genital organs (2.1%), or were coded as general disorders (1.9%). The median time from inclusion until death was three days, but with a wide range (0-62). Of the 463 patients, after one week (0-8 days) 384 (82.9%) had died and 79 were alive. After two weeks (8-15 days), 35 patients were alive, and after three weeks (15-22 days), 20 patients were alive.

Table 1 Demographic and clinical characteristics of patients on inclusion (N=463)

Demographic characteristics	n	%
Age on inclusion (years)		
Mean age (min-max; SD)	83.4 (45-100; 8.2)	
Gender		
Male	136	29.2
Female	330	70.8
Actual living status before admittance to nursing home		
Single	311	67.6
Together, with partner	149	32.4
Clinical characteristics		
No. of days from inclusion until death		
Median (min–max)	3.0 (0-62)	
Stage of dementia (Global Deterioration Scale)		
Stage 1 No cognitive decline (normal clinically appearance)	152	34.4
Stage 2 Very mild cognitive decline (phase of forgetfulness)	4	0.9
Stage 3 Mild cognitive decline (earliest clear-cut clinically deficits)	9	2.0
Stage 4 Moderate cognitive decline (clear-cut deficit is apparent)	12	2.7
Stage 5 Moderately severe cognitive decline (phase of early dementia)	34	7.7
Stage 6 Severe cognitive decline (middle phase of dementia)	117	26.5
Stage 7 Very severe cognitive decline (late dementia)	114	25.8

continue **Table 1**

Main underlying cause of terminal status on inclusion (with separate statement of malignant neoplasms, including secondary malignant neoplasm)		
Mental and behavioural disorders	141	30.5
- Malignant neoplasms	0	0.0
Diseases of the circulatory system	93	20.1
- Malignant neoplasms	0	0.0
Diseases of the respiratory system	36	7.8
- Malignant neoplasms	6	1.3
General disorders	34	7.3
- Malignant neoplasms	9	1.9
Diseases of the digestive system	27	5.8
- Malignant neoplasms	15	3.1
Diseases of the nervous system	19	4.1
- Malignant neoplasms	2	0.4
Diseases of the genitourinary system	19	4.1
- Malignant neoplasms	2	0.4
Endocrine, nutritional and metabolic diseases	14	3.0
- Malignant neoplasms	0	0.0
Breast and female genital organs	10	2.1
- Malignant neoplasms	10	2.1
Other systems	18	4.0
- Malignant neoplasms	9	1.1
Missing	52	11.2

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 cerebrovasculair diseases	11	2
Other	107	23
Missing	5	1

[a] Only data on diseases 2% above the diseases in the total study population are presented

Table 2 shows the main direct causes of death in these NH patients, as reported by the NH physician. The most prevalent causes of death were pneumonia (17%), renal failure (13%), disorders of electrolyte and fluid balance, not classified elsewhere (= dehydration) (13%), cachexia (11%) and heart failure (8%). The remaining diseases accounted for < 4%.

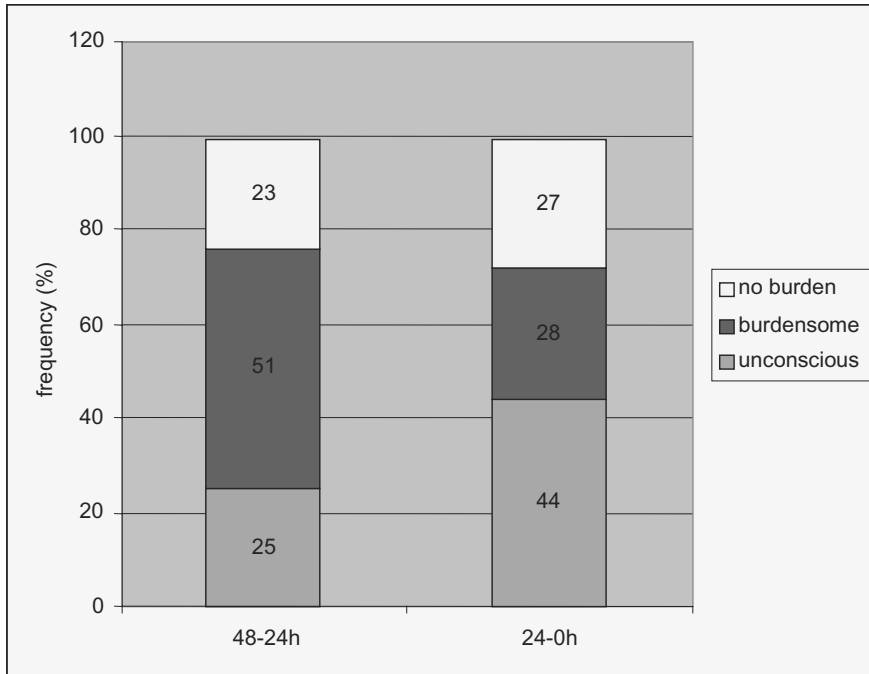**Figure 1**   Prevalence of unconsciousness and burdensome symptoms (n=463)

Figure 1 shows the prevalence of unconsciousness and one or more burdensome symptom(s) in patients in the last two days of their life. Some 12% of patients, assessed with 'no burden' 48-24 hours before death (23%), developed burdensome symptoms 24 hours before death (data not shown).

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

Symptoms	48-24 hours before death			24-0 hours before death			P-value
	median score	% (> 60 on VAS)		median score	% (> 60 on VAS)		
Pain	20.0	30		12.0	22		0.000
Decreased activity	90.0	86		95.0	91		0.000
Nausea	5.0	17		4.0	17	**	0.001
Depression	10.0	30	***	5.0	33	***	0.000
Anxiety	13.0	25		10.0	21		0.000
Increased drowsiness	77.0	69		90.0	82		0.000
Poor appetite	95.0	92		97.0	93	**	0.000
Well being	67.5	66	***	52.0	61	****	0.003
Shortness of breath	10.0	21		10.0	23		0.131

[a] Frequencies of symptoms on the Visual Analogue Scale (VAS) at a cut-off point of 60> = burdensome

[b] Range 0 mm (lowest degree of symptoms) – 100 mm (highest degree of symptoms) for all symptoms ESAS items were only assessed in conscious patients

[c] Conscious 48-24 and 24-0 hours before death

** Missing data 10-20%

*** Missing data 20-30%

**** Missing data 30-34%

Table 3 shows the assessment of ESAS items for patients who were conscious 48-24 hours before death, as well as 24-0 hours before death. The median VAS scores for pain, nausea, depression, anxiety and shortness of breath were low (favorable), but the score for the frequency of one or more burdensome symptom(s) (> 60) at both points in time remained at 17-33%, eg, pain 30→22%, depression 30→33%, shortness of breath 21→23%. The median score of decreased activity, increased drowsiness and poor appetite worsened towards death. Out of nine ESAS symptoms, eight showed a statistically significant difference across the last two days; median score of five symptoms (pain, nausea, depression, anxiety and well-being) were decreasing and three (decreased activity, increased drowsiness, poor appetite) were increasing. Shortness of breath remained the same.

Table 4 Prevalence (%) of dichotomized symptoms of the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC) in the last two days of the life of conscious patients[a] (n=253)

Symptoms	48-24 hours before death Present, distressed (%)	24-0 hours before death Present, distressed (%)	P-value
Difficulty coughing	14	6	0.000
Dry mouth	12	6	0.002
Fever	7[c]	2[c]	0.004
Infections (eg, pneumonia, UTI)	17[c]	10	0.004
Fatigue[b]	28[c]	17[c]	0.000
Pressure ulcer[b]	14	8	0.001

[a] Conscious 48-24 hours as well as 24-0 hours before death

[b] Additional symptoms not listed in RAI MDS-PC, but assessed similarly

[c] Missing data 11-19%

Table 4 shows the prevalence of dichotomized RAI MDS-PC items (category 2: present, distressed). At both points in time, the prevalence of three out of 16 symptoms remained higher than 10% (end-stage restlessness, infections, fatigue) and for five symptoms it was higher than 5% (difficulty coughing, dry mouth, death rattle (excessive pulmonary secretions), confusion, pressure ulcer) (data not shown). Statistically significant differences between the two time-points were found for difficulty coughing (P =0.000), dry mouth (P =0.002), fever (P =0.004), infections (P =0.004), fatigue (P =0.000) and pressure ulcer (P =0.001), all of which improved.

Figure 2 shows the score for the quality of death, assessed by the NH physician on a VAS, ranging from 0 (no gentle death) to 100 (gentle death), was over 50 for 92% (n=427) of the patients. The state of consciousness 24-0 hours before death had a slightly significant influence on this assessment (P =0.001), with a score of over 50 for 96% of the unconscious patients and 90% of the conscious patients. The score for the quality of death by family members was over 50 for 89.5% (n=221) of the patients.

Figure 2 Quality of death assessed by the Nursing Home Physician of total population (N=463)
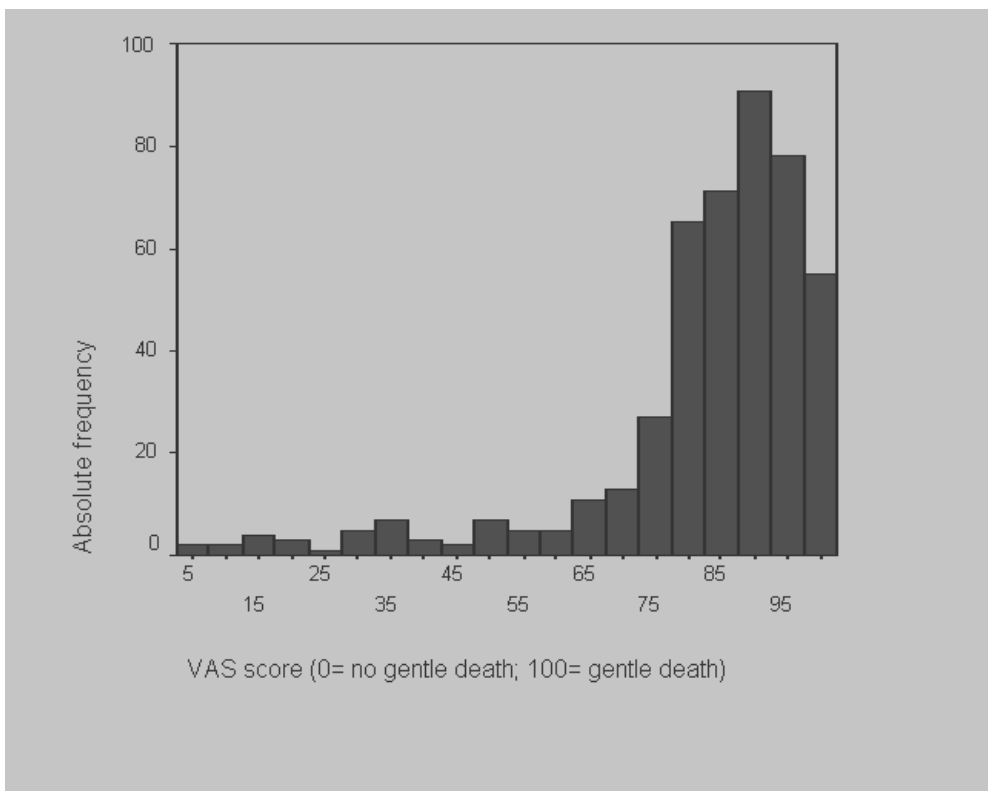
Discussion

Very little research has focused on the experience of dying in nursing homes (NHs).(23) To our knowledge, this is the first study of NH patients that explores the state of consciousness prior to death and provides insight into the final 48 hours of life with regard to the direct causes of death and the physical and psychological symptoms that burden these patients. It gives detailed and robust information about the final phase of the life of an increasing number of older people with a chronic disease. The large-scale study design and the representativeness of the NHs enhance the validity and reliability of these findings, except for the unconscious patients, for whom too many missings were registered on symptoms.

However, this study has some limitations. Firstly, the use of proxy data may have resulted in under- or over-estimation of symptoms, which could have influenced the validity of the data. Symptoms were retrospectively assessed by the NH physicians. Self rating scores of patients was not possible, since the exact time of death is not to foreseen. Therefore, proxy rating was the only feasible approach and the ESAS was the best alternative. In general, proxy ratings of symptoms that are directly observable (physical health, disability) are more valid than proxy ratings of more subjective symptoms, such as pain, anxiety, depression and dyspnea.(24-28) In this study, ESAS items have been assessed, which were considered to be potentially burdensome in the last 48 hours of life: pain, nausea, depression, anxiety, well-being and shortness of breath. Nekolaichuk et al., reported in their study on comparison of patient and proxy symptom assessment with the ESAS, that proxy assessments of symptom intensity, particularly by physicians, were generally lower than patient assessments.(29) This indicates an underestimation of symptom intensity in this study. However, the ESAS is an instrument for patient and proxy assessment.(30) Our analyses were not focused on the value of the symptom itself, but on changes within symptoms. Scoring has been consistent and, therefore, allows interpretation. Second, the inclusion of patients could also have been subjected to selection bias. However, no significant differences were found between included and non-included patients with regard to gender and type of ward. Third, the retrospective approach to assess symptoms. Because the NH physicians were instructed to fill in the questionnaire soon after death, recall bias has possibly been limited. Finally, there was missing information about a large number of terminally ill patients. These patients should have been included. Although we did not find substantial differences between the study sample and the omitted group in demographic variables (age, sex, and ward), we cannot, in case physicians selectively missed patients, exclude a possible bias on the outcome variables of this study.(22)

In this study population, mental and behavioural disorders (mainly dementia) and diseases of the circulatory system dominated as the main underlying cause of terminal status on inclusion. This also reflected a non-cancer population, since the prevalence of malignant neoplasms in all disease systems remained <11%. The most prevalent main and direct causes of death, as assessed by the NH physician,

were pneumonia, renal failure, disorders of electrolyte and fluid balance, not classified elsewhere (= dehydration) or cachexia. With regard to pneumonia and dehydration, the results of the present study are in line with those reported by Hanson et al., who found that NH deaths are preceded by a slow trajectory punctuated by acute and reversible illnesses, such as pneumonia, sepsis, or dehydration.(31)

A quarter (25%) of the patients were unconscious 48-24 hours before death, and this percentage increased to 44% 24-0 hours before death. Dutch policy gives provision in curative and supportive care for all terminally ill patients according to the course of their illness. Nevertheless, two days before their death, 51% of all conscious patients suffered from at least one burdensome symptom. This decreased to 28% towards death. A minority of patients (12%) developed burdensome symptoms 24 hours before their death, whereas they had none previously.
These findings are supportive evidence for the concern of the World Health Organization that older, terminally ill patients have many unmet needs, and suffer unnecessarily.(32) However, depending on the symptom, there are substantial differences in the prevalence of burdensome symptoms. In this study, pain seemed to improve in the last 48 hours before death (median 100 point VAS score on severity from 20.0 to 12.0), but still 22% were suffering burdensome pain in the last day before death. The median severity score for nausea, depression and anxiety was quite low (favourable). Well-being increased, but the severity of decreased activity, drowsiness, and poor appetite worsened towards death.
Of all the symptoms in palliative medicine, those concerning respiration are considered to be the most excruciating and most difficult to treat.(33) In this study, around 20% suffered from shortness of breath in the last 48 hours. In general, the number of patients with burdensome symptom(s) stayed roughly the same towards death, but there was a significant decrease in difficulty coughing, dry mouth, fever, infections, fatigue and pressure ulcer. Despite the high prevalence of fatigue, little is known about its pathogenesis, and consequently treatment may be less successful than treatment for other symptoms at the end of life.(34)

In 72% of NH patients studied, the last two days of life were accompanied by either unconsciousness or burdensome symptoms. Despite the fact that these symptoms are sometimes difficult to treat, the quality of dying for the majority of NH patients was considered good by the NH physicians and family members.
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 potential for improvement of symptom management.

References

1.   Morita T, Tei Y, Inoue S. Impaired communication capacity and agitated delirium in the final week of terminally ill cancer patients: prevalence and identification of research focus. J Pain Symptom Manage. 2003;26: 827-34.
2.   World Health Organization. Palliative Care. The solid facts. World Health Organization, 2004.
3.   Hall P, Schroder C, Weaver L. The last 48 hours of life in long-term care: a focused chart audit. J Am Geriatr Soc 2002; 50: 501-6.
4.   American Board of Internal Medicine, Identification and Promotion of Physician Competency. Caring for the Dying, 1996.
5.   Klinkenberg M, Willems DL, van der Wal G, Deeg DJ. Symptom burden in the last week of life. J Pain Symptom Manage 2004; 27: 5-13.
6.   Aangenendt-Siegers IP, Cools HJ. [Cause of death in nursing homes]. Ned Tijdschr Geneeskd 1992; 136: 2015-17.
7.   Boersma F, Van den Brink W, Deeg DJ, Eefsting JA, Van Tilburg W. Survival in a population-based cohort of dementia patients: predictors and causes of mortality. Int J Geriatr Psychiatry 1999; 14: 748-53.
8.   Muder RR. Pneumonia in residents of long-term care facilities: epidemiology, etiology, management, and prevention. Am J Med 1998; 105: 319-30.
9.   Rietjens JA, van der Heide A, Vrakking AM, Onwuteaka-Philipsen BD, van der Maas PJ, van der Wal G. Physician reports of terminal sedation without hydration or nutrition for patients nearing death in the Netherlands. Ann Intern Med 2004; 141: 178-85.
10. Driscoll CE. Symptom control in terminal illness. Prim Care 1987; 14: 353-63.
11. Frederich ME. Nonpain symptom management. Prim Care 2001; 28: 299-316.
12. Prismant/Arcares. Verpleeghuizen in Cijfers 2000 [Statistical Data on Dutch Nursing Homes 2000]. Prismant/Arcares; 2002.
13. van der Steen JT, Ooms ME, Ader HJ, Ribbe MW, van der Wal G. Withholding antibiotic treatment in pneumonia patients with dementia: a quantitative observational study. Arch Intern Med 2002; 162: 1753-60.
14. Ribbe MW. Care for the elderly: the role of the nursing home in the Dutch health care system. Int Psychogeriatr 1993; 5: 213-22.
15. Hoek JF, Ribbe MW, Hertogh CM, van der Vleuten CP. The role of the specialist physician in nursing homes: the Netherlands' experience. Int J Geriatr Psychiatry 2003; 18: 244-49.
16. Statistics Netherlands (CBS). Vademecum Health Statistics Netherlands. Statistics Netherlands (CBS); 2001.
17. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139: 1136-39.
18. Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Classificatie van ziekten voor de verpleeghuisgeneeskunde [Classification Codes of Diseases for Nursing Home Medicine]. SIG; 1994.
19. World Health Organization. International Classification of Diseases, tenth revision (ICD-10). World Health Organization, 1992.

20. Steel K, Ljunggren G, Topinkova E et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003; 20: 211-19.
21. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000; 88: 2164-71.
22. Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients: a nationwide observational study in the Netherlands. Arch Intern Med 2005; 165: 314-20.
23. Baer WM, Hanson LC. Families' perception of the added value of hospice in the nursing home. J.Am.Geriatr.Soc. 2000; 48: 879-82.
24. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Soc Sci Med 2003; 56:95-109.
25. Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. J Am Geriatr Soc 2000; 48: 1646-54.
26. Novella JL, Jochum C, Jolly D, Morrone I, Ankri J, Bureau F, Blanchard F. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. Qual Life Res 2001; 10: 443-52.
27. Sneeuw KC, Aaronson NK, Sprangers MA, Detmar SB, Wever LD, Schornagel JH. Evaluating the quality of life of cancer patients: assessments by patients, significant others, physicians and nurses. Br J Cancer 1999; 81: 87-94.
28. Sneeuw KC, Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. J Clin Epidemiol 2002; 55: 1130-43.
29. Nekolaichuk CL, Bruera E, Spachynski K, MacEachern T, Hanson J, Maguire TO. A comparison of patient and proxy symptom assessments in advanced cancer patients. Palliat Med 1999; 13: 311-23.
30. Bruera E, Kuehn N, Miller MJ, Selmser P, Macmillan K. The Edmonton Symptom Assessment System (ESAS): a simple method for the assessment of palliative care patients. J Palliat Care 1991; 7: 6-9.
31. Hanson LC, Henderson M, Menon M. As individual as death itself: a focus group study of terminal care in nursing homes. J Palliat Med 2002; 5: 117-25.
32. World Health Organization. Better Palliative Care for Older People. World Health Organization, 2004.
33. Binsack T. [Dyspnea in the terminal stage]. Schmerz 2001; 15: 370-3.
34. Ross DD, Alexander CS. Management of common symptoms in terminally ill patients: Part I. Fatigue, anorexia, cachexia, nausea and vomiting. Am Fam Physician 2001; 64: 807-14.

Part 3

End-of-life decisions

7

End-of-life decisions in terminally ill long-term care patients in Dutch nursing homes

Abstract

Background
Medical end-of-life decisions with a certain or possible life shortening effect (ELDs), namely non-treatment decision (NTD), alleviation of pain and symptoms with possible life-shortening effect (APS) and physician assisted death (PAD), have been discussed for several years, but little is known about these decisions in terminally ill long-term care patients.

Methods
Prospective cohort study in 16 nursing homes (NHs) representative for the Netherlands. All deceased long-term care patients, assessed by a NH physician to have a maximum life- expectancy of 6 weeks, were enrolled in the study (n=467).

Results
ELDs occurred in 70% of all deaths and 79% among patients with diseases of the circulatory system. Withholding of treatment occurred in 26%, withdrawing of treatment in 13% and alleviation of pain and symptoms in 30%. In conscious and non-demented patients, significantly fewer ELDs were performed than in unconscious or demented patients. Withholding of treatment occurred most often among unconscious patients. In conscious patients, the frequency of withholding medical treatment was significantly higher among demented than among non-demented patients (30% versus 15%). The frequency of alleviation of pain and symptoms with possible life-shortening effect did not differ by state of consciousness or stage of dementia. In conscious patients, the symptom burden had no influence on ELDs.

Conclusion
In long-term care of the terminally ill patients in Dutch NHs, the incidence of medical ELDs is strongly related to consciousness and the patients' stage of dementia. In incompetent patients significantly more ELDs precede death than in competent patients.

Introduction

The number of people living to an old age in industrialized countries is rapidly increasing and the pattern of morbidity and mortality is changing,(1) leading to more deaths from chronic disease.(2) Medical practice will therefore be increasingly confronted with the process of dying and of care for the dying. In this last phase of life, patients, physicians and families will be confronted with different options and will have to discuss end-of-life decisions (ELDs) and their potential effects on the patients' survival.

Since end-of-life research in general has focused primarily on people with a diagnosis of cancer, several studies have stressed the lack of information about end-of-life issues in nursing homes (NHs).(3-5) Because of growing numbers of elderly admitted to NHs (6-8) and the need for quality in palliative care, health care providers have to become more knowledgeable about the process of death and dying in NHs.(4) ELD incidence studies in the general population have been conducted in Europe, United States, Australia and New Zealand.(9-12) These studies have shown that ELDs are frequent. Withholding or withdrawing of potentially life-prolonging treatments (non-treatment decisions), and the alleviation of pain and suffering with opiates with possible life-shortening effects (APS), occur most often in those of 80 years and older and in NH patients.(13-15) None of these studies has focused on terminally ill long-term care patients or on NH patients.

This study describes the frequency of ELDs in terminally ill long-term care patients in Dutch NHs and examines whether ELDs are related to the condition of the patient (consciousness, stage of dementia, main direct causes of death, burdensome symptoms). It focuses on the two main categories of ELDs in NHs: withholding or withdrawal of potentially life-prolonging treatments (non-treatment decisions); and the alleviation of pain and suffering with opiates in doses with a potential possible life-shortening effect (APS).(14;15) Since research which specifically compares withholding and withdrawing of treatment is scarce we will also focus on the differences between these two ELD categories.(13)

Methods

Setting and design
A prospective observational study was carried out in 16 Dutch NHs from November 2001 to March 2003.(3) In 2000, there were 334 NHs in the Netherlands with a total of 58,778 beds.(16) Three types of NHs exist: those for physically ill patients, those for psychogeriatric patients and combined types with separate wards for each category. The vast majority (96%) of psychogeriatric patients suffer from dementia, and will stay in a nursing home until they die.(17) All patients benefit from the different NH functions, mainly rehabilitation and long-term care. Nevertheless, patients admitted for rehabilitation are not included in our study as the majority are usually discharged after 4 to 8 weeks. Staff includes specially

trained NH physicians (in general one full-time physician per 100 patients), who provide medical care and are employed by the NH.(18)

The NHs in the present study were deliberately chosen to be representative of all NHs in the Netherlands. First, the proportion of the three types of NHs was calculated: nine combined NHs, three for physically ill patients and three for psychogeriatric patients. Secondly, the mean number of beds for physically ill and psychogeriatric patients per NH was calculated, and the NHs were arranged in order of this. Finally, the nearest NHs above and below the mean were invited to participate in the study. During the course of the data collection, one nursing home for physically ill patients stopped collecting data for organisational and capacity reasons. It was replaced by another from the same stratum for the remaining period. The total number of participating homes was 16, with an average of 103 NH beds for physically ill patients, 156 for psychogeriatric patients and 157 for combined care.

Selection of patients

This study was introduced in each NH by two researchers (HB, MEO). Written and verbal instructions were given to the NH physicians in how to fill in the questionnaires. They were asked to include on a daily basis all (physically ill and psychogeriatric) patients who met the following criteria:

(1) expected maximum life-expectancy of six weeks, according to the NH physicians' own clinical assessment; (2) admitted for long-term care (admitted to the NH permanently) or (3) previously admitted for rehabilitation but transferred to long-term care during their stay (i.e. where it becomes obvious that the patient would not leave the nursing home).

Patients who died suddenly and unexpectedly (i.e. with no clear terminal palliative phase) were not included. Patients who recovered unexpectedly, or survived the maximum follow-up period of 12 weeks, were excluded from the study.

The maximum life-expectancy of six weeks is based on prior consultation with the NH physician who participated in the study. After the pilot study the NH physicians considered that a weekly follow-up registration of six weeks with a maximum follow-up of 12 weeks was the longest possible period over which any meaningful prediction could be made.

Measurements

On inclusion, the NH physician completed a questionnaire for each patient concerning basic demographics and disease characteristics (e.g. stage of dementia/cognitive decline, main underlying cause of terminal status on inclusion). The stage of dementia/cognitive decline was assessed by the NH physician according to the validated Global Deterioration Scale (GDS).(19) This instrument identifies three major clinical phases: forgetfulness, confusion, and a late phase of dementia. These phases are further sub-divided into seven clinically identifiable stages, ranging from stage 1 (no cognitive decline) to stage 7 (very severe cognitive decline). Stage 5 represents the phase of early dementia, and patients in this stage can no longer survive without some assistance. Patients with stage

1-4 GDS were considered as 'not demented' and stage 5-7 GDS as 'demented'. Written information about the characteristics of these 7 stages was provided to the NH physician to assist assessment.

The validated Dutch Classification Codes of Diseases for Nursing Home Medicine (CvZ-V)(20) was used by the researchers to classify the main underlying diseases on inclusion (disease which was the underlying cause of the disorder on which the NH physician based the limited life-expectancy). The CvZ-V is a Dutch standard, based on the International Classification of Diseases, 10th Edition (ICD-10),(21) with codes for the classification of diseases, intercurrent diseases, disorders, injuries, other problems, and causes of death in NH patients. However, unlike the ICD-10, the CvZ-V contains a 'General' section with codes for diseases, disorders and problems which involve more than one particular organ system, because this situation is common in NH patients. The strength of this instrument is that the Classification of Diseases is tailored to the average NH population.

At the time of death, the NH physician completed for all long-term care patients a questionnaire on the occurrence of (possible) life-shortening end-of life decisions (ELDs), including an estimate of the time by which life was shortened.
The questions were essentially the same as those used in several other Dutch ELD studies(15,22) in which the questionnaire has been validated.(23) For each case of death the NH physician answered 'yes' or 'no' to all the following questions
(a) Did you withhold (the same questions were posed for withdrawing) medical treatment
- if yes, did you do this taking into account the possibility or certainty that this would hasten the patient's death?
- if yes, did you do this with the explicit intention of hastening the patient's death?
(b) Did you intensify the alleviation of pain and suffering
- if yes, did you do this while taking into account the possibility or certainty that this would hasten the patient's death?
- if yes, did you do this partly with the intention of hastening the patient's death?
(c) Was death the result of the administration, supply, or prescription of drugs with the explicit intention of hastening the patient's death?
When at least one of the questions (a) was answered 'yes' the case was classified as a non-treatment decision (NTD). When at least one of the questions (b) was answered 'yes' the case was classified as alleviation of symptoms with possible life-shortening effect (APS). When question (c) was answered 'yes' the case was classified as physician assisted death. In cases where the physician answered 'yes' more than once, the 'yes' answer representing the most explicit intention regarding the hastening of the patient's death was considered to be the most important, and within each intention category the last 'yes' answer was considered to be most important.
Also at the time of death the NH physician reported the main direct cause of death, analogous to the cause-of-death question on Dutch death certificates. For coding the researchers used the CvZ-V codes.(20)

In the same questionnaire after death, the NH physician assessed retrospectively, over two time-periods (48-24 hours and 24-0 hours before death), a number of physical and psychosocial symptoms according to the Edmonton Symptom Assessment Scale (ESAS)(24) and the observational Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC draft 1.8).(25) This instrument has recently been developed for inclusion in the RAI instruments. Draft 1.8 was made prior to the final validation of this instrument, but changes were negligible. RAI MDS-PC items were assessed in conscious as well as unconscious patients, but ESAS items were only assessed in conscious patients. The validated ESAS consists of nine 100 mm VASs including pain, activity, nausea, depression, anxiety, drowsiness, appetite, well-being and shortness of breath. Scores can range from 0-100 (higher scores reflect greater symptom severity). There are 19 physical symptoms/conditions listed in the RAI MDS-PC. From these, 15 were selected, because the other 4 symptoms corresponded with the ESAS (shortness of breath at rest, shortness of breath with exertion, impaired endurance and loss of appetite).

For deceased patients who had not been included in the study, the NH physician completed a shorter questionnaire at the time of death checking the reason for non-inclusion.

Statistics
The analyses were performed in SPSS for Windows, version 11.0, and descriptive statistics were used to characterise the patients. Eligible patients were those for whom questionnaires on inclusion and at the time of death were received. Based on the hierarchy of intentions to hasten the end of life, exclusive categories were analysed by taking for each patient the highest ranking intention; thus in cases where more than one intention applied, the most explicit prevailed. Differences in frequencies were tested with the Chi^2 test.

The association of 'demographics' (gender, age, marital status, actual living status before admittance to nursing home, number of children, religion), 'disease characteristics' (type of ward on inclusion, stage of dementia/cognitive decline) and 'main direct causes of death' with total ELDs, NTDs and APS, was performed with logistic regression analysis.

Analysis of symptom burden 24-0 hours before death
Because most symptom data were missing for unconscious patients, the analyses were limited to conscious patients (n=259). The outcome variables of the ESAS were screened for normality and standard transformations were made if necessary. Two selection criteria were applied for the symptoms in both instruments. Firstly, a selection of symptoms considered to be burdensome in the last 24 hours of life was made. Secondly, ESAS items were considered to be burdensome at an arbitrary cut-off point of 60 or more on the VAS range 0-100 (e.g., 0 = no pain; 100 = extreme pain). This dichotomisation is an analytical classification aimed at providing data on frequencies of burdensome symptoms, since higher scores reflect greater symptom severity. RAI MDS-PC response categories (0=not present; 1=present, not distressed; 2=present, distressed) were dichotomized:

0 and 1 were combined to category 1, and 2 was category 2. Since they distress the patient, symptoms in the latter category were considered to be burdensome.

Ethical review
The Medical Ethics Committee of the VU University Medical Center approved the study. Confidentiality of data was guaranteed by providing only coded information to the researchers. No patients or members of their family were interviewed. Because the NH physicians were simply reporting information collected as part of their usual care observations, no informed consent was required according to the VU Medical Ethics Committee. As required by Dutch law, the patients and their families were informed about the study through an information flyer, and were given the option to refuse the transfer of data.

Results

The total number of deaths studied was 467. For these patients the researchers received a complete set of data (questionnaire on inclusion and at the time of death) for analysis. An additional 272 deceased patients were found to have been incorrectly not included in the study. The main reasons for non-inclusion, given in the shorter questionnaire in order of sequence by the NH physicians, were pressure of work, organisational reasons (e.g. should have been included during the weekend), forgotten (to be included), other reasons (e.g. death not foreseen), family had objections to inclusion in the study.

Table 1 Demographics and disease characteristics of patients included in the study (n=467)

Demographics	n	%
Gender (missing=1)		
Male	136	29.2
Female	330	70.8
Age on inclusion (missing=6)		
Mean age (min-max; SD*)	83.4 (45-100; 8.2)	
Actual living status before admittance to nursing home (missing=3)		
Single	314	67.7
Together with partner	150	32.3
Disease characteristics		
Number of month in nursing home		
Median (min–max)	14.0 (0.0-214.6)	
Reason for admission to nursing home (missing=7)		
Chronic care	346	75.2
Rehabilitation	73	15.9
Terminal care	29	6.3
Other (e.g. special care)	12	2.6
Stage of dementia (Global Deterioration Scale)[19] (missing=21)		
Stage 1 no cognitive decline	152	34.1
Stage 2 – 4 very mild to moderate cognitive decline	26	5.8
Stage 5 moderately severe cognitive decline	34	7.6
Stage 6 severe cognitive decline	120	26.9
Stage 7 very severe cognitive decline	114	25.6
Consciousness		
On inclusion (missing=3)	385	83.0
48 – 24 hours before death (missing=5)	345	74.7
24 – 0 hours before death (missing=3)	259	55.8

continue **Table 1**

Main underlying disease on inclusion (CvZ-V codes†)[20]		
Mental and behavioral disorder	142	30.4
Diseases of the circulatory system	93	19.9
Diseases of the respiratory system	36	7.7
General disorders	34	7.3
Diseases of the digestive system	28	6.0
Other systems	81	17.4
Missing	53	11.3
Malignant neoplasms‡	54	11.2

* SD = Standard deviation

† Only data on diseases 5% above the diseases in the total study population are presented

‡ Separate statement of malignant neoplasms (including secondary malignant neoplasm), within all systems

Table 1 presents the demographics and disease characteristics of patients on inclusion. Most of the patients were female (70.8%), with a mean age of 83.4 years. Patients were predominantly single (67.7%). The median duration of stay in the NH was 14 months. One third (34.1%) had no cognitive decline (stage 1 GDS), the remaining had mostly stage 6 (26.9%) and stage 7 (25.6%) GDS. On inclusion 83% of the patients was conscious, which decreased to 74.7% 48-24 hours before death and 55.8% 24-0 hours before death. The main underlying diseases on inclusion were mental and behavioral disorder (30.4%) and diseases of the circulatory system (19.9%).

Table 2 Frequency of end-of-life decisions (ELDs) according to consciousness and stage of dementia (stage 1-4 vs 5-7 dementia GDS)[19] (n=467)

	Netherlands 2001	Total study population		Conscious* (missing n=14)				Unconscious† (missing n=3)		Group 1 vs 2	Group 1 vs 3	Group 2 vs 3
				Group 1 Stage 1-4 GDS[19]		Group 2 Stage 5-7 GDS[19]		Group 3				
	n=23,613‡	n=467		n=111		n=134		n=205		P-value §**	P-value §**	P-value §**
	%	n	%	n	%	n	%	n	%			
End-of-life decision occurred (ELD)	74.5	326	69.8	64	57.7	95	70.9	156	76.1	0.031	0.001	0.285
Non-treatment decision (NTD)	36.2	183	39.2	33	29.7	52	38.8	92	44.9	0.137	0.009	0.269
- Withholding medical treatment	24.6	121	25.9	17	15.3	40	29.9	63	30.7	0.007	0.003	0.863
- Withdrawing medical treatment	11.6	62	13.3	16	14.4	12	9.0	29	14.1	0.181	0.948	0.152
Alleviation of pain and symptoms with possible life-shortening effect (APS)	37.4	140	30.0	31	27.9	41	30.6	63	30.7	0.648	0.603	0.979
Physician assisted death **	0.9	3	0.6	0	-	2	1.5	1	0.5	-	-	0.334

* Conscious 24 hours before death

† Unconscious 24 hours before death

‡ Only the non-sudden deaths certified by the nursing home physicians, excluding hospital deaths[26]

§ Chi-square

** Only cases in study population of ending of life without the patient's explicit request. The Dutch population of 2001 included also voluntary euthanasia (0.3%) and Physician-assisted suicide cases (0.1%)[12]

Table 2 shows the frequency of end-of-life decisions (ELDs) in conscious and unconscious patients, compared with the Dutch population (only non-sudden deaths). The frequency of any ELD in the total study population was 69.8%, which is somewhat less than the 74.5% calculated from the database of a previous study among a sample of all deaths in the Netherlands. The frequency of non-treatment decisions (NTDs), and alleviation of pain and suffering with possible life-shortening effect (APS) was 39.2% and 30.0% respectively. The frequency of medical treatments withheld was 25.9% and medical treatments withdrawn was 13.3%. These percentages correspond approximately to ELD frequencies for all deaths in the Netherlands, except for APS which occurred in 30% of deaths studied, compared to 37.4% in all Dutch deaths.

Physician assisted death (PAD) was reported in three cases (0.6%). These cases concerned 2 women (89 and 91 years old, with stage 6 and 5 GDS, respectively) and 1 man (age missing, with stage 7 GDS). Their stay in the NH varied between 1 month and 4,5 years. The two female patients had no fluid and nutritional intake, the male patient was being tube fed. As direct cause of death cachexia and dementia were reported. Twenty-four hours before death two of the patients were unconscious, the other patient was conscious and experienced among other symptoms, pain (VAS-score 69), shortness of breath (VAS-score 74) and poor well-being (VAS-score 74). The NH physicians estimated the life shortening in every case differently: 1-7 days, at most 24 hours, and possibly no life shortening.

In conscious patients with stage 1-4 GDS (group 1) the frequency of ELDs and NTDs occurred significantly less often than in conscious patients with stage 5-7 GDS (group 2) and unconscious patients (group 3): 57.7% versus 70.9% and 76.1%, respectively. In conscious patients with stage 1-4 GDS (group 1) the frequency of NTDs occurred significantly less often than in unconscious patients (group3): 29.7% versus 44.9%.

The estimated amount of time by which life was shortened according to the NH physicians for NTD cases (n=163) was: 'at most 24 hours' for 11% (n=18), '1 to 7 days' for 36.2% (n=59), '1 to 4 week(s)' for 19.0% (n=31); and for APS cases (n=124): 25.8% (n=32), 19.4% (n=24) and 9.7% (n=12), respectively. Life was probably not shortened due to a NTD for 20.2% (n=37) and due to an APS for 40.3% (n=50) of the cases (data not shown).

In demented patients (stage 5-7 GDS), regardless of their state of consciousness, significantly more ELDs (P=0.014) and NTDs (P=0.038) occurred than in not demented patients (stage 1-4 GDS). Analysis also showed that significantly more demented patients stage 5-7 GDS were unconscious 24 hours before death (group 3) (67.2%) than were not demented patients stage 1-4 GDS (32.8%) (P=0.008) (data not shown).

Table 3 Frequency of end-of-life decisions (ELDs) according to main direct causes of death (n=467)

Disease† (CvZ-V codes)[20]	Total	Deaths preceded by an ELD*	Death preceded by a NTD*	Death preceded by an APS*
	n	n (%)	n (%)	n (%)
General disorders	106	69 (65.1)	33 (31.1)§	34 (32.1)
Diseases respiratory system	102	71 (69.6)	47 (46.1)	24 (23.5)
(mainly pneumonia N=78)				
Diseases circulatory system	82	65 (79.3)‡	34 (41.5)	31 (37.8)
Diseases genitourinary system	71	48 (67.6)	31 (43.7)	17 (23.9)
(mainly renal failure N=59)				
Endocrine, nutritional and metabolic diseases	62	44 (71.0)	28 (45.2)	16 (25.8)
(mainly dehydration N=61)				
Mental and behavioral disorders	17	12 (70.6)	6 (35.3)	5 (29.4)

* ELD = End-of-life decision, NTD = Non-treatment decision, APS = Alleviation of pain and symptoms with possible life- shortening effect related to main direct causes of death (e.g. diseases respiratory system vs remaining systems)

† Only data on diseases 3% above the diseases in the total study population are presented

‡ Significance P=0.020

§ Significance P=0.040

Table 3 presents the frequency of end-of-life decisions by main direct causes of death, as assessed by the NH physician. The most prevalent causes of death were general disorders, diseases of the respiratory system and circulatory system. Among patients with diseases of the circulatory system significantly more end-of-life decisions (ELDs) occurred than in patients with other diseases (P=0.020); among patients with 'general disorders' significantly fewer non-treatment decisions occurred than in other groups (P=0.040). Demographics and disease characteristics were not significantly associated with the occurrence of an ELD, a NTD or APS (data not shown).

Table 4 shows the frequency of end-of-life decisions (ELDs) in conscious and unconscious patients and, for conscious patients, by burdensome symptoms 24-0 hours prior to death. ELDs and NTDs occurred significantly more often in unconscious patients than in conscious patients. Burdensome symptoms were not related to the frequency of ELDs.

Table 4 Frequency of end-of-life decisions (ELDs) in conscious and unconscious patients, and according to burdensome* symptoms 24-0 hours before death in conscious patients (n=467)

| | Total | End-of-life decision | | Non-treatment decision | | Alleviation of pain and symptoms with possible life-shortening effect | |
| | | (ELD) | | (NTD) | | (APS) | |
	n	n (%)	P-value†	n (%)	P-value†	n (%)	P-value†
Conscious patients	259	170 (65.6)		91 (35.1)		77 (29.7)	
Unconscious patients	205	156 (76.9)	0.014‡	92 (44.9)	0.033‡	63 (30.7)	0.815‡
In conscious patients:							
- no burdensome symptoms	127	80 (63.0)		45 (35.4)		34 (26.8)	
- burdensome symptoms	132	90 (68.2)	0.379§	46 (34.8)	0.922§	43 (32.6)	0.307§

* Assessed according to the Edmonton Symptom Assessment Scale (ESAS) [24] and the Resident Assessment Instrument

Minimum Data-Set Palliative Care (RAI MDS-PC). [25] Conscious patients had 1 or more symptoms, which were considered as burdensome

† Chi² test

‡ ELD, NTD, APS related to unconscious versus conscious patients

§ ELD, NTD, APS related to no burdensome versus burdensome symptoms in conscious patients

Discussion

Medical end-of-life decisions with a certain or possible life shortening effect (ELDs), namely non-treatment decision (NTD), alleviation of pain and symptoms with possible life-shortening effect (APS) and physician assisted death (PAD) have been discussed for several years, but little is known about these decisions in terminally ill long-term care elderly. This study succeeded in measuring end-of-life decisions among long-term care terminally ill patients dying in Dutch nursing homes (NHs).

ELDs occurred in 70% of all deaths and in 79% of patients with disease of the circulatory system. Withholding of treatment occurred in 1 in 4 patients, withdrawing of treatment in just over 1 in 10 and alleviation of pain and symptoms in 3 out of 10 of all studied deaths. Nevertheless, the frequency of NTDs is probably higher because they are 'overruled' by an APS (according to the sequence of ELD classification). In conscious and non-demented patients, significant fewer ELDs were performed than in unconscious or demented patients (58% vs 76% vs 71%, respectively). Withholding of treatment occurred most often among unconscious patients. In conscious patients, the frequency of withholding of medical treatment was significantly higher among demented than among non-demented patients (30% vs 15%). The frequency of alleviation of pain and symptoms with possible life-shortening effect did not differ by competence of the patient or stage of dementia. Symptom burden in conscious patients, assessed by the NH physician, had no relation with ELDs. In this study three cases (0.6%) of physician assisted death were reported.

One of the strengths of this study is that most existing studies on end-of-life decisions are restricted to one specific NH or the elderly in general, whereas this study is performed on a national level in a population-based NH sample. Therefore the large-scale design, the representativeness of the NHs and the prospective character of the study enhance the validity and reliability of these findings. Given the difficulties of measuring sensitive ELDs, this study succeeds in estimating the frequency of ELDs. For this we used validated questionnaires used in several other studies on end-of-life decisions.(12,15,22) Compared with the overall ELD incidence in the Netherlands, previously estimated in robust epidemiological studies based on large-scale death certificate sampling, the results of this study seem valid and reliable. Except for APS, the overall frequency figures didn't differ from the general population of deaths. The lower frequency of APS can be explained by the difference in morbidity of long-term care populations in nursing homes, with very few cancer patients and a large group of psychogeriatric patients with dementia.

This study also has some limitations. First, there is missing information about a large number of terminal patients, who should have been included. Although no substantial differences were found between the study sample and the non-included group with regard to gender and type of ward, a possible bias on the outcome variables of this study cannot be excluded.(3) Secondly, though medical practices

regarding ELDs in the Netherlands are discussed openly, we cannot fully exclude the possibility of a response bias, especially an under-reporting of specific ELDs such as physician-assisted dying. Thirdly, the specific medical (non) treatment decisions (e.g. forgoing artificial nutrition or hydration, withholding or withdrawal of antibiotics) and motives for ELDs did not fit into the scope of the present study, therefore we could not gather additional information about these subjects and relate these to actual practice.

As this study shows, ELDs occurred frequently in Dutch NHs. The frequency of physician assisted death (the administration of drugs with the explicit intention of shortening the patient's life) without the patient's explicit request, was low (0.6%, n=3), similar to the frequency of all deaths in the Netherlands (0.9%).(26) Those reported cases involved demented patients of whom two were unconscious in the last day of life and one experienced severe pain and shortness of breath. Although the estimated life-shortening effect in these patients was very small, the NH physicians explicitly intended to hasten death.

The frequency of ELDs was significantly different between competent and conscious non-demented patients (58%), conscious demented patients (71%) and unconscious patients (76%). In this study, medical ELDs seem to be influenced by the consciousness or competency of the patient: there is uncertainty whether these life ending actions were made by the NH physicians with the involvement of the competent patients or without the involvement of the incompetent patients. Pijnenborg et al. (1995) reported in their nationwide study on the occurrence of withdrawal or withholding of treatment at the end of life, that 19% of non-treatment decisions (NTDs) were made at the explicit request of the patient, 22% after discussion with the patient or after a previous wish, or without involvement of the patient (59%). Of this last group, 87% were not competent.(27) Similar findings were found by Deliens et al. (2000) who stated that the withdrawal or withholding of treatment mainly occurred among incompetent patients.(14)

Within the non-treatment decisions (NTDs), the frequency of withholding medical treatment occurred more often than withdrawing medical treatment (26% vs 13%). This tendency was also found in a study of Bosshard et al. (2005) on forgoing treatment at the end of life in six European countries, which found a ratio of treatments withheld to treatments withdrawn of 60% to 40%.(13) The estimated life shortening effect for NTDs was, in more than one third of patients, 1 to 7 days and for one fifth 1 to 4 weeks. But again, withholding medical treatment occurred significantly less often in conscious, competent patients than in incompetent patients.

Patients' competence is of no relevance in the category of alleviation of pain and symptoms with possible life-shortening effect (APS). In one third of the study population APS was applied and the distribution among competent and incompetent patients was approximately the same (28%-31%). The estimated life shortening effect for APS was in a quarter of patients less than 24 hours and for one fifth 1-7 days, but for 40% had no life shortening effect. The data suggests that pain management and symptom relief are standards of palliative care and acceptable to NH physicians, even when premature death is a likely consequence.

Of all palliative treatments available, the NH physician chooses the least harmful alternative. Demographics, burdensome symptoms and most main direct causes of death apparently were not related to the performance of ELDs.

During their stay in a NH, patients can become unable to express their wishes in several ways and this study shows, ELDs are affected by the competence of the patient. This raises the question of whether these ELDs were supported by communication with the patient, their family or by a living will. Decreased consciousness frequently develops in the terminal phase, due to metabolic disturbances or unintended side effects of intensifying symptom treatment. Patients and/or their families should be aware of the consequences of decreased consciousness in order to make an informed decision on treatment which concerns patients' autonomy. The best option to comply with the wish of the patient seems to be advance care planning (ACP). Considering illness trajectories as reported by Murray et al. (2005) and The et al. (2002)(28,29) and planning appropriately may be helpful in developing the highest possible standards for palliative care.(28) More research on the quality of advance care planning related to the experience of the terminal phase is needed, concerning the extent to which patients and/or their families are involved in planning future end-of-life situations.

In conclusion, in long-term care of the terminally ill patients in Dutch nursing homes, the incidence of medical ELDs is strongly related to consciousness and the patient's stage of dementia. In incompetent patients significantly more ELDs precede death than in competent patients.

References

1   World Health Organization. Palliative Care: The Solid Facts. Copenhagen, Denmark: World Health Organization; 2004.

2.   World Health Organization. Better Palliative Care for Older People. Copenhagen, Denmark: World Health Organization; 2004.

3.   Brandt HE, Deliens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing home patients: a nationwide observational study in the Netherlands. Arch Intern Med 2005; 165(3):314-320.

4.   Forbes S, Bern-Klug M, Gessert C. End-of-life decision making for nursing home residents with dementia. J Nurs Scholarsh 2000; 32(3):251-258.

5.   van der Steen JT, van der Wal G, Mehr DR, Ooms ME, Ribbe MW. End-of-life decision making in nursing home residents with dementia and pneumonia: Dutch physicians' intentions regarding hastening death. Alzheimer Dis Assoc Disord 2005; 19(3):148-155.

6.   Froggatt KA. Palliative care and nursing homes: where next? Palliat Med 2001; 15(1):42-48.

7.   Happ MB, Capezuti E, Strumpf NE, Wagner L, Cunningham S, Evans L et al. Advance care planning and end-of-life care for hospitalized nursing home residents. J Am Geriatr Soc 2002; 50(5):829-835.

8.   Zimmerman S, Sloane PD, Hanson L, Mitchell CM, Shy A. Staff perceptions of end-of-life care in long-term care. J Am Med Dir Assoc 2003; 4(1):23-26.

9.   Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 166(4):191-196.

10.   Meier DE, Emmons CA, Wallenstein S, Quill T, Morrison RS, Cassel CK. A national survey of physician-assisted suicide and euthanasia in the United States. N Engl J Med 1998; 338(17):1193-1201.

11.   Mitchell K, Owens RG. National survey of medical decisions at end of life made by New Zealand general practitioners. BMJ 2003; 327(7408):202-203.

12.   van der Heide A, Deliens L, Faisst K, Nilstun T, Norup M, Paci E et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003; 362(9381):345-350.

13.   Bosshard G, Nilstun T, Bilsen J, Norup M, Miccinesi G, van Delden JJ et al. Forgoing treatment at the end of life in 6 European countries. Arch Intern Med 2005; 165(4):401-407.

14.   Deliens L, Mortier F, Bilsen J, Cosyns M, Vander SR, Vanoverloop J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.

15.   Onwuteaka-Philipsen BD, van der Heide A, Koper D, Keij-Deerenberg I, Rietjens JA, Rurup ML et al. Euthanasia and other end-of-life decisions in the Netherlands in 1990, 1995, and 2001. Lancet 2003; 362(9381):395-399.

16.   Prismant/Arcares. Verpleeghuizen in Cijfers 2000 [Statistical Data on Dutch Nursing Homes 2000]. Utrecht, the Netherlands: Prismant/Arcares; 2002.

17.   van der Steen JT, Ooms ME, Ader HJ, Ribbe MW, van der Wal G. Withholding antibiotic treatment in pneumonia patients with dementia: a quantitative observational study. Arch Intern Med 2002; 162(15):1753-1760.

18   Hoek JF, Ribbe MW, Hertogh CM, van der Vleuten CP. The role of the specialist physician in nursing homes: the Netherlands' experience. Int J Geriatr Psychiatry 2003; 18(3):244-249.

19)   Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139(9):1136-1139.

20.   Stichting Informatiecentrum voor de Gezondheidszorg (SIG). Classificatie van ziekten voor de verpleeghuisgeneeeskunde [Classification Codes of Diseases for Nursing Home Medicine]. Utrecht, the Netherlands: Stichting Informatiecentrum voor de Gezondheidszorg (SIG); 1994.

21.   World Health Organization. International Classification of Diseases, 10th Revision (ICD-10). Geneva, Switzerland: World Health Organization; 1992.

22.   van der Maas PJ, van der Wal G, Haverkate I, de Graaff CL, Kester JG, Onwuteaka-Philipsen BD et al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. N Engl J Med 1996; 335(22):1699-1705.

23.   van der Maas PJ, van Delden JJ, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. Lancet 1991; 338(8768):669-674.

24.   Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000; 88(9):2164-2171.

25.   Steel K, Ljunggren G, Topinkova E, Morris JN, Vitale C, Parzuchowski J et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003; 20(3):211-219.

26.   van der Wal G, van der Heide A, Onwuteaka-Philipsen BD, van der Maas PJ. Medische besluitvorming aan het einde van het leven. De praktijk en de toetsingsprocedure euthanasie [Medical Decision-Making at the End of Life. Practice and Notification Procedure for Euthanasia].Utrecht, the Netherlands: de Tijdstroom, 2003.

27.   Pijnenborg L, van der Maas PJ, Kardaun JW, Glerum JJ, van Delden JJ, Looman CW. Withdrawal or withholding of treatment at the end of life. Results of a nationwide study. Arch Intern Med 1995; 155(3):286-292.

28.   Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ 2005; 330(7498):1007-1011.

29.   The AM, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G. Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study. BMJ 2002; 325(7376):1326.

8

Summary and General Discussion

Introduction

Nursing home care in the Netherlands aims at good curative, supportive and palliative care for patients according to the course of their illness and therefore terminal care is provided according to the principles of palliative care. The general goal of this thesis was to increase information and knowledge of Dutch NH patients regarding palliative care and the quality of dying in NHs. The focus of this thesis was to gain insight into the incidence and quality of care of terminally ill patients in Dutch nursing homes (NHs).
This chapter addresses the main questions, discusses the main findings and describes strengths and limitations. Finally, implications for health policy and practice and further research are drawn.

The main questions addressed in this thesis are:

Part 1   Identification and prognostication of the terminal phase

Research question 1 (chapter 2)
What symptoms, signs, problems and diseases are the direct causes of the terminal phase and what is the incidence of terminal care in nursing homes?

Research question 2 (chapter 3)
How does the estimated length of survival accord with the actual survival period?

Part 2   Problems, symptoms and quality of palliative care

Research question 3 (chapter 4)
What are the psychosocial and spiritual problems found in the terminal phase?

Research question 4 (chapter 5)
What is the quality of palliative care in the terminal phase in a nursing home?

Research question 5 (chapter 6)
What morbidity and symptoms are present in the last two days of life of nursing home patients?

Part 3   End-of-life decisions

Research question 6 (chapter 7)
What is the frequency and character of end-of-life decisions in terminally ill nursing home patients?

Main findings

The main findings of the study are presented and discussed chronologically following the first three parts of this study: the identification and prognostication of the terminal phase (Part 1), problems, symptoms and quality of palliative care in the last days of life (Part 2) and end-of-life decisions (Part 3).

Part 1   Identification and prognostication of the terminal phase (chapter 2 and chapter 3)

In chapter 2 the first research question concerned symptoms, signs, problems and diseases which are the direct cause of the terminal phase, and the incidence of terminal care. Inclusion in the study was decided on the basis of clinical daily practice by the NH physician and was the first step taken in the study. A major challenge was the prognostication of survival time, with a maximum life-expectancy of six weeks or less (chapter 3).

The four most frequently reported symptoms, signs, or problems in the terminal phase of NH patients, which physicians identified as related to the terminal illness, were problems of low fluid intake and nutritional intake, generalized weakness and respiratory problems or dyspnea (chapter 2). Together with this patients were frequently in a state of somnolence and suffering from recurrent fever. At this point the NH physician decides that the patient has entered the terminal phase. The direct causes of the terminal phase, accompanied by the previous symptoms, were diseases of the respiratory system (24.4%), mostly pneumonia, and disorders of a general nature (23.8%) such as cachexia, malaise, coma, fever and septicaemia.

The two main underlying diseases of the terminal phase were mental and behavioral disorders (mostly dementia) (30.2%) and diseases of the circulatory system (20.5%). Only 12% of patients had cancer as the underlying disease, which was also present in a different symptom pattern compared to the non-cancer population. Contrary to non-cancer patients, patients with cancer more often experienced generalized weakness (47% vs 28%), cachexia/anorexia (27% vs 10%), (extreme) tiredness (27% vs 10%), vomiting 12 : 1, nausea 13 : 1 and feeling sick 5:1. The identified period of terminal illness was limited; median survival was 3 days. Within seven days 82.9% of the patients had died and after 14 days 92.2%. It was estimated that in an NH with 100 beds, 34 patients would enter the terminal phase each year. In other words, for every 3 beds, an NH can expect 1 patient per year to reach a terminal phase requiring palliative care.

When NH physicians identified a patient as having a limited life-expectancy, they had to give an estimation of the survival time (chapter3). The physicians, except when death was imminent, inaccurately predicted the survival of patients. Prediction was accurate in more than 90% of cases when death occurred within 7 days. Predicted and actual survival became substantially less accurate over a period longer than seven days. Accurate prediction decreased to 16% (predicted

survival 1-3 weeks) and 13% (predicted survival 4-6 weeks). In the categories 1-3 weeks survival and 4-6 weeks survival, 69% and 52% respectively died earlier.

These findings reflect a mainly non-cancer population with less definable illness trajectories, in contrast to most cancer patients, which makes identification and prognostication difficult. The death of these patients was preceded by a slow trajectory punctuated by acute and reversible illnesses such as pneumonia, sepsis, or dehydration.(1) AM The et al. (2003) in their ethnographic study of the withholding of artificial administration of fluids and food from patients with dementia, also described different illness trajectories. They identified a 'slow downward curve' (the natural course for patients with dementia) 'the interruption' (slow downward curve interrupted by an acute illness, such as pneumonia) and 'unexpected fluctuation in the illness process' (sudden illness followed by death or unexpected recovery).(2) Although this study concerned patients with dementia, it reflects the course of death of many NH patients without dementia as well.

As well as the difficulty of identifying a 'terminal phase', the study revealed an interrelated problem, namely the prediction of life-expectancy (in this study set at six weeks or less). The length of survival is an important aspect, when decisions have to be made concerning further burdensome treatment, beginning or forgoing supportive care etc. Identification might give the patient the opportunity to prepare for death and the ending relationships with loved ones. When patients were included as entering a terminal disease phase, death was only a few days off. These findings are in line with Oxenham et al. (1998) who reported in their study of survival in a hospice that members of the clinical staff were able to predict the imminent death of patients with diagnosis of advanced malignant disease with significant accuracy, either based on increased knowledge of the individual patients or on the stage of the illness.(3) One might expect a better prognostication of long-term survival from NH physicians because of their profound knowledge of the patient. This study indicates that intimate knowledge of the patient is no guarantee of accuracy; because predictions over a longer period of time (longer than 7 days) were prone to inaccuracy, in more than half of cases patients died earlier. Within 14 days after inclusion more than 90% of patients were deceased. Christakis et al. (2000) associated prognostic inaccuracy with a stronger doctor-patient relationship and the majority of predictions in his study were over-estimated (63%).(4) Nevertheless, the reason for this difficulty in prediction of life-expectancy may be due to the fact that NH patients become frail and die from multifactorial causes (comorbidity and intercurrent diseases). Deterioration in one health area influences other health areas, resulting in a cumulative negative effect on the patient's overall health condition and thus making prognostication inaccurate. Moreover, two-third of the patients in this study had dementia (stage 5-7 of the Global Deterioration Scale [GDS])(5), a complicated disease with an unpredictable course.
It may be concluded that even the advantage that the physicians are employed by the NH and therefore know the patient well (probably over a longer period of time)

appears to be no guarantee of an accurate prediction; this therefore continues to be a challenging task for physicians.

NH staff have the difficult task of providing palliative care while living up to the principles formulated by the World Health Organization.(6) Since the identified period of terminal illness is limited, the question remains whether palliative care is sufficiently addressed, to this phase of rapid changes. Perhaps it is more difficult to provide appropriate palliative care for elderly patients with chronic diseases than for patients with cancer, because the course of chronic disease is difficult to predict in contrast to that of cancer. This indicates that the traditional focus of palliative terminal care on patients with cancer needs to be extended and adapted to the specific needs of elderly patients without cancer, which is also a public health challenge of the World Health Organization.(7) The reported symptoms, signs and problems (chapter 2) may be an indication that the patient is approaching death and may serve as a cue to the physician, patient, and family that the person is dying. However, this must be confirmed in future research with specific prognostic models.

The incidence of NH patients who will require palliative terminal care is high and already gives an indication of the difficult challenges NHs have to face, because these patients and their families require more attention from staff and more financial resources than 'regular' patients. The gathering of information about incidence is useful for policymaking and for assessment of the requirements of terminal care.

Part 2   Problems, symptoms and quality of palliative care (chapter 4, chapter 5 and chapter 6)

Palliative care concerns assessment and treatment of pain and other problems, physical, psychological and spiritual. Chapter 4, chapter 5 and chapter 6 indirectly describes the quality of palliative care in daily practice, and addresses research question 3 (psychosocial and spiritual problems), question 4 (quality of palliative care), and question 5 (what symptoms are present in the last two days of life). These chapters give at least an indication of the current state of affairs in Dutch NHs. They are not meant as normative judgments of the quality of palliative care, but perhaps give clues for a broader discussion.

Psychosocial and spiritual needs
Results, gathered with the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC draft 1.8),(8) revealed high psychosocial and spiritual needs in the last days of life of NH patients (chapter 4). Almost a quarter (22%) of the conscious NH patients with stage 1-5 dementia, according to the Global Deterioration Scale (GDS),(5) did not seem to be at peace with life in the last three days of their lives. Half of patients showed sad, pained, worried facial expressions, one-third exhibited expressions of fear and expressed feelings of sadness or depression. One-fifth suffered from insomnia or change in the usual sleep pattern.

At the same time NH physicians reported significant improvement in depression, anxiety and well being (psychological needs) nearer death. This may be due to the alleviation of pain and symptoms with opiates, frequently reported in patients (30%) (chapter 7). Nurses had knowledge of the more concrete wishes of the patient with regard to religious or spiritual guidance or support. They reported that more than four out of 10 patients (44.8%) wished for religious or spiritual guidance or support.

Quality of palliative care
On average the outcomes on palliative care, measured with the Palliative care Outcome Scale (POS),(9) (chapter 5) appeared to be favourable for both non-demented and demented patients. Pain and other symptoms (e.g., nausea, coughing or constipation) seemed to be under control, information given to the patient and their family or friends was sufficient, little time was wasted on health care (e.g., waiting around for transport or repeating tests), and financial or personal affairs were adequately addressed. With regard to symptom control, a key point of attention in palliative care, these results are not in line with other findings. Mitchell et al. (2004) concluded that NH residents in their study did not receive optimal palliative care.(10) There has to be acknowledged that from the recently published literature review of McPherson & Addington-Hall (2003) the following conclusions about the validity of reports of significant others can be drawn: Levels of agreement tend to be good for quality of services, and on observable symptoms. With respect to proxy reports on health and well-being, agreement is best on more overt symptoms, e.g. immobility, activities of daily life and symptoms such as fatigue, dyspnoea and vomiting. Agreement is poorest for aspects of the patient's experience which are more subjective, like pain and affective status.(11) So there is a possibility that staff over estimated the care they provided.

Symptoms
Burdensome symptoms were present to a high extent in dying NH patients (chapter 6). In 72% of NH patients studied, either unconsciousness or burdensome symptoms accompanied the last two days of life. Two days before death, 51% of all conscious patients suffered from at least one burdensome symptom, which decreased 24 hours before death to 28%. A minority of patients (12%) developed burdensome symptoms 24 hours before their death, whereas they had none previously. Pain, measured with the Edmonton Symptom Assessment Scale (ESAS),(12) decreased significantly in the last 48 hours before death (median VAS score on severity from 20 to 12), but still one out of 5 patients (22%) was suffering burdensome pain in the last day before death. This supports the assumption that staff probably over estimated the outcome of palliative care with regard to pain (chapter 5). Also Zerzan et al. (2000) stated that dying residents experience high rates of untreated pain and other symptoms.(13) These findings underpin the concern of the World Health Organization that older terminally ill patients have many unmet needs, and suffer unnecessarily.(14) In a study on barriers to effective pain management for NH residents Jones et al. (2005) concluded that staff nurses need to make more effort to systematically assess pain and offer pain medication to residents rather than to rely on resident requests.(15) Nevertheless, one should

be cautious of interpreting pain as the main parameter of quality of care, because this could be a misinterpretation according to Weiss et al. (2001). They stated that the conclusion regarding the extent of pain as a sign of poor end-of-life care is questionable and might be not the best outcome measure. About one third of the patients they studied seemed to balance the experience of pain with the desire to avoid troublesome side-effects of treatment, and therefore were willing to tolerate pain.(16)

Although the prevalence of burdensome symptoms in this study was high, the quality of dying for the majority of NH patients was considered by the NH physicians and family members to be good. This may be plausible because of the high prevalence of unconscious patients, 44% one day before death, and the frequently-reported alleviation of pain and symptoms with opiates. The number of patients with burdensome symptom(s) stayed roughly the same towards death, but the frequency of difficulty coughing (14%→6%), dry mouth (12%→6%), fever (7%→2%), infections (17%→10%), fatigue (28%→17%) and pressure ulcer (14%→8%) decreased significantly.

An interesting finding of this study was the high frequency of 'non-scores' ('not applicable' and 'unknown' together) in the less observable psychosocial and spiritual aspects of palliative care. As an evaluation of palliative care these results give an indication of the quality of care.

Results with the Minimum Data-Set Palliative Care (chapter 4) showed that in 33% of the non-score cases the NH physician had no knowledge of whether patients were at peace with life or not and in 25% of non-scores, of whether they expressed feelings of sadness or depression (psychosocial needs). Non-scores were even higher for spiritual needs when compared to psychological needs. Nurses did not know whether patients were struggling with the meaning of life (54%) or felt anger towards God, religion or fate (52%) (spiritual needs).

For the Palliative care Outcome Scale, used to assess the palliative care (chapter 5), high non-scores were given for the items patient anxiety (psychosocial), support of patient, life worthwhile and self-worth (spiritual domain). Within the group of patients with dementia (stage 5, 6 and 7 of the Global Deterioration Scale)(5) non-scores were, in relation to the sequence of the stages of dementia, highest in patients with stage 7 dementia. These results show that the Palliative care Outcome Scale can be used to assess a considerable subgroup of demented patients. As communication with the patient and proxy (e.g. family, nurses, doctors) is hampered by the presence of cognitive disorders, it could be expected that differences will exist in the Palliative care Outcome Scale-scores between patients with and without dementia. However, further research is needed to determine to what stage of dementia palliative care can be assessed validly with the Palliative care Outcome Scale; in dementia stage 7 the use of the Palliative care Outcome Scale is apparently questionable.

On the basis of the available results it may be concluded that palliative care in Dutch NHs was weakest in psychosocial and spiritual support for the dying, because staff find it difficult to assess subjective aspects in patients. It is known that during the dying process the spiritual domain is an unmet need among

patients, which is confirmed by this study. These aspects receive insufficient attention and staff, whether or not in cooperation with family or other relatives, should learn more about these needs. This is supported by Georges et al. (2005) who stress in their prospective study on symptoms, treatment and 'dying peacefully' in cancer patients, that attention should be paid to psychosocial well-being in the dying process of the terminally ill.(17)

Burdensome symptoms are present in high frequencies and need improvement. Also, non-scores (no assigned score) might be seen as an indicator of quality of care. In this study healthcare providers had insufficient knowledge of these needs, which suggests potential improvement of assessment in end-of-life care. The question of whether these results were due to lack of knowledge of the patients and/or the absence of feasible assessment instruments is unanswered. In any case it can be concluded that psychosocial and spiritual aspects of care should be better integrated into the continuing professional education and training of health professionals.

Part 3   End-of-life decisions (chapter 7)

When the health condition of patients declines and death becomes imminent, caregivers are confronted with end-of-life decisions (ELDs), i.e. decisions that may have a potential life-shortening effect.(18)

As a response to the last research question of this thesis, chapter 7 discussed two main end-of-life decisions common in the daily practice of NHs, namely withholding or withdrawal of potentially life-prolonging treatments (non-treatment decisions or NTD) and the alleviation of pain and symptoms with opiates in doses with a possible life-shortening effect (symptom alleviation or APS).

End-of-life decisions, such as NTD and APS, are frequently made in Dutch NHs.(19) This indicates a general attitude in Dutch NH physicians of predominately striving for quality of life at the expense of survival. According to the definition of palliative care by the World Health Organization (WHO)(6) euthanasia and physician-assisted suicide are not part of palliative care. In this study, the frequency of physician-assisted death (the administration, prescription or supply of drugs with the explicit intention of shortening the patients' life or enabling the patient to shorten his or her life) was rare (0.6%, n=3). In this study no case of euthanasia was reported and all were cases of active life ending without the patient's explicit request.

ELDs occurred in 70% of all non-sudden deaths. Most frequent ELDs in this study were non-treatment decisions (NTD) (39% of all non-sudden deaths), and alleviation of pain and symptoms with possible life-shortening effect (APS) (30% of all non-sudden deaths). Within the NTDs, withholding medical treatment occurred more often than withdrawing medical treatment (26% versus 13%). This tendency was also found in a study of Bosshard et al. (2005) in six European countries, which found a ratio of treatments withheld to treatments withdrawn of 60% to 40%.(20)

In this study, there was a significant difference in the frequency of end-of-life decisions between unconscious patients (76%), incompetent demented patients (71%) and conscious competent non-demented patients (58%). Therefore, medical end-of-life decisions seem to be partly determined by the consciousness or competency of the patient. This opens the question whether these decisions were supported by communication with the patient, family or a living will. At the end of life a physician, has to evaluate medical and non-medical burdens and benefits. To do this properly, the patient should be involved whenever possible. A study performed in the Netherlands by Pijnenborg et al. revealed that in 19% of the cases NTDs were made at the explicit request of the patient, in 22% after discussion with the patient or after a previous wish and 59% without involvement of the patient.(20) Decisions made by NH physicians without involvement of the patient mainly occurred among incompetent patients.(21;22) As discussed earlier in the section on 'Identification and prognostication of the terminal phase' these results are significant for implementation of advance care planning (ACP) in NHs.

During their stay in a NH patients can become unable to express their wishes in several ways, either becoming unconscious or demented. Georges et al. (2005) reported in their study that in general over 20% of people who die of cancer become unconscious before death.(17) In this study 44% were unconscious in the last 24 hours of life (chapter 6). Patient involvement and discussion should not be postponed until the patient has become incompetent. Decreased consciousness frequently develops in the terminal phase, due to the metabolic consequences of disease or the unintended side effect of intensifying symptom treatment. Ideally, the patient should be aware of the consequences of decreased consciousness before it occurs in order to make an informed decision on treatment; this is an issue of patient autonomy. Doctor-patient and doctor-family relationships are often longstanding and therefore allow for early and personal discussions on end-of-life care. It may be difficult for relatives and NH physicians to make end-of-life decisions when they are not sure what the patient would have wanted. However, uncertainty can be prevented and medical decisions can reflect the patient's wishes. A way for the NH physician to anticipate possible future end-of-life situations is to discuss these with the patient and/or family, preferably soon after admission to the NH. In this study patients in 15 cases (3.2%) had a written living will.
Alleviation of pain and symptoms with possible life-shortening effect (APS), was applied equally in competent and non-competent patients. This may be due to the fact that this practice is in accordance with the inherent goal of alleviating patients' symptoms, and therefore enhancing quality of life. In daily practice pain management and symptom relief are standards of palliative care and acceptable to NH physicians, even when they sometimes result in a hastening of death.
In this study life was shortened due to the alleviation of pain and symptoms with opiates in doses with a possible life-shortening effect, by approximately 24 hours in 26%, 1-7 days in 19%, and 1-4 week(s) in 10% of the cases.

Strengths and limitations

This study generates information on an important and under-researched area. The NH population is large and growing and has significant impact on the national health care system. The study provides useful information on terminally ill patients who suffer mostly from diseases other than cancer. The design was prospective observational, which minimised recall bias. Representative sampling in this study was checked against two parameters: the distribution of physically ill and psychogeriatric patients, and gender. No significant differences were found between the national NH population and the study population for either parameter. Furthermore, most studies are restricted to one specific NH or elderly people in general, whereas this study is performed at national level in a population-based NH sample. Therefore, the prospective character, representativeness and large-scale design of this study enhances the validity and reliability of its findings.

However, the study design had limitations, which may have affected the quality of the data. A main limitation of the study was that it relied on the reports of proxies, namely caregivers. Hence, the patient's experiences can be biased, because these proxies may have under-reported or over-reported the patient's symptoms and other preferences concerning palliative care. However, several studies have evaluated the use of proxy reports on the quality of life, and the quality of care in elderly patients with and without dementia.(11;23-26) In general, these studies focusing on the reliability of proxy ratings show different outcomes. Assessments made by significant others and health care providers are reasonably accurate, and nurses may be the most suitable source of proxy information. Fairly good agreements between patient and proxy are reported with regard to physical functioning and cognitive status, but agreement is poorest for subjective aspects of the patient's experience such as pain, anxiety and depression. In patients with dementia, agreement decreased with the increasing severity of the dementia and therefore proxy assessments should be interpreted with caution.(24)
A second limitation is missing information on a large number of terminal patients who should have been included in the study but who were not. The main reasons for non-inclusion in order of sequence, given by the NH physicians, were: pressure of work, organizational reasons (e.g. should have been included during the weekend), forgotten (to be included), other reasons, and family had objections to inclusion in the study. Although we did not find substantial differences between the study sample and the non-included group with regard to gender and type of ward, we cannot exclude selection bias, in case physicians selectively missed patients (e.g., in complicated cases).
A third limitation is the physicians' judgment of sudden and unexpected death. Although sudden and unexpected death was an exclusion criterion, different physicians may have possibly missed the signs of nearing death and mistakenly described patients as having died suddenly. However, we believe that NH physicians have not deliberately misclassified patients.

Furthermore, the data collected by the NH physician perceived as having a limited life-expectancy of six weeks or less may have led to individual interpretations, but was decided on the basis of clinical daily practice.

A fourth limitation is the retrospective approach to assessment of burdensome symptoms in the last two days of life by the NH physician. However, because NH physicians were instructed to fill in the questionnaire soon after death, we assume that recall or retrospective bias has been limited.

Finally, the underlying disease of the terminal phase was assessed with a question analogous to the cause of death question on the Dutch death certificate.(27) The NH physicians who participated in the study might have had difficulties in reporting the underlying disease of the terminal phase and therefore may have incorrectly registered the cause of death on the death certificates. It is known that problems occur mainly with regard to the sequence of the primary and secondary causes of death, and the primary cause (underlying disease) cannot always be determined.(28;29)

Implications for health policy and practice

Part 1 Identification and prognostication of the terminal phase

Within the gradual decline in physical and psychosocial functioning, common in NH patients, it remains difficult to determine whether a patient has entered an irreversible terminal stage. A more accurate prognostication of survival contributes to appropriate end-of-life care, although the principles of palliative care should not be influenced by the estimate of survival. Reported symptoms, signs, or problems prior to death may be an indication of approaching death (chapter 2) and therefore need special attention in daily care. The Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC),(8) developed for quality of NH care is one of the few instruments which measure e.g. nutritional state, nutritional and fluid intake, and appears to be helpful in assessing the moment of entering the terminal phase.

Once it is acknowledged that the patient is approaching death, the NH physician has the difficult task of estimating life-expectancy and providing patients and their families with accurate information about future expectations. In the terminal phase the frequent evaluation and adaptation of the patients' policy (care plan), owing to the apparent speed of deterioration, is important. In Dutch NHs the most important instrument of prognosis is the clinical experience of NH physicians. Multivariable prognostic models, another use of prognostication in defining the end-of-life, do not seem to be a feasible option, because they require a substantial array of laboratory tests and Dutch NH practice is known for its low-technology interventions.(30) An instrument like the RAI MDS-PC, which allows among other things scrutiny monitoring of patients' functional status, is needed in Dutch NHs.

Part 2 Problems, symptoms and quality of palliative care

According to this study, palliative care for NH patients seems to be a challenge and there is still potential for improvement. There is evidence suggesting that there are considerable differences in quality of care between Dutch NHs.(31) Systematic monitoring the quality of palliative care in NHs in the Netherlands could be the first step towards improvement. However, it is not a standard activity, and procedures for evaluation of the quality of end-of-life care are absent in many NHs.
Current instruments for evaluation of different dimensions of care are the Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC),(8) the Support Team Assessment Schedule (STAS),(32) Palliative care Outcome Scale (POS),(9) and the Edmonton Symptom Assessment Scale (ESAS).(12) Rather than developing new ones, it is advisable to use some of these instruments on a regular basis. Some of these instruments have proved their value within the field of palliative care, as stated by the Council of Europe expert committee in their report on organization of palliative care.(33) The POS,(9) the RAI MDS-PC,(8) and the ESAS(12) have been used in this study as assessment instruments and have been workable in daily clinical practice in NHs. For further development of the concept of palliative care for non-cancer patients, it is advisable to start a discussion with groups of experts and national professional associations in order to develop evidence-based guidelines.
This study revealed that the psychological and spiritual dimensions of care especially lacked the appropriate attention of health care providers, whereas the more physical and observable dimensions like pain, giving information to family and patient etc. were well addressed. In international research spirituality has been even less frequently investigated than psychosocial needs. We assume that lack of knowledge about psychological and spiritual aspects has led to these results. Current practice in Dutch NHs will not easily change, but skills in the observation of subjective, less observable needs of patients could be developed. Possibilities for improvement rely primarily on education and training at medical school and nursing school and in post-academic courses on palliative care.

Part 3 End-of-life decisions

In the traditional model of health care, physicians made decisions for their patients. In the current model, physicians increasingly make decisions together with their patients. As shown, end-of life decisions were frequently made in NHs and will probably increase with growing numbers of elderly dying in NHs. Undoubtedly, end-of-life issues should be discussed openly with the patient and family, preferably at an early stage after admission. The best option to comply with the wishes of the patient is advance care planning (ACP). ACP depends upon forecasting the challenges that the patient and family will face due to illness, medical treatment or other concerns. When an important decision can be anticipated, the decision-making process includes a prediction of the situation, awareness of alternative care plans (different scenarios), and the formulation of preferences. As reported by Murray et al. (2005) thinking in terms of illness

trajectories (how patients may die) and then planning appropriately may be helpful in developing the highest possible standards for palliative care.(34) Earlier studies revealed that advance care planning is common in Dutch NHs and it would be advisable that the plan is made shortly after admission, with a recurrent evaluation due to changes in patients condition.(35) Nevertheless aspects of discussion are the quality of advance care planning. Several issues need attention, like how fare patient/family is involved in this planning, how advanced written directives are addressed, keeping agreements, and what effect advance care planning has on the experience of the terminal phase from the viewpoint of the family.

Implications for further research

The World Health Organization has acknowledged that research into older people health information, the quality of care received and policy concerned with their needs in the last years of life is scarce.(7) Recommendations for further research should be concentrated on more targeted research in NHs.

Improved knowledge on end-of-life care in NHs will facilitate the quality and effectiveness of palliative care in NHs. Reliable information about NH patients' symptoms, emotions, treatment, and health as they approach death is largely unknown. Yet such information is essential in planning health services, educating practitioners, guideline development, medical audits, and in framing problems. Medical literature includes little information about dying; only the growing literature on palliative care for patients with cancer provides tested and reliable information. In the Netherlands, these patients are mostly admitted to hospices or hospitals and to a lesser degree to NHs.

Even the advantage that the physicians are employed by the NH, and therefore know their patients very well, is no guarantee for an accurate prediction of life-expectancy. The difficulty of defining non-cancer patients as terminally ill or predicting their life-expectancy has been recognized in several studies.(36-38) As is shown in chapter 2, NH patients suffer mostly from chronic diseases and their deaths are mostly preceded by trajectories of slow decline with periodic crises and a less well-defined terminal phase. Additional studies of the direct causes of death in relation to observed symptoms, signs and specific problems prior to death in prognostic models may help for a better identification of the terminal disease phase and the prediction of life-expectancy.

Another issue that requires further research concerns psychosocial and spiritual needs. These needs were mostly unknown by healthcare providers and the assumption is that this was due to, either lack of knowledge and/or lack of feasible instruments to measure this specific aspects. Therefore, these aspects of palliative care merit special emphasis. Firstly, the assumption of lack of knowledge should be subject of further research. The level of knowledge about palliative care and their aspects, especially those of psychosocial and spiritual needs, could be starting point for targeted improvement. Whether education is helpful is described by Hutt et al. (2006) who conducted an intervention study to improve pain practices in NHs. Results of the effect of the intervention were measured with the Pain

Medication Appropriateness Scale (PMAS). PMAS sores were better for residents in homes where nurses' knowledge of pain assessment and management improved or stayed the same during the intervention.(39)

Secondly, research should pay attention to the development, improvement and testing of measurement instruments which take into account the different dimensions of care. Rather than developing new ones, we recommend using and improving existing ones, e.g. the instruments used in this study. Nevertheless, developing instruments is an ongoing process and we think that subjective concepts such as psychosocial and spiritual needs deserve more attention in palliative care assessment scales, especially for patients with dementia.

Finally, further research is needed concerning the relief of burdensome symptoms. As shown in chapter 6, two days before death 51% of all conscious patients suffered from at least one burdensome symptom. In many cases dying will inevitably be accompanied by suffering; nevertheless there is potential for the decrease in the symptom burden. Nonetheless, the findings of this study provide supportive evidence for the concern of the World Health Organization that older terminally ill patients have many unmet needs, and suffer unnecessarily.(14)

Symptoms concerning respiration are considered to be the most excruciating and most difficult to treat. Around 20% of the study population suffered from shortness of breath in the last two days of life. Pain, depression, anxiety, shortness of breath was present in high frequencies. A high quality of symptom control and organization of palliative care in NHs is needed due to the apparent speed of deterioration and therefore a steep increase in symptoms. We believe that more research into interventions addressing these problems is justified. Research on barriers(15) or facilitators to effective symptom management is justified, and will contribute to a better quality of end-of-life care.

Samenvatting

Inleiding

De populatie in Nederland veroudert en net als in andere Westerse landen overlijden steeds meer mensen op hoge leeftijd. De Nederlandse populatie telt op dit moment ongeveer 16.2 miljoen mensen, waarvan 13.3% 65 jaar en ouder is. Naar verwachting zal dit percentage 65+ in 2040 tot 25% gestegen zijn. In 2005 overleed 22.2% van de totale Nederlandse populatie in een verpleeghuis. Met het groeiend aantal ouderen zal er een toename naar de behoefte van palliatieve zorg in verpleeghuizen plaatsvinden.

Palliatieve zorg is door de Wereld Gezondheidsorganisatie in 2002 gedefinieerd als: een benadering die de kwaliteit van het leven verbetert van patiënten en hun naasten die te maken hebben met een levensbedreigende aandoening, door het voorkomen en verlichten van lijden, d.m.v. vroegtijdige signalering en zorgvuldige beoordeling en behandeling van pijn en andere problemen van lichamelijke, psychosociale en spirituele aard.

Traditioneel is palliatieve zorg gericht op patiënten met kanker, maar de meeste ouderen in verpleeghuizen overlijden ten gevolge van andere chronische ziekten. Er is een groeiend besef dat relatief weinig onderzoek is gedaan naar de behoeften van ouderen aan palliatieve zorg.

De beginselen voor een professionele stervensbegeleiding dateren uit de 70er jaren van de vorige eeuw. Pas vanaf de negentiger jaren is de ontwikkeling van de palliatieve zorg in Nederland in een stroomversnelling gekomen, resulterend in de oprichting van de eerste hospices.

De Nederlandse gezondheidszorg beschikt momenteel over een breed scala aan diensten die palliatieve zorg verlenen. Het principe is dat goede kwaliteit van palliatieve zorg voor iedere terminale zieke patiënt en diens familie toegangbaar en beschikbaar moet zijn (generalistische benadering). Binnen de intramurale zorg telt het verpleeghuis tot de grootste dienstinstelling waarin palliatieve zorg verleend wordt. Met het stijgend aantal ouderen wordt verwacht dat in de nabije toekomst het verpleeghuis een steeds belangrijker plaats zal worden voor het geven van palliatieve zorg aan stervenden.

Omdat er tot op heden geen representatieve data beschikbaar waren over de incidentie en kwaliteit van de palliatieve terminale zorg in Nederlandse verpleeghuizen, heeft het COPZ (Centrum voor Ontwikkeling van Palliatieve Zorg) dit onderzoek, dat onderwerp is van dit proefschrift, geïnitieerd.

Dit proefschrift richt zich op verschillende aspecten van palliatieve zorg (symptomen, psychosociale en spirituele problemen, medische beslissingen rond het levenseinde) aan patiënten in de terminale fase, opgenomen in een verpleeghuis. Het hoofddoel is het vergroten van inzicht in de situatie van Nederlandse verpleeghuispatiënten met betrekking tot de palliatieve zorg. De resultaten kunnen bijdragen aan een verbetering van de kwaliteit van sterven in verpleeghuizen.

Van November 2001 tot maart 2003 werden in een representatieve steekproef van 16 verpleeghuizen alle verblijfspatiënten geïncludeerd, die volgens het oordeel van de verpleeghuisarts een maximum levensverwachting van 6 weken of minder hadden. Deze patiënten werden tot aan hun overlijden gevolgd, met een maximum follow-up van 12 weken, tenzij zij herstelden. Revalidatiepatiënten en patiënten die plotseling waren overleden, werden niet geïncludeerd.

De resultaten richten zich naast de identificatie en prognose van de terminale fase (inclusief de incidentie van de terminale fase), op problemen en symptomen in deze fase, de kwaliteit van de palliatieve zorg en beslissingen rond het levenseinde. De beschrijving van de resultaten bestaat uit drie delen: in deel 1 worden de identificatie en prognose van de terminale fase beschreven (hoofdstukken 2 en 3). Deel 2 beschrijft problemen, symptomen en de kwaliteit van de palliatieve zorg (hoofdstukken 4, 5 en 6). In deel drie komen medische beslissingen rond het levenseinde aan bod (hoofdstuk 7).

Deel 1 (hoofdstuk 2 en hoofdstuk 3)

Hoofdstuk 2 beschrijft de symptomen, verschijnselen, problemen en ziekten/aandoeningen die de directe oorzaken zijn van de terminale fase (identificatie van de terminale fase). Daarnaast komt de incidentie van de terminale fase in Nederlandse verpleeghuizen aan bod.

Bij inclusie van een patiënt werd de verpleeghuisarts gevraagd maximaal 3 van de belangrijkste symptomen, verschijnselen, problemen in volgorde van belangrijkheid te geven, die voor de arts aanleiding zijn om bij deze patiënt van een beperkte levensverwachting van 6 weken of korter te spreken. De vier meest voorkomende symptomen, verschijnselen, problemen die de terminale fase markeerden, waren (zeer) weinig of géén vochtinname, (zeer) weinig of géén voedselinname, (algehele) verzwakking en ademhalingsmoeilijkheden/dyspnoe. Deze symptomen gingen frequent gepaard met somnolentie (slaperigheid) en (recidiverende) koorts. De ziekten/aandoeningen die rechtstreeks aanleiding waren voor de beperkte levensverwachting en de eerder genoemde symptomen, verschijnselen, problemen, waren ziekten van het ademhalingsstelsel (24.4%)(meestal pneumonie) en algemene aandoeningen (23.8%) zoals chachexie, malaise, coma, koorts en sepsis. De onderliggende aandoeningen die deze problemen veroorzaakten waren psychische stoornissen (30.2%), meestal dementie, en ziekten van het hartvaatstelsel (20.5%). Slechts bij 12% van de patiënten was kanker als onderliggende oorzaak aangegeven. Patiënten mét kanker vertoonden duidelijk een ander symptomenpatroon dan patiënten zónder. In tegenstelling tot de niet-kanker patiënten vertoonden patiënten met kanker vaker (algehele) verzwakking) (47% versus 28%), chachexie/anorexia (27% versus 10%), (extreme) vermoeidheid (27% versus 10%), braken 12 : 1, misselijkheid 13 : 1 en zich ziek voelen 5 : 1. Uit de resultaten blijkt dat de verpleeghuispopulatie uit hoofdzakelijk patiënten met een chronische aandoening bestaat. Het ziektetraject van chronisch zieken is minder goed te voorspellen dan dat van patiënten met kanker. Hun

ziektetraject wordt gekenmerkt door een langzame achteruitgang, die onderbroken wordt door acute en omkeerbare ziekten zoals pneumonie, sepsis of dehydratie. De gerapporteerde symptomen zouden voor de verpleeghuisarts een goede voorspeller kunnen zijn van het naderende overlijden.

De door de verpleeghuisarts onderkende terminale fase was kort, met een mediaan van 3 dagen. Binnen zeven dagen was 82.9% van de patiënten overleden en binnen veertien dagen 92.2%. De incidentie van de terminale fase was 0.34. Dit betekent dat in een verpleeghuis met honderd bedden per jaar 34 patiënten in de terminale fase raken. Met andere woorden, voor elk derde bed kan een verpleeghuis een patiënt verwachten die in de terminale fase komt en extra zorg nodig heeft. De hoge incidentie van verpleeghuispatiënten die palliatieve terminale zorg nodig hebben, geeft aan dat de verpleeghuizen een moeilijke taak te vervullen hebben. Deze patiënten en hun families vereisen immers meer aandacht en zorg dan de 'gewone' patiënten. Deze informatie is belangrijk voor het beleid van het verpleeghuis en de vaststelling van de benodigde terminale zorg.

Hoofdstuk 3 gaat in op de voorspelling van de levensverwachting door de verpleeghuisarts, m.a.w. de duur van de terminale fase tot aan het overlijden (prognose van de terminale fase). De voorspelling werd vergeleken met de werkelijke overlevingsduur. Verpleeghuisartsen konden met een nauwkeurigheid van 90% een juiste schatting van de levensverwachting geven als de patiënten binnen 7 dagen overleden. De overeenstemming tussen geschatte en werkelijke levensverwachting werd onnauwkeuriger naarmate de voorspelde levensverwachting langer dan zeven dagen was. De nauwkeurigheid daalde tot 16% (voorspelde levensverwachting 1-3 weken) en 13% (voorspelde levensverwachting 4-6 weken). In deze categorieën overleden de patiënten eerder dan voorspeld. Dit was in de categorie 1-3 weken 69% en in de categorie 4-6 weken 52%. Het voordeel dat de verpleeghuisarts, omdat hij in dienst is bij het verpleeghuis, de patiënten goed kent, is geen garantie van een juiste inschatting van de levensverwachting.
Een juiste inschatting is belangrijk voor beslissingen die betrekking hebben op verdere belastende behandelingen of het stoppen, respectievelijk starten van ondersteunende behandelingen. Bovendien geeft het de patiënt de mogelijkheid zich op de dood voor te bereiden en het leven af te ronden (in hoeverre dit nog niet gebeurd is).

Deel 2 (hoofdstuk 4, hoofdstuk 5, hoofdstuk 6)

In hoofdstuk 4 worden psychosociale en spirituele behoeften in de laatste dagen van bewuste niet-demente patiënten gemeten.
Volgens de verpleeghuisarts vertoonde in de laatste dagen van hun leven ruim de helft (51.6%) van de patiënten een droevig, pijnlijk en zorgelijk gelaat, een derde liet uitingen van angst (36.4%) en een gevoel van droefheid of depressie (29.1%) zien. Eenvijfde (21.2%) leed aan slapeloosheid of een verandering in het

gebruikelijke slaappatroon. Tegelijkertijd hadden ongeveer de helft (44.7%) van de patiënten vrede met het leven. Verpleeghuisartsen rapporteerden een significante verbetering van depressie, angst en welbevinden bij de naderende dood.

Spirituele behoeften werden door de verzorgenden beoordeeld. Meer dan tweevijfde (44.8%) van de patiënten wenste religieuze of spirituele begeleiding of bijstand, maar 15.8% had moeite met de betekenis van het leven.

Wat opviel was het hoge percentage van de score 'onbekend' (niet-scores). Zo was voor de verpleeghuisarts bij 33% van de patiënten onbekend of deze vrede met het leven hadden en bij 25% was onbekend of ze een gevoel van droefheid of depressie vertoonden (psychosociale behoeften). In vergelijking met psychosociale behoeften was het percentage niet-scores voor de spirituele behoeften zelfs hoger. Spirituele aspecten van zorg bleken bij het grootste deel van de verzorgenden onbekend te zijn, zoals moeite hebben met de betekenis van het leven (54%) of boos zijn op God, godsdienst of het noodlot (52%). Deze resultaten laten ruimte voor verbetering van de beoordeling van psychosociale en spirituele behoeften.

Hoofdstuk 5 beschrijft de beoordeling van de palliatieve zorg in de laatste drie dagen voor overlijden van niet-demente en demente patiënten met de Palliatieve care Outcome Scale (POS) (oorspronkelijk ontwikkeld voor patiënten met kanker). Er zijn geen noemenswaardig verschillen in de beoordeling van palliatieve zorg tussen niet-demente en demente patiënten gemeten. Pijn en andere symptomen (b.v. misselijkheid, hoesten of verstopping) bleken goed onder controle te zijn. Er was voldoende informatie aan de patiënt en diens familie of vrienden gegeven, er was weinig tijd verloren gegaan aan afspraken die in verband stonden met de zorg voor de patiënt (b.v. wachten op vervoer of herhaalde onderzoeken) en praktische zaken ten gevolge van de ziekte van de patiënt (financieel of persoonlijk) waren behandeld. Verschillen in de gemiddelde POS-scores tussen beide groepen waren klein en werden voornamelijk in de subjectieve aspecten van zorg gevonden, namelijk 'heeft de patiënt zijn of haar gevoelens met familie of vrienden kunnen delen', 'heeft de patiënt het gevoel gehad dat zijn of haar leven de moeite waard is', 'heeft de patiënt een goed gevoel over zichzelf gehad' (spirituele domein). De verzorgenden beoordeelden deze aspecten gemiddeld negatiever bij demente patiënten dan bij niet-demente.

Sociodemografische aspecten speelden evenmin een rol bij de zorg tussen beide groepen patiënten. De resultaten lieten zien dat de POS een geschikt instrument is voor de evaluatie van palliatieve zorg voor niet-kanker patiënten én patiënten tot een bepaald stadium van dementie.

Terwijl over het algemeen de fysieke en praktische zaken van palliatieve zorg positief beoordeeld werden, werden de meeste tekortkomingen in de subjectieve, minder goed observeerbare psychosociale ('voelde de patiënt zich angstig of maakte zich zorgen over zijn ziekte of over de behandeling') en spirituele domeinen gemeten ('is de patiënt in staat geweest zijn gevoelens met familie of vrienden te delen'; 'heeft de patiënt het gevoel gehad dat zijn of haar leven de moeite waard is'; 'heeft de patiënt een goed gevoel over zichzelf gehad').

Hoofdstuk 6 is gericht op het meten van morbiditeit en symptomen in de laatste twee dagen voor het overlijden.

Ná het overlijden van een patiënt werd aan de verpleeghuisarts gevraagd, welke ziekte rechtstreeks de dood tot gevolg had, en retrospectief een beoordeling van symptomen 48-24 uur en 24-0 uur voor overlijden te geven. Als de meest belangrijke oorzaak voor de terminal fase (bij inclusie) werden psychische stoornissen (meestal dementie) en ziekten van het hartvaatstelsel gerapporteerd. In minder dan 11% werd kanker als oorzaak genoemd. Tot de meest prevalente rechtstreekse ziekten die de dood ten gevolge hadden hoorden pneumonie, nierinsufficiëntie, electrolyten- en vochtstoornissen (meestal dehydratie) of cachexie. Een kwart (25%) van de patiënten was 48-24 uur voor het overlijden niet bij bewustzijn en dit percentage steeg tot 44% 24-0 uur voor het overlijden. Twee dagen voor het overlijden leed 51% van alle patiënten die bij bewustzijn waren aan tenminste één belastend symptoom en dit percentage verminderde tot 28% 24-0 uur voor overlijden. Een klein deel van de patiënten (12%) ontwikkelde 24 uur voor het overlijden belastende symptomen, terwijl deze symptomen een dag van tevoren niet aanwezig waren. Met de naderende dood verminderde de intensiteit van pijn, maar de frequentie van patiënten mét pijn, één dag voor het overlijden, was nog steeds 22%. De mediaan voor misselijkheid, depressie en angst was laag (de intensiteit van symptomen nam af). Het welbevinden verbeterde, maar de ernst van verminderde activiteit, dufheid en slechte eetlust verslechterde. Met de naderende dood bleef het aantal patiënten met belastende symptomen ongeveer gelijk. Er was wel een significante vermindering van de frequentie van symptomen 48-24 uur en 24-0 uur voor overlijden: moeite met ophoesten (14%→6%), droge mond(12%→6%), koorts (7%→2%), infecties (17%→10%), moeheid (28%→17%) en decubitus (14%→8%).

Op basis van de resultaten is te zien dat bij 72% van de verpleeghuispatiënten in de laatste twee dagen van hun leven sprake was van bewusteloosheid of aanwezigheid van tenminste één belastend symptoom. Dit suggereert dat er meer aandacht moet komen voor symptoombestrijding in de terminale fase. Ondanks het feit dat de symptomen vaak moeilijk te behandelen zijn, werd de kwaliteit van overlijden van de meeste verpleeghuispatiënten door de verpleeghuisarts en de familie als goed beoordeeld.

Deel 3 (hoofdstuk 7)

Hoofdstuk 7 heeft betrekking op de frequentie en de aard van medische beslissingen rond het levenseinde (MBLs).

Medische beslissingen rond het levenseinde zijn dagelijkse praktijk in Nederlandse verpleeghuizen. In dit onderzoek ging in 70% een MBL aan het overlijden vooraf en in 79% bij patiënten met ziekten van het hartvaatstelsel. Binnen de niet-behandel besluiten (afzien of staken van medisch handelen) werd vaker van een medische behandeling afgezien (26%) dan dat deze gestaakt werd (13%). De geschatte levensverkorting was voor 36% van de patiënten 1-7 dagen, en voor 19% 1-4 weken.

In 30% van de gevallen werd de pijn- en / of symptoombestrijding d.m.v. medicamenten geïntensiveerd. De geschatte levensverkorting was voor 26% van

de patiënten korter dan 24 uur en voor 19% korter dan 1-7 dagen, maar had voor 40% geen levensverkortend effect.

Bij patiënten die bij bewustzijn én niet-dement (= wilsbekwaam) waren, werden significant minder MBLs gemeten dan bij bewusteloze of demente patiënten (= wilsonbekwaam) (respectievelijk 58%, 76% en 71%). Bij bewusteloze patiënten werd het vaakst van een behandeling afgezien. Binnen de groep patiënten die bij bewustzijn waren, werd bij dementen significant vaker van een behandeling afgezien dan bij niet-dementen (30% versus 15%). De frequentie van de intensivering van pijn- en / of symptoombestrijding was gelijk (rond de 30%) tussen alle groepen patiënten (wel/niet bewusteloos, wel/niet dement). De aanwezigheid van belastende symptomen, zoals pijn, misselijkheid, depressie angst, kortademigheid, vermoeidheid waren niet van invloed op het nemen van een medische beslissing. In deze studie werden 3 gevallen (0.6%) van actieve levensbeëindiging door de arts (gebruik van een middel met het uitdrukkelijke doel het levenseinde te bespoedigen) gerapporteerd.

De incidentie van medische beslissingen rond het levenseinde lijkt samen te hangen met de wilsbekwaamheid (wel/niet bewusteloos, wel/niet dement) van een patiënt. Aan het overlijden van een wilsonbekwame patiënt (bewusteloos of dement) ging significant vaker een medische beslissing vooraf dan bij een wilsbekwame patiënt (bij bewustzijn en niet dement).

In de terminale fase worden vaak medische beslissingen genomen die invloed hebben op de levensduur van de patiënt. Het is belangrijk dat deze conform de wens van de patiënt en/of diens familie genomen worden. De beste manier om dit te bereiken is anticiperend zorgbeleid (= advance care planning). Anticiperend zorgbeleid is erop gericht toekomstige scenario's betreffende ziekte en medische behandelingen met de patiënt en/of diens familie te bespreken en vervolgens te besluiten hoe er in een bepaalde situatie gehandeld dient te worden.

Het laatste hoofdstuk 8 geeft tenslotte de resultaten van de eerdere hoofdstukken samengevat weer en bespreekt de belangrijkste beperkingen van het onderzoek. Dit hoofdstuk wordt afgesloten met enkele aanbevelingen voor de praktijk en beleid, en voor toekomstig onderzoek. Deze worden hier kort samengevat.

Aanbevelingen voor de praktijk en het beleid

Deel 1 Identificatie en prognose van de terminale fase

Voor een optimale palliatieve zorg is het van belang de signalen van de naderende dood te onderkennen en een enigszins betrouwbare voorspelling van de resterende levensduur te kunnen geven. Bepaalde symptomen bleken een indicatie voor de terminale fase te zijn: (zeer) weinig of géén vochtinname, (zeer) weinig of géén voedselinname, (algehele) verzwakking en ademhalingsmoeilijkheden/dyspnoe. Een instrument als de Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC)(8) is geschikt voor het nauwkeurig monitoren van de functionele status (o.a. voedselinname,

voedingsstatus, vochtinname en voedingtoestand) van verpleeghuispatiënten. Het is aan te bevelen om dit instrument (standaard) in verpleeghuizen in te voeren en te gebruiken. Voor een schatting van de levensverwachting van patiënten is de verpleeghuisarts op zijn klinische ervaring aangewezen. Andere mogelijkheden, zoals multivariate prognosemodellen, vereisen een substantieel aantal testen. Ze lijken geen standaard optie voor de Nederlandse verpleeghuispraktijk, want deze staat bekend om haar lage technologische interventies.

Deel 2 Problemen, symptomen en de kwaliteit van palliatieve zorg

De studie heeft laten zien dat de kwaliteit van de palliatieve zorg in Nederlandse verpleeghuizen verbeterd kan worden. Met name de psychologische en spirituele aspecten verdienen meer aandacht. Voor de evaluatie van de verschillende dimensies van palliatieve zorg staat een aantal instrumenten ter beschikking die hun waarde in de praktijk hebben bewezen. Dit zijn de Resident Assessment Instrument Minimum Data-Set Palliative Care (RAI MDS-PC), Support Team Assessment Schedule (STAS), Palliative care Outcome Scale (POS) en de Edmonton Symptom Assessment system (ESAS). Met uitzondering van de STAS, zijn alle genoemde instrumenten in dit onderzoek toegepast. Deze instrumenten hebben hun waarde binnen de palliatieve zorg bewezen en het is aan te bevelen deze instrumenten verder te ontwikkelen, eerder dan geheel nieuwe te ontwerpen. Psychologische en spirituele aspecten kregen, waarschijnlijk door gebrek aan kennis, onvoldoende aandacht van de verpleeghuisartsen en verzorgenden. Er zal geïnvesteerd moeten worden in de opleiding en training van verpleegkundigen/verzorgenden en artsen in het ontwikkelen van vaardigheden die betrekking hebben op deze aspecten van palliatieve zorg. Daarover zouden specifieke bij- en nascholingen voor deze groepen ontwikkeld en gegeven moeten worden.

Deel 3 Medische beslissingen rond het levenseinde

Het aantal medische beslissingen rond het levenseinde (MBLs) zullen met het groeiende aantal ouderen toenemen. Vanzelfsprekend moeten deze open met de patiënt en/of diens familie besproken worden. De beste manier om aan de wensen van de patiënt en/of familie tegemoet te komen, is de ontwikkeling van een anticiperend zorgbeleid (advance care planning, oftewel ACP). ACP is zeer gebruikelijk in Nederlandse verpleeghuizen. Een punt van blijvende aandacht is de kwaliteit van de ACP. Er zal verder uitgezocht moeten worden in hoeverre, wanneer en hoe bijvoorbeeld de familie bij de planning betrokken wordt en of afspraken nagekomen worden.

Aanbevelingen voor toekomstig onderzoek

Toekomstig onderzoek zou zich vanwege het huidige gebrek aan informatie over ouderen in de laatste levensjaren meer op verpleeghuizen kunnen richten. Dit impliceert relatief meer onderzoek in niet-kanker populaties die hoofdzakelijk aan andere chronische ziekten lijden. De meeste informatie rondom overlijden is beschikbaar over patiënten met kanker. In verschillende studies is onderkend dat het moeilijk is om een terminale fase bij niet-kanker patiënten te definiëren of de levensverwachting te voorspellen. De resultaten van deze studie bevestigen dit. Een verbetering van de prognosetechnieken voor het vaststellen van de levensverwachting is wenselijk, want die is belangrijk voor de patiënt, diens familie, de verpleeghuisarts en verpleegkundigen/verzorgenden. Dit maakt bovendien een planning van adequate medische zorg makkelijker.

Meer onderzoek zou gericht moeten zijn op de ontwikkeling van geschikte instrumenten die betrekking hebben op psychosociale en spirituele behoeften. In deze studie waren deze behoeften meestal onbekend bij de verpleeghuisartsen en de verpleegkundigen/verzorgenden of ontbrak het aan geschikte instrumenten. De instrumenten in deze studie bleken bruikbaar te zijn maar zouden verder ontwikkeld moeten worden voor specifieke doelgroepen, zoals patiënten met dementie.

Tot slot is meer aandacht nodig voor de oorzaken van belastende symptomen. Twee dagen voor overlijden leed 51% van de patiënten aan tenminste één belastend symptoom. Dit bevestigt het beeld dat vele behoeften van de oudere terminale zieke patiënten niet onderkend worden en dat sprake is van onnodig lijden. Gericht onderzoek naar interventies bij belastende symptomen en bevorderende en belemmerende factoren voor symptoom controle is wenselijk, allen gericht op een betere kwaliteit van zorg aan het levenseinde.

References

1. Hanson LC, Henderson M, Menon M. As individual as death itself: a focus group study of terminal care in nursing homes. J Palliat Med 2002; 5(1):117-125.
2. The AM, Pasman R, Onwuteaka-Philipsen B, Ribbe M, van der Wal G. Withholding the artificial administration of fluids and food from elderly patients with dementia: ethnographic study. BMJ 2002; 325(7376):1326.
3. Oxenham D, Cornbleet MA. Accuracy of prediction of survival by different professional groups in a hospice. Palliat Med 1998; 12(2):117-118.
4. Christakis NA, Lamont EB. Extent and determinants of error in doctors' prognoses in terminally ill patients: prospective cohort study. BMJ 2000; 320(7233):469-472.
5. Reisberg B, Ferris SH, de Leon MJ, Crook T. The Global Deterioration Scale for assessment of primary degenerative dementia. Am J Psychiatry 1982; 139(9):1136-1139.
6. World Health Organization. National cancer control program: policies and managerial guidelines. Geneva: World Health Organization (2nd edition). 2002.
7. World Health Organization. Palliative Care: The Solid Facts. Copenhagen, Denmark: World Health Organization; 2004.
8. Steel K, Ljunggren G, Topinkova E, Morris JN, Vitale C, Parzuchowski J et al. The RAI-PC: an assessment instrument for palliative care in all settings. Am J Hosp Palliat Care 2003; 20(3):211-219.
9. Hearn J, Higginson IJ. Development and validation of a core outcome measure for palliative care: the palliative care outcome scale. Palliative Care Core Audit Project Advisory Group. Qual Health Care 1999; 8(4):219-227.
10. Mitchell SL, Kiely DK, Hamel MB. Dying with advanced dementia in the nursing home. Arch Intern Med 2004; 164(3):321-326.
11. McPherson CJ, Addington-Hall JM. Judging the quality of care at the end of life: can proxies provide reliable information? Soc Sci Med 2003; 56(1):95-109.
12. Chang VT, Hwang SS, Feuerman M. Validation of the Edmonton Symptom Assessment Scale. Cancer 2000; 88(9):2164-2171.
13. Zerzan J, Stearns S, Hanson L. Access to palliative care and hospice in nursing homes. JAMA 2000; 284(19):2489-2494.
14. World Health Organization. Better Palliative Care for Older People. Copenhagen, Denmark: World Health Organization; 2004.
15. Jones KR, Fink RM, Clark L, Hutt E, Vojir CP, Mellis BK. Nursing home resident barriers to effective pain management: why nursing home residents may not seek pain medication. J Am Med Dir Assoc 2006; 7(3 Suppl):S21-8, 20.
16. Weiss SC, Emanuel LL, Fairclough DL, Emanuel EJ. Understanding the experience of pain in terminally ill patients. Lancet 2001; 357(9265):1311-1315.
17. Georges JJ, Onwuteaka-Philipsen BD, van der Heide A, van der Wal G, van der Maas PJ. Symptoms, treatment and "dying peacefully" in terminally ill cancer patients: a prospective study. Support Care Cancer 2005; 13(3):160-168.

18. van der Wal G. Clinical and epidemiological aspects of end-of-life decision-making: a conceptual framework. Amsterdam: Royal Netherlands Academy of Arts and Sciences, 2001.

19. Groenewoud JH, van der Heide A, Kester JG, de Graaff CL, van der Wal G, van der Maas PJ. A nationwide study of decisions to forego life-prolonging treatment in Dutch medical practice. Arch Intern Med 2000; 160(3):357-363.

20. Bosshard G, Nilstun T, Bilsen J, Norup M, Miccinesi G, van Delden JJ et al. Forgoing treatment at the end of life in 6 European countries. Arch Intern Med 2005; 165(4):401-407.

21. Pijnenborg L, van der Maas PJ, Kardaun JW, Glerum JJ, van Delden JJ, Looman CW. Withdrawal or withholding of treatment at the end of life. Results of a nationwide study. Arch Intern Med 1995; 155(3):286-292.

22. Deliens L, Mortier F, Bilsen J, Cosyns M, Vander Stichele R, Vanoverloop J et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000; 356(9244):1806-1811.

23. Neumann PJ, Araki SS, Gutterman EM. The use of proxy respondents in studies of older adults: lessons, challenges, and opportunities. J Am Geriatr Soc 2000; 48(12):1646-1654.

24. Novella JL, Jochum C, Jolly D, Morrone I, Ankri J, Bureau F et al. Agreement between patients' and proxies' reports of quality of life in Alzheimer's disease. Qual Life Res 2001; 10(5):443-452.

25. Sneeuw KC, Aaronson NK, Sprangers MA, Detmar SB, Wever LD, Schornagel JH. Evaluating the quality of life of cancer patients: assessments by patients, significant others, physicians and nurses. Br J Cancer 1999; 81(1):87-94.

26. Sneeuw KC, Sprangers MA, Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease. J Clin Epidemiol 2002; 55(11):1130-1143.

27. Statistics Netherlands (CBS). Vademecum Health Statistics Netherlands. Voorburg/Heerlen, the Netherlands: Statistics Netherlands (CBS); 2001.

28. Bouter LM, Rosendaal RF. Wrong tracks in methodology [in Dutch]. Ned Tijdschr Geneeskd. 2002; 146: 57-60. 2006.

29. Das C. Overlijdensverklaringen en artsen: wet en praktijk. PhD Thesis. Vrije Universiteit Amsterdam, 2004.

30. Helton MR, van der Steen JT, Daaleman TP, Gamble GR, Ribbe MW. A cross-cultural study of physician treatment decisions for demented nursing home patients who develop pneumonia. Ann Fam Med 2006; 4(3):221-227.

31. Achterberg WP. Caring for quality. The use of the Minimum Data Set (MDS) for research into quality of care and patient functioning in nursing homes. PhD Thesis. Vrije Universiteit Amsterdam, 2004.

32. Carson MG, Fitch MI, Vachon ML. Measuring patient outcomes in palliative care: a reliability and validity study of the Support Team Assessment Schedule. Palliat Med 2000; 14(1):25-36.

33. Council of Europe expert committee. Organization of palliative care. 2003.

34. Murray SA, Kendall M, Boyd K, Sheikh A. Illness trajectories and palliative care. BMJ 2005; 330(7498):1007-1011.

35. Pasman HR, Onwuteaka-Philipsen BD, Ooms ME, van Wigcheren PT, van der Wal G, Ribbe MW. Forgoing artificial nutrition and hydration in nursing home patients with dementia: patients, decision making, and participants. Alzheimer Dis Assoc Disord 2004; 18(3):154-162.
36. Addington-Hall J, Fakhoury W, McCarthy M. Specialist palliative care in nonmalignant disease. Palliat Med 1998; 12(6):417-427.
37. Field D. Special not different: general practitioners' accounts of their care of dying people. Soc Sci Med 1998; 46(9):1111-1120.
38. Teno JM, Coppola KM. For every numerator, you need a denominator: a simple statement but key to measuring the quality of care of the "dying". J Pain Symptom Manage 1999; 17(2):109-113.
39. Hutt E, Pepper GA, Vojir C, Fink R, Jones KR. Assessing the appropriateness of pain medication prescribing practices in nursing homes. J Am Geriatr Soc 2006; 54(2):231-239.

Dankwoord

Allereerst wil ik iedereen bedanken die belangeloos aan dit onderzoek heeft meegewerkt. Zonder de medewerking van de verpleeghuisartsen, verzorgenden en lokale onderzoekscoördinatoren van de 16 deelnemende verpleeghuizen zou dit onderzoek niet mogelijk zijn geweest.

Ik wil de medewerkende verpleeghuizen bij name noemen.
Psychogeriatrische verpleeghuizen: Zonnehoeve (Hilversum); Hogewey (Weesp); Slingedael (Rotterdam).

Somatische verpleeghuizen: Coendershof (Groningen); Maartenshof (Groningen); Liduina (Boxtel); Rheumaverpleeghuis (Rotterdam).

Gecombineerde verpleeghuizen: Den Koogh (Den Helder); Wendhorst (Heerde); De Volckaert (Dongen); Verpleeghuis Zevenaar (Zevenaar); Het Zonnehuis (Zwolle); Sonnevanck (Harderwijk); Pronsweide (Winterswijk); St. Elisabethshuis (Etten-Leur); Birkhoven (Amersfoort).

Miel Ribbe, mijn eerste promotor, bedank ik voor zijn stimulerende ideeën. In onze projectvergaderingen wist jij me altijd weer te enthousiasmeren doordat je de belangrijkheid van het onderzoek voor de verpleeghuisgeneeskunde steeds wist te benadrukken. Hartelijk dank voor de prettige samenwerking.

Gerrit van der Wal, mijn tweede promotor, jij bent in al de jaren een consistente begeleider geweest. Ondanks je drukke agenda had je alles op tijd klaar en kon ik altijd bij je aankloppen. Hartelijk dank voor de prettige samenwerking.

Luc Deliens, mijn derde promotor. Jij was tot aan het einde mijn rots in de branding. Zo kwam je steeds weer met goede ideeën als zich een knelpunt aangediend had. Voor jou zal het niet altijd makkelijk geweest zijn, want het verpleeghuis is niet echt je specialisatie. Ik wil je heel hartelijk bedanken voor je prettige en uitstekende begeleiding.

Marcel Ooms. Jij was degene die me de eerste "kneepjes' van het vak geleerd heeft. Ik kan me nog goed herinneren toen ik op 1 september 2000 voor je stond en zei: "Vandaag begin ik met het onderzoek. En nu?" Helaas hebben we dit project niet samen af kunnen maken. Jouw expertise heb ik node gemist. Hartelijk dank voor de prettige samenwerking en steun in de moeilijkere dagen.

De leden van de leescommissie: prof.dr. Wouter Zuurmond, prof.dr. Raymond Koopmans, prof.dr. Kees Knipscheer, prof.dr. Jan Eefsting, prof.dr. Dick Willems, prof.dr. Knight Steel, prof.dr. Robert Vander Stichele ben ik zeer erkentelijk voor het lezen en beoordelen van mijn proefschrift.

Bregje van de Wal, jij was de 'reddende engel' toen het met de dataverwerking van het project de verkeerde kant op dreigde te gaan. Mede dankzij jou is het project goed verlopen. Je werkte snel, heel accuraat en dacht altijd met me mee. Het was aangenaam en prettig om met je samen te werken.

Michael Echteld. Wij zijn samen op een bijna lege kamer B-550 aan onze projecten begonnen. Ik weet niet of jij altijd zo blij met mij geweest bent als ik met jou. Na een basiscursus Windows begon ik aan mijn onderzoek, veel ervaring met computers had ik dus niet en als er iets mis ging was jij het eerste aanspreekpunt. Jij was altijd bereid dingen aan mij uit te leggen, niet alleen over computers maar ook over onderzoek, of ergens mee te helpen. Hartelijk dank voor je geduld en grote hulpvaardigheid.

Petra van Wigheren wil ik hartelijk bedanken voor haar steun op alle vlakken. Onder het genot van een kop koffie in de keuken van Verpleeghuisgeneeskunde hebben we 'lief en leed' met elkaar gedeeld.

Mijn andere collegae, Jenny van der Steen, Debby Gerritsen, Roeline Pasman, Lineke Jongenelis, Marieke Kuil, Dinnus Frijters, Martin Smalbrugge, Wilco Achterberg, Cees Hertogh en Marike de Boer, dank ik eveneens voor hun blijvende belangstelling, betrokkenheid en adviezen gedurende mijn onderzoek.

Salome Sahusilawane, Manigeh Ershadi en Rita Verdurmen dank ik voor hun secretariële ondersteuning en prettige samenwerking gedurende mijn hele promotietraject.

Niet te vergeten mijn cohort-genoten Sander Borgsteede en Marjan Westerman. Wij zijn tegelijk met onze onderzoeken begonnen en konden daarom alle perikelen die we in een bepaalde fase tegenkwamen goed met elkaar bespreken. Ik hoop dat we elkaar niet uit het oog verliezen.

Familie en vrienden
Ganz herzlich möchte ich mich bei meinem Vater, Johann Brandt aus Granstedt, für seine endlose Unterstützung während all dieser Jahre bedanken. Als kleines Mädchen, ich glaube von ungefähr neun Jahren, wurde mir einmal die Frage gestellt was ich später werden möchte. Meine Antwort war damals: "Am liebsten würde ich für immer zur Schule gehen". Wenn ich zurückschaue, ist dieser Wunsch Wahrheit geworden. Auf gewisse Art und Weise habe ich immer studiert. Papa, es hat lange gedauert, aber ich habe es geschafft. Ich möchte Dir meine unendliche Dankbarkeit für alles zeigen und widme Dir dieses Buch!

Malte Schönbohm, meinem Neffen und Waltraud Campe, meiner lieben Verwandten, möchte ich ganz herzlich für ihre unermüdliche Unterstützung und Aufmerksamkeit danken, die sie mir geschenkt haben. In dem Wissen Euch zu haben, ist mir alles gelungen.

Mijn lieve buren Ena en Jan Bezemer wil ik heel hartelijk bedanken voor hun niet aflatende steun en hulp in de afgelopen jaren. Ik ben Jan zeer erkentelijk voor de lay-out van mijn proefschrift.

Last but not least, meine lieben Töchter Marchella, Marcelline und Marielle. Ihr habt es die letzten Jahre nicht einfach gehabt, weil ich oft zu wenig Zeit für Euch hatte. Es hat mich aber gefreut zu hören, dass Ihr stolz auf mich seit. Ich bin auch ganz stolz auf Euch!

Curriculum Vitae

Hella Brandt was born on the 12th of July,1956 in Zeven, Germany. After finishing her secondary school she obtained a diploma as a civil servant at the district of Bremervörde in 1976. In 1977 she moved to the Netherlands. At the Pieter Nieuwland college in Amsterdam she obtained her Atheneum-B diplom in 1983. At the Hogeschool Holland in Diemen she followed higher vocational education for nursing (HBO-V). After receiving her registration as a nurse in 1990, she worked as a district nurse.

In 1996 she started with the study Social Gerontology at the Vrije Universiteit in Amsterdam on a part-time basis and graduated in 1999. In September 2000, she started working as a researcher at the Institute for Research in Extramural Medicine (EMGO Institute) of the Vrije Universiteit in Amsterdam, where she conducted the work described in this thesis. During the project she attended methodological and statistical courses in the Postgraduate Epidemiology Program of the EMGO Institute. From April 1st 2005 till June 2006 she worked at the Municipal Health Services, department of Infectious Diseases of Amsterdam where she was involved in a study concerning treatment of hepatitis C virus infected hard drug users. Since June 2006 she works as a researcher at the Netherlands Institute for Health Services Research (NIVEL) in Utrecht.

Hella has three children: Marchella (18), Marcelline (16) and Marielle (13) Sang Ajang.

Hella Brandt is geboren op 12 juli 1956 in Zeven (West-Duitsland). Na het beëindigen van haar middelbare school verkreeg ze in 1976 het diploma Verwaltungsangestellte bij het gemeentehuis in Bremervörde. In 1977 verhuisde ze naar Nederland. Op het Pieter Nieuwland college in Amsterdam behaalde ze in 1983 haar Atheneum-B diploma. Na de Hogere Beroepsopleiding voor Verpleegkundigen (HBO-V), van 1986 tot 1990, werkte zij als wijkverpleegkundige. In 1996 begon zij met de verkorte deeltijdstudie Sociale Gerontologie aan de Vrije Universiteit in Amsterdam, die ze in 1999 afgerond heeft. In september 2000 is zij als onderzoeker bij het Instituut voor Extramuraal Geneeskundig Onderzoek (EMGO Instituut) aan de Vrije Universiteit begonnen aan het onderzoek beschreven in dit proefschrift. Gedurende het onderzoek heeft zij methodologische en statistische cursussen in het kader van het Postdoctoraal Onderwijs Epidemiologie van het EMGO Instituut gevolgd. Vanaf 1 april 2005 tot juni 2006 werkte ze bij de Gemeeentelijke Gezondheidsdienst (GGD) Amsterdam, waar zij betrokken was bij een haalbaarheidstudie naar de behandeling van hepatitis C geinfecteerde harddruggebruikers. Sinds 1 juni 2006 werkt zij als onderzoeker bij het Nederlands instituut voor onderzoek van de gezondheidszorg (NIVEL) in Utrecht.

Hella is moeder van drie kinderen: Marchella (18), Marcelline (16) en Marielle (13) Sang Ajang.

Hella Brandt wurde am 12. Juli 1956 in Zeven (Deutschland) geboren. Nach der Sekundarstufe absolvierte sie eine zweijährige Ausbildung als Verwaltungsangestellte beim Landkreis Bremervörde, welche sie 1976 abschloss. Im Jahre 1977 zog sie in die Niederlande. Am Pieter Nieuwland College in Amsterdam bestand sie 1983 ihr Abitur (Atheneum-B). Nach dem Studium der Hogere Beroepsopleiding voor Verpleegkundigen (HBO-V) an der Hogeschool Holland in Diemen, von 1986 bis 1990, arbeitete sie als Krankenschwester auf einer Sozialstation in Amsterdam. Danach studierte sie von 1996 bis 1999 Soziale Gerontologie an der Vrije Universiteit van Amsterdam. Im September 2000 begann sie als Sozialforscherin beim Instituut voor Extramuraal Geneeskundig Onderzoek (EMGO Institut) bei der Vrije Universiteit von Amsterdam an einem Projekt zu arbeiten, das in dieser Dissertation beschrieben ist. Während dieses Projektes belegte sie im Rahmen des Postdoctoraal Onderwijs Epidemiologie vom EMGO Institut Methodologische und Statistische Kurse. Vom 1. April 2005 an bis Juni 2006 arbeitete sie beim Gesundheitsamt in Amsterdam, wo sie an einem Projekt beteiligt war, welches die Untersuchung von Behandlungsmöglichkeiten von Hepatitis C infizierten Drogensüchtigen beinhaltete. Seit dem 1. Juni 2006 arbeitet sie als Sozialforscherin beim Nederlands instituut voor onderzoek van de gezondheidszorg (NIVEL) in Utrecht.
Hella hat drei Kinder: Marchella (18), Marcelline (16) und Marielle (13) Sang Ajang.