END-OF-LIFE CARE IN OLDER PEOPLE

A STUDY OF ADVANCE CARE PLANNING AND END-OF-LIFE DECISION-MMAKING IN FLANDERS, BELGIUM

CINDY DE GENDT

Studies presented in this dissertation were funded by:

- different grants from the Research Council of the Vrije Universiteit Brussel
- financial support from the Geriatric Departments of the Vrije Universiteit Brussel and the Ghent University.
- a grant from the Fifth Framework Programme of the European Commission (contract QLRT-1999-30859)

Print: Silhouet, Maldegem

© 2010 Cindy De Gendt

2010 Uitgeverij VUBPRESS Brussels University Press VUBPRESS is an imprint of ASP nv (Academic and Scientific Publishers nv) Ravensteingalerij 28 B-1000 Brussels Tel. +32 (0)2 289 26 50 Fax +32 (0)2 289 26 59 E-mail: info@vubpress.be www.vubpress.be

ISBN 978 90 5487 845 2 NUR 882 Legal Deposit D/2010/11.161/166

All rights reserved. No parts of this book may be reproduced or transmitted in any form or by any means, electronic, mechanical, photocopying, recording, or otherwise, without the prior written permission of the author.

END-OF-LIFE CARE IN OLDER PEOPLE

A study of advance care planning and end-of-life decision-making in Flanders, Belgium

Dissertation

Thesis, neergelegd tot het verkrijgen van de graad van Doctor in de Sociale Gezondheidswetenschappen: Medisch Sociale Wetenschappen

Vrijde Universiteit Brussel

Faculteit Geneeskunde en Farmacie Vakgroep Medische Sociologie VUB-UGent Onderzoeksgroep Zorg rond het Levenseinde

14 januari 2011

CINDY DE GENDT



Vrije Universiteit Brussel



Promoter:	Prof. dr. Luc Deliens		
Co-promoters:	Prof dr. Johan Bilsen		
	Prof. dr. Robert Vander Stichele		

Examination Committee

President:	Prof. dr. Sigrid Sterckx	
Other members;	Prof. dr. Anne-Marie Depoorter	
	Prof. dr. Dirk Devroey	
	Prof. dr. Judith Rietjens	
	Prof. dr. Miel Ribbe	
	Prof. dr. Johannes van Delden	

Contents

Pref	ace and acknowledgements	7
Part	I: Introduction	9
1	Introduction to this dissertation	11
Part	II: Medical end-of-life decision-making and terminal sedation at the very end of life	31
2	Medical end-of-life decision-making and terminal sedation among very old patients (Gerontology 2009;55:99-105)	33
Part	III: Do-not-resuscitate decision-making on acute geriatric wards	47
3	Do-not-resuscitate policy on acute geriatric wards (Journal of the American Geriatrics Society 2005;53:2221-2226)	49
4	Prevalence of patients with do-not-resuscitate status on acute geriatric wards (The Journals of Gerontology. Series A, Biological Sciences and Medical Sciences 2007;62:395-399)	65
5	Nurses' involvement in do not resuscitate decisions on acute geriatric wards (Journal of Advanced Nursing 2007;57:404-409)	81
Part	IV: Advance care planning in nursing homes	93
6	Nursing home policies regarding advance care planning <i>(European Journal of Public Health 2010;20:189-194)</i>	95
7	Advance care planning and dying in nursing homes (submitted)	113
Part	V: General discussion	135
8	General discussion	137
Sam	envatting	179
Curr	iculum vitae	191

CHAPTER 2-7 ARE BASED ON THE FOLLOWING PUBLICATIONS

Chapter 2 - De Gendt C, Bilsen J, Mortier F, Vander Stichele R, Deliens L. Endof-life decision making and terminal sedation among very old patients. Gerontology 2009;55:99-105.

Chapter 3 - De Gendt C, Bilsen J, Vander Stichele R, Lambert M, Van Den Noortgate N, Deliens L. Do-not-resuscitate policy on acute geriatric wards in Flanders, Belgium. Journal of the American Geriatrics Society 2005;53:2221-2226.

Chapter 4 - De Gendt C, Bilsen J, Van Den Noortgate N, Lambert N, Vander Stichele R, Deliens L. Prevalence of patients with do-not-resuscitate status on acute geriatric wards in Flanders, Belgium. The Journals of Gerontology. Series A, Biological Scienses and Medical Sciences 2007;62:395-399.

Chapter 5 - De Gendt C, Bilsen J, Vander Stichele R, Van Den Noorgate N, Lambert M, Deliens L. Nurses' involvement in 'do not resuscitate' decisions on acute elder care wards. Journal of Advanced Nursing 2007;57:404-409.

Chapter 6 - De Gendt C, Bilsen J, Vander Stichele R, Deliens L. Nursing home policies regarding advance care planning in Flanders, Belgium. European Journal of Public Health 2010;20:189-194.

Chapter 7 - De Gendt C, Bilsen J, Vander Stichele R, Deliens L. Advance care planning and dying in nursing homes in Flanders, Belgium. A nationwide survey. (submitted)

PREFACE AND ACKNOWLEDGEMENTS

Providing qualitative end-of-life care has become an important goal in medical practice in general, but also for the increasing group of old and very old people in our society. However, little information is available concerning end-of-life care in this age group. Since death is less often completely unexpected among older people and decision-making at their end of life is often complicated by loss of competence, this PhD-thesis has focussed on advance care planning concerning end of life care and end-of-life decision-making at the very end of life of older people.

Before presenting you the end product of my PhD-thesis, I would like to thank some people.

First, my PhD could not have been realised without the help of my promoter and co-promoters: Luc Deliens, Johan Bilsen and Robert Vander Stichele. Luc, you have given me the opportunity to make this PhD and to be part of a successful research group which has always been a stimulating environment. Johan, thanks for investing your precious time to give thorough feedback on my work and to discuss best strategies, to believe in me and for respecting the time I needed. Bob, thank you for your support, discussions and inspiring ideas during the past years. You were most familiar with health care for older people and the structural organisation of it. I can imagine that all of you had doubts about finishing this PhD when I decided in 2008 to leave the research group. But, although it has taken longer than I expected myself, here it is!

I also would like to thank Margareta Lambert and Nele Van Den Nortgate who have given their full support to the DNR-study. At that time, doing a PhD was not really thought of, but afterwards this study appeared to be the very beginning of 'my research career'.

It goes without saying that my colleagues of the research group and Department of Medical Sociology meant a lot to me. It was a pleasure to work in a multidisciplinary environment where experiences, opinions and frustrations of all kind could be shared.

I also would like to thank my current employer and colleagues of the Cancer Registry. From the start you all have encouraged me to finish this PhD, although it is of less importance in this setting. But the same old question "How are you doing with your PhD?" had to be stopped. I hope to be part of this team for many years and will probably always be very enthusiastic about end-of-life care topics, now related to cancer patients.

Tenslotte wil ik graag nog een woordje richten aan een aantal mensen op het thuisfront. Voor jullie was het de voorbije jaren waarschijnlijk vaak een ver-vanjullie-bed-show. Toch hebben jullie op indirecte wijze jullie steentje bijgedragen aan het volbrengen van dit werk. Mijn beide ouders, jullie hebben me steeds gesteund, ook telkens opnieuw wanneer ik op het laatste nippertje besliste toch weer nog verder te studeren. Dat is bij ons steeds verre van 'een must' geweest, maar ik weet dat jullie fier zijn dat het me tot op dit punt gebracht heeft. Ook mijn zussen, schoonbroers, kids en vrienden, dank je voor alle interesse, ondersteuning en momenten van afleiding die jullie mij bezorgden.

Als allerlaatste dank ik natuurlijk ook Benny, zonder wie ik aan dit doctoraat wellicht nooit was begonnen. Jij hebt zonder twijfel al die tijd voor de meeste afleiding gezorgd en kon me via je eigen ludieke manier mijn zorgen wat doen relativeren. Eindelijk komt er nu een tijd waarbij een aantal grote werken (zowel professioneel als privé) op dit moment op hun einde lopen. Ik heb zo uitgekeken naar de periode die nu is aangebroken, waarbij mijn aandacht voor het levenseinde helemaal verdrongen wordt door onze aandacht voor het prille begin van nieuw leven... Dank je voor alles!!

Brussels, January 2011

Part I

Introduction

Chapter 1

Introduction to this dissertation

INTRODUCTION

1 Demographic evolution and changing patterns at the end of life

Due to better living conditions and hygiene, healthier lifestyles, advances in medical knowledge and technological innovation, people in Europe and other developed countries are now living longer than ever before and life expectancy will continue to rise. In Flanders (the Dutch-speaking part of Belgium, with six million inhabitants and 1% mortality) life expectancy at birth has risen during the past ten years by more than two life years (from 76.01 to 78.58 in males and from 81.94 to 84.22 in females) and demographers expect that this will rise by another seven life years during the upcoming 50 years (to 85.66 and 91.11 respectively – Figure 1.1).¹



Figure 1.1: Change in life expectancy at birth in Flanders, 2000-2060

Source: National Institute of Statistics (website: http://statbel.fgov.be)

This development influences the structure of the population, with the number and proportion of older people becoming more and more important (Figure 1.2). The number of older people aged 65 years or older has risen in Flanders from 993,816 in 2000 to 1,129,825 in 2010, and is expected to increase to 1,943,547 by the year 2060 (proportion of the total population 16.7%, 18.1% and 27.7% respectively). The number of very old people, aged 80 years or older, will more than triple in the same period; there were 201,884 people aged 80 years or older

in 2000, 308,472 in 2010 and there will be 780,562 by the year 2060 (3.4%, 5.0% and 11.1% of the population respectively).¹

With an ageing population, the pattern of disease and dying also changes. Currently, more than 80% of all those who die in Flanders are aged 65 years or older and almost half of them are over 80, and these proportions are still rising.^{2,3} Many of these old and very old people have serious underlying comorbidities and die after a long period of chronic and degenerative disease, whereas before, deaths occurred more suddenly, at younger age, and were often caused by infectious diseases.^{4,5} At this time, one third of all deaths in Flanders occur suddenly and totally unexpected.^{2,4} The other two thirds are non-sudden deaths and are likely to involve some type of end-of-life care before death. During the last few decades the awareness has grown that for these patients prolonging life at any cost may not always be the best solution; palliation and improvement of the quality of life may prevail over futile and often burdensome treatments; delivery of optimal end-of-life care has become part of current medical practice.



Figure 1.2: Population pyramid of Flanders (2010 and 2060)

Source: National Institute of Statistics (website: http://statbel.fgov.be)

During the last century the process of dying has also become more and more institutionalised with increasing numbers of people dying in hospitals and in nursing homes. However, in recent years the proportion of deaths in hospitals has decreased slightly in contrast to that in nursing homes.⁶⁻¹¹ At the beginning of the 21st century, in Flanders, 54% of people aged 65 years or older died in hospital (about 25,000) and a quarter died in a nursing home (about 13,000).^{3,4,12}

In general, little information is available concerning end-of-life care in older people and the preceding decision-making processes (advance care planning and medical decision-making at the very end of life). However, this age group needs special attention because decision-making at their end of life is often complicated by loss of competence caused by dementia or other final stage diseases,¹³⁻¹⁵ and by lower general condition and comorbidities.

This dissertation is dedicated to end-of-life care for the increasing group of older people in our society. First, we will focus on medical end-of-life decision-making and terminal sedation at the very end of life for this group in general. Second, the focus is on advance care planning in institutionalised care for older people. Because death is to be expected among those in institutions, advance care planning is very relevant. In the acute setting of geriatric wards, policy and actual practice concerning do-not-resuscitate decision-making is considered. In the long-term care setting of nursing homes, policy and actual practice regarding advance care planning in general (several end-of-life decisions) is considered.

2 Medical end-of-life decision-making and terminal sedation

Since many older people die non-suddenly, their deaths are very likely to be preceded by one or more medical end-of-life decisions. Although many decisions before death will have no effect on the length of life, medical end-of-life decisions are here defined, as in previous studies, as decisions made by a physician that probably or certainly have a life-shortening effect according to the physician and can be categorised according to (1) the actual practice of the physician at the end of life (e.g. administering drugs, forgoing treatments); (2) the intention of the physician (whether he/she explicitly intended, co-intended or had taken into account a possible life-shortening effect); and (3) the involvement of the patient (actively involved in the decision-making process or not).^{2,4,16-19} According to these characteristics medical end-of-life decisions are usually classified in the following categories: non-treatment decisions, intensified alleviation of pain and/or other symptoms, euthanasia, physician-assisted suicide and the use of life-ending drugs without the patient's explicit request (Box 1.1).

Besides these medical end-of-life decisions, terminal sedation (also called continuous deep sedation until death) is another important practice at the end of life. This is the administration of drugs, such as barbiturates or benzodiazepines, to keep the patient continuously in deep sedation or coma until death, and is used when regular treatment of severe, refractory symptoms in the last phase of life is not effective.^{20,21} It is not uncommon to forgo life-sustaining treatment such as artificial hydration or nutrition in these patients, since most of them are in the dying phase. This practice has been much debated because it remains unclear whether terminal sedation, especially when administration of artificial hydration or nutrition is withheld, intentionally or unintentionally hastens death.²² However, research showed that in most cases death is expected but not explicitly intended.^{21,23}

Box 1.1: Conceptual framework of medical end-of-life decisions with possible or certain life-shortening effect according to the physician^{2,4,16-19}

Non-treatment decisions	withholding or withdrawing a possible life- prolonging medical treatment, taking into account the possibility that this would hasten the patient's death or with the explicit intention of hastening the patient's death
Intensified alleviation of pain	intensifying pain and/or symptom alleviation,
and/or other symptoms	taking into account the possibility that this would
	hasten the patient's death or with the co-
	intention of hastening the patient's death
Euthanasia	administration of drugs with the explicit intention
	of ending life at the explicit request of the patient
Physician-assisted suicide	prescription or supply of drugs with the explicit
	intention of enabling the patient to end his/her
	own life
Use of life-ending drugs	administration of drugs with the explicit intention
without the explicit request	of ending life without the explicit request of the
of the patient	patient

Legal status of medical end-of-life decision-making and terminal sedation²⁴

Non-treatment decisions, i.e. the withholding or withdrawing of potentially lifeprolonging treatments, are accepted as normal medical practice in Belgium when properly executed. Physicians are permitted to refuse treatments that are deemed futile by prevailing medical standards, even if the patient explicitly requests them. Withholding or withdrawing life-prolonging treatment at the explicit request of the patient is equally legal. Physicians are however liable to criminal charges if they do not grant such a request, as this refusal would be a violation of patients' rights to self-determination and personal integrity.²⁴⁻²⁶ Only in rare cases can the patient's wish be overruled. Finally, if treatment is withheld or withdrawn from a patient who can be cured or has the prospect of improved quality of life, physicians can be charged with 'reckless neglect' of the patient's care.^{24,26}

Intensified pain and/or symptom alleviation is considered as a permissible medical practice when the usual methods are inadequate and when it aims to alleviate pain and/or other symptoms and the possible life-shortening is merely foreseen but not explicitly intended, the so called 'principle of double effect'.^{27,28} If life-shortening is partially intended, the physician exposes him/herself to possible litigation just as is the case with use of lethal drugs.

Euthanasia has been legal in Belgium since 2002²⁹ but only when several due care criteria are fulfilled, e.g. life-ending has to be at the explicit request of the

patient and the patient is suffering continuously and unbearably and has no prospects of improvement in his/her medical condition. Moreover, the physician must consult at least one other, independent, physician who examines the patient's situation and ensures that all legal conditions are met. The performance of euthanasia must be reported to the Federal Control and Evaluation Committee on Euthanasia who can further examine the legality of the case. Physicianassisted suicide is not legal under the Euthanasia Law but the Federal Control and Evaluation Committee on Euthanasia,³⁰ to which physicians has to report all cases where life-ending drugs were used to explicitly hasten the patient's death, treats these acts as similar to euthanasia, but legal due care criteria need to be respected to avoid prosecution. The use of life-ending drugs without the explicit request of the patient remains illegal and is considered as murder. However, prosecution is difficult because it is difficult to prove and will most of the time be performed as 'compassionate care' for incompetent patients who are suffering unbearably, have no prospects of improvement, and after consultation with next of kin.

There are no formal regulations concerning terminal sedation, but a number of international guidelines and expert recommendations have been published³¹⁻³⁸ which, if followed, safeguard good practice and rule out the possibility of life-shortening.

3 Advance care planning in institutionalised care settings for older people

Recently, there has been an increasing awareness that medical staff often have little knowledge of patients' wishes about their medical treatment at the point when they lose the capacity to make decisions,³⁹⁻⁴¹ resulting in patients being cared for in ways they would not have chosen.⁴⁰ Apart from progress in palliative care, advance care planning has been developed to deal with this problem, especially in care settings for older people who often lack competence at the end of life.^{13,42} Advance care planning involves the 'discussion with patients and/or their representatives about the goals and desired direction of the patient's care, particularly end-of-life care, in the event that the patient is or becomes incompetent to make decisions' (MeSH Database). The aim is that the patient's wishes are taken into account as much as possible by healthcare workers and unwarranted, often burdensome, interventions can be avoided.⁴³⁻⁴⁵ Timing of advance care planning concerning end-of-life care preferences can be very diverse. It is possible to start planning the end of life when death is very close in palliative or terminal situations. If the patient is no longer competent but had previously authorised a representative, this representative can act for him/her. However, it is also possible to plan end-of-life care issues when death, or even disease, seems far away, at older as well as at younger age. This way, people can think about end-of-life situations when they are competent, but this has the disadvantage that wishes can change over time and that it is not possible to include all care situations.

The process of advance care planning can be documented in written advance care plans. This facilitates an easy transition of information to different health care workers in one care setting and between different care settings. Advance care plans about the patient's preferences concerning medical treatments can be either patient-driven (advance directives) or physician-driven (physician's orders).⁴⁶ Advance directives are 'declarations by patients, made in advance of a situation in which they may be incompetent to decide about their own care, stating their treatment preferences or authorising a third party to make decisions for them' (MeSH Database). These advance directives can also be indicative for the patient's care in future situations when he/she is still competent, but in these cases the patient's advance directives should always be verified with the patient, taking into account the situation at that time. Physician's orders on the other hand are written by the physician with the consent and input of the patient or his/her representative. Consequently, these orders can still be made in more advanced clinical situations, when the patient has less physical and mental capability, than compared with advance directives because of the less active role of the patient in this process. In these more advanced situations the initiative to discuss advance care planning will usually be taken by the physician.

In the USA the Patient Self Determination Act of 1991 obliges health care institutions to inform patients of their right to accept or reject medical treatments and to authorise a representative who speaks for the patient when he/she is not able to do so, and to encourage patients to write advance directives.^{47,48} More recently, patients in some other countries (e.g. Australia) have been enabled by law to participate actively in medical decision-making.⁴⁷

In Belgium, since 2002, the Patients' Rights Act also gives patients the right to accept or reject medical treatment and to authorise a representative,²⁵ but in contrast to some other countries Belgian legislation does not regulate how healthcare institutions should implement these rights in practice; implementation of policies regarding advance care planning to guide healthcare workers in daily practice is not obligatory. However, two possible aspect of advance care planning policies can be differentiated, namely institutional guidelines and patient-specific planning forms; (1) institutional guidelines are generally accepted agreements adopted by the institution to guide physicians and nurses in advance care planning forms, which are standardised forms to document anticipatory instructions from the physician (=physician's orders) and/or the patient (=advance directives), concerning an individual patient. They concern

anticipatory instructions regarding resuscitation, hospitalisation and other medical end-of-life decisions.

Besides the implementation of advance care policies, it is stated that advance care planning in institutionalised care can only be successful when trained staff are available with the time, competence and confidence to discuss the issue with patients and when all actors involved in this process understand and support it.⁴² However, there is some controversy about the outcome of advance care planning, more specifically about the usefulness of advance directives,⁴⁹ in other words: is the care received at the end of life consistent with the previously documented end-of-life care preferences of the patient and do advance directives result in better quality of end-of-life care? An argument in favour of advance directives is that the documents reflect patients' wishes and consequently enhance a more qualitative end of life.14,50,51 It is also shown that physicians endorse the use of advance directives as a standard in end-of-life decision-making.⁵² Others who are against their use will claim that people are not able to make valid choices about possible future end-of-life issues⁵³⁻⁵⁵ or that an authorised representative is able to take decisions according to another person's preferences,⁵⁶ and several studies have guestioned the role of written advance directives in medical decision-making for seriously ill people.⁵⁷⁻⁶³ These studies reporting the limitations of advance directives have been criticised for selection bias (overuse of hospital-based sampling procedures) and the suggestion that the true effect of written advance directives may only be found outside the acute care setting (persons who had completed a written advance directive were more likely to die at home than in an acute care hospital).⁶⁴

At the onset of the studies discussed in this dissertation, no information was available concerning institutional policies and actual practices regarding advance care planning in acute geriatric wards and nursing homes in Flanders, the most important institutional care settings for older people.

3.1 Do-not-resuscitate decision-making on acute geriatric wards

In Flanders, Belgium, acute geriatric wards are embedded in acute hospitals. They were installed since 1984 for specialised acute geriatric care, restricted in length of hospital stay and with a multidisciplinary approach. They serve a minimum of 24 beds and are supervised by a geriatrician (a specialist in internal medicine with a supplementary specialisation in geriatric medicine).⁶⁵ In 2002, there were 94 acute geriatric wards in Flanders with a total of 4,072 beds and a yearly occupancy rate of 85.9%, serving 41,138 hospitalisations, with an average length of stay of 31 days.⁶⁶

In the context of this dissertation only the subject of physicians' orders concerning do-not-resuscitate decision-making is addressed within the setting of

acute geriatric wards, because it is the most clear and relevant example of advance care planning in this acute care setting. First, older people admitted to acute geriatric wards have a high immediate risk of cardiopulmonary arrest and many of them are less likely to benefit from resuscitation, especially in the long term, because of severe underlying comorbidity.⁶⁷⁻⁷⁰ Second, knowing the patient's wish in this matter is necessary because it is never possible to consult a patient at the time of a cardiopulmonary arrest. Finally, a decision not to resuscitate the patient in case of a cardiopulmonary arrest is often the first of several advance care planning decisions concerning the end of life in this setting.

3.2 Advance care planning in nursing homes

Professional residential care for older people in Flanders is organised in 745 care homes for older people (2006). These care homes can be divided into those not recognised as nursing homes, usually residing less elderly and less dependent people, and into those that are also recognised as nursing homes (Table 1.1). Only the latter subset of institutions is considered in this dissertation.

	Number of institutions	Total number of beds	Number of traditional care home beds	Number of nursing home beds
Traditional care homes for older people	151	5,145	5,145	/
Nursing homes	594	57,858	26,307	31,551
Total	745	63,003	31,452	31,551

Table 1.1: Descri	ption of care	homes for	older peo	ple in I	Flanders ((2006)	71
						/	

These nursing homes provide skilled nursing care to older people who have serious problems in activities of daily living and/or mental capacity, but who do not need daily medical supervision or full-time specialised medical treatment as in hospitals.⁷² Medical care in these nursing homes is provided by general practitioners chosen by the individual resident. These general practitioners are not part of the management of the institution. Each nursing home is also obliged by law to have one coordinating and advisory physician, also a general practitioner, who participates in the management of the nursing home. This person has the task of facilitating the cooperation between the nursing home management and the visiting general practitioners, coordinating and streamlining medical (end-of-life) care and organising training for general practitioners and nurses.^{73,74}

Since nursing home residents often lack competence at the end of life, advance care planning regarding different end-of-life decisions should be considered in this care setting.¹³

AIMS AND RESEARCH QUESTIONS

In this dissertation various aspects concerning the end of life of older people in Flanders will be addressed in the hope of contributing to the understanding and improvement of care of older people at the end of life.

The main research questions are:

Medical end-of-life decision-making and terminal sedation at the very end of life

 What is the frequency and what are the characteristics of end-of-life decision-making and terminal sedation among very old patients who die non-suddenly, what are the characteristics of the preceding decisionmaking process, and is there a difference with younger patients? (Chapter 2)

Do-not-resuscitate decision-making on acute geriatric wards

- 2) How many acute geriatric wards have a policy on do-not-resuscitate decision-making, since when was this implemented, what are the characteristics of the development and implementation of such policies and what is their global content? (Chapter 3)
- 3) What is the prevalence of patients with do-not-resuscitate status on acute geriatric wards and what are the characteristics of the preceding decision-making process? (Chapter 4)
- 4) Are nurses involved in do-not-resuscitate decision-making (Chapter 4 and 5) and how often do they adhere to the resuscitation status of patients? (Chapter 5)

Advance care planning in nursing homes

- 5) How many nursing homes have a policy on advance care planning, since when was this implemented, and what is their global content? (Chapter 6)
- 6) How many nursing home residents have documented advance care plans at time of death and how many had authorised a legal representative, and is this related to the demographic, clinical and care characteristics of dying in the nursing home? (Chapter 7)

METHODS

Study 1: Death certificate study

To answer research question 1, a secondary analysis of a previously published death certificate study was performed, to compare patients aged 80 years or older who died non-suddenly with younger patients.

This study was conducted in Flanders in 2001, the year before euthanasia was legalised in Belgium.⁴ A random sample (N=5,005) of all death certificates of people aged one year or older and dying between June and December 2001 was taken from the official death register of the Health Care Division of the Ministry of Flanders and stratified for the likelihood that an end-of-life decision had preceded the patient's death; larger samples were taken for strata in which the cause of death had made an end-of-life decision more likely. For each sampled death certificate the certifying physician was sent an anonymous structured questionnaire, identifying non-sudden deaths and medical end-of-life decision-making which might have preceded death.

A complex mailing procedure, approved by the Belgian National Disciplinary Board of Physicians and supervised by a legal attorney, was developed to ensure anonymity for physicians and patients.^{2,4,75} The Total Design Method was used to assure an appropriate response rate.⁷⁶

Prior to the analysis, data were adjusted for disproportional stratification of the sample and weighted for patient characteristics (sex, age, place and cause of death) of all deaths in Flanders during the study period. More details on the methodology of this study are described in chapter 2 and in previous publications with these data.^{2,4,77}

Until now, the death certificate method seems to be the most reliable for estimating the incidence of end-of-life decisions. It was first done in The Netherlands but later in other European and non-European countries which makes international comparison possible.^{2,4,16,17,19,78-81}

Study 2: Do-not-resuscitate decision-making on acute geriatric wards

Research questions 2 to 4 are answered via a study conducted in the spring of 2002 in Flanders on acute geriatric wards. At that time, there were 70 acute hospitals, of which 64 had at least one acute geriatric ward. Due to previous administrative mergers between formerly independent hospitals, some of these 64 hospitals had an acute geriatric ward at different hospital sites (39 hospitals had one site with a geriatric ward, 21 had two sites, three had three sites, and

one had four sites). All 94 hospital sites in Flanders with an acute geriatric ward were included in this study. A list of these hospital sites was obtained from administrative databases from the National and Regional Ministries of Health, including addresses and characteristics.

Three different structured mail questionnaires were sent to each hospital site.

The first questionnaire about the existence, development and implementation of the do-not-resuscitate policy was addressed to the head geriatrician and was inspired by an existing questionnaire regarding policies and guidelines in medical decisions concerning the end of life in health care institutions in the Netherlands.⁸² Head geriatricians were also requested to return copies of existing do-not-resuscitate guidelines and order forms.

The second questionnaire was, via the Head geriatrician, sent to the geriatrician who performed the bulk of the clinical work on the acute geriatric ward. This questionnaire asked about the existence of a do-not-resuscitate policy, the point prevalence of patients with a do-not-resuscitate status on the ward, and the characteristics of the last decision-making process leading to the attribution of a do-not-resuscitate status, e.g. timing, reasons, actors involved.

The third questionnaire was sent to the head nurse of the acute geriatric ward. They were asked whether nurses had been involved in the last do-notresuscitate decision-making process on their ward, not necessarily the same case on which geriatricians reported in the second questionnaire. Furthermore, head nurses were asked about the level of adherence to the patient's resuscitation status in the case of an actual cardiopulmonary arrest and whether nurses 'never', 'rarely', 'sometimes', 'often' or 'always' started resuscitation in cases of a cardiopulmonary arrest of patients with do-not-resuscitate status and those without.

To assure an appropriate response rate the Total Design Method was used.⁷⁶ One week before the questionnaires were sent, a recommendation letter from the Belgian Society of Gerontology and Geriatrics was sent to all geriatricians.

Approval of the study design was received from the Medical Ethical Commission of the UZ Brussel (University Hospital of Brussels).

Study 3: Advance care planning in nursing homes

To answer the last two research questions (5 and 6) another study was conducted at the end of 2006 in nursing homes. All 594 nursing homes (57,858 beds) in Flanders were included in this study. A list with addresses and institutional characteristics was obtained from the Flemish Ministry of Health.

Two different structured mail questionnaires were developed.

The first questionnaire was sent to the nursing home administrator of each institution. They were asked about nursing home characteristics relating to end-of-life care and about the nursing home policy regarding advance care planning. Two possible aspects of such a policy were explored, written institutional guidelines and patient-specific planning forms. Where these documents were available, respondents were asked when they were enacted and about their content, differentiating several medical end-of-life decisions.

Together with this questionnaire, the nursing home administrator was sent a package of identical structured mail questionnaires of a second kind. He/she was asked to report the number of residents who had died during September-October 2006 and to pass on a questionnaire for each of these residents to the nurse most involved in the care for this specific resident, or to the head nurse in cases where it was not possible to identify this nurse. This questionnaire asked nurses about the characteristics of the deceased nursing home resident, the prevalence of hospital transfers at the end of life and the characteristics of palliative care delivery, and focussed on the prevalence of documented advance care plans (advance directives and physician's orders) and authorisation of a legal representative.

To improve the response rate the Total Design Method was used,⁷⁶ and a letter of recommendation signed by six relevant organisations for this setting was enclosed in the mailing.

Approval of the study design was received from the Medical Ethical Commission of the UZ Brussel (University Hospital of Brussels).

OUTLINE OF THIS DISSERTATION

Following this introduction, the chapters 2-7 are based on articles of which five have been published and one has been submitted. This implies that the various chapters overlap in some way, particularly the introduction and methods sections, but these are retained so that each chapter can be read independently.

Chapter 2 explores the differences in the prevalence of different types of end-oflife decisions and terminal sedation among very old patients compared with younger patients, and describes the preceding decision-making process. People in different care settings in Flanders are taken into account.

The following three chapters concern do-not-resuscitate decision-making on acute geriatric wards in Flanders (research questions 2 to 4). Chapter 3 describes the development and status of do-not-resuscitate policy on these wards. Do-not-resuscitate decision-making in actual practice is discussed in chapter 4, and chapter 5 is focussed on nurses' involvement in this decision-making process and adherence to patients' resuscitation status.

The next two chapters examine advance care planning in nursing homes in Flanders. Chapter 6 describes the existence and content of policies regarding advance care planning and chapter 7 the documentation of advance care plans and the authorisation of a legal representative.

Finally, in chapter 8 the most important results are summarised and discussed and some implications for health policy and practice will be listed, and recommendations for further research.

REFERENCES

- 1. National Institute of Statistics. http://www.statbel.fgov.be. Accessed May 1, 2010.
- 2. Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356:1806-1811.
- 3. Cohen J, Bilsen J, Hooft P, Deboosere P, van der Wal G, Deliens L. Dying at home or in an institution using death certificates to explore the factors associated with plase of death. Health Policy 2006;78:319-329.
- 4. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362:345-350.
- 5. Lunney JR, Lynn J, Hogan C. Policies of older medicare decedents. J Am Geriatr Soc 2002;50:1108-1112.
- 6. Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last phase of care. JAMA 2004;291:88-93.
- 7. Mazey M, Dubler NN, Mitty E, Brody AA. What impast do setting and transitions have on the quality of life at the end of life and the quality of the dying process? Gerontologist 2002;42(Spec No 3):54-67.
- 8. 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.
- 9. Hunt RW, Bond MJ, Groth RK, King RM. Place of death in South Australia. Patterns from 1910 to 1987. Med J Aust 1991;155:549-553.
- Bickel H. The last year of life: a representative study of deceased patients. Living arrangement, place of death and utilization of health resources. Z Gerontol Geriatr 1998;31:193-204.
- 11. Flory J, Yinong YX, Gurol I et al. Place of death: U.S. trends since 1980. Health Aff (Millwood) 2004;23:194-200.
- 12. Pacolet J, Deliège D, Artoisenet C, et al. Vergrijzing, gezondheidszorg en ouderenzorg in België. Rapport voor de FOD Sociale Zekerheid Directie-Generaal Sociaal Beleid,2006 [in Dutch].
- 13. Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. Arch Fam Med 1998;7:417-423.
- 14. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes of surrogate decision making before death. N Eng J Med 2010;362:1211-1218.
- 15. Livingston G, Leavey G, Manela M. Making decisions for older people with dementia who lack capacity: qualitative study of family carers in UK. BMJ 2010;341:c4184.

- 16. van der Maas PJ, van Delden JJ, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. Lancet North Am Ed 1991;338:669-674.
- 17. van der Maas PJ, van der Wal G, Haverkate I, er al. Euthanasia, physician-assisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. N Eng J Med 1996;335:1699-1705.
- 18. Seale C. National survey of end-of-life deciseons made by UK medicam practitioners. Palliat Med 2006; 20:3-10.
- 19. Mitchell K, Owens RG. National survey of medical decisions at the end of life made by New Zeeland general practitioners. BMJ 2003; 327:202-203.
- 20. Fainsinger RL, Waller A, Barcovici M, et al. A multicentre international study of sedation for uncontrolled symptoms in terminally ill patients. Palliat Med 2000;14:257-265.
- 21. Miccinesi G, Rietjens JA, Deliens L, et al. Continuous deep sedation: physician's experiences in six European countries. J Pain Symptom Manage 2006;31:122-129.
- 22. Rietjens J. Medical decision-making at the end of life: experiences and attitudes of physicians and the general public. Erasmus Universiteit Rotterdam; 2006.
- 23. Rietjens JA, van Delden JJ, van der Heide A, et al. Terminal sedation and euthanasia: a comparison of clinical practices. Arch Intern Med 2006;166:749-753.
- 24. Chambaere K. Medical end-of-life practices in Flanders and Brussels, Belgium. Vrije Universiteit Brussel, Brussel, 2010.
- 25. Wet betreffende de rechten van de patient [Patients' Rights Act]. Belgisch Staatsblad van 26 september 2002 [Belgian Law Gazette of September 26, 2002] [in Dutch].
- 26. Nys H. Handelen en nalaten door een arts bij een stervende patiënt [Acting and forgoing by a physician in a dying patient]. Panopticon 1995;1:7-24. [in Dutch]
- 27. Sulmasy DP, Pellegrino ED. The rule of double effect: clearing up the double talk. Arch Intern Med 1999; 159(6):545-550.
- 28. Magnusson RS. The devil's choice: re-thinking law, ethics, and symptom relief in palliative care. J Law Med Ethics 2006; 34(3):559-569.
- 29. Wet betreffende euthanasie [Law concerning euthanasia]. Belgisch Staatsblad van 22 juni 2005 [Belgian Law Gazette of June 22, 2002]. [in Dutch]
- 30. Federal Control and Evaluation Committee for Euthanasia. [Information brochure for physicians.] Available at: <u>http://www.ieb-eib.org/fr/pdf/euthanasie-informatiebrochure-artsen.pdf</u>. [in Dutch]

- 31. Committee on National Guideline for Palliative Sedation RDMA. Guideline for palliative sedation. Utrecht:KNMG, 2005.
- 32. Committee on National Guideline for Palliative Sedation RDMA. Guideline for palliative sedation. Utrecht:KNMG, 2009.
- 33. de Graeff A, Dean M. Palliative sedation therapy in the last weeks of life: a literature review and recommendations for standards. J Pall Med 2007;10:67-85.
- 34. Morita T, Tsuneto S, Shima Y. Definition for sedation for symptom relief: a systematic literature review and a proposal of operational criteria. J Pain Symptom Manageme 2002;24:447-453.
- 35. Verhagen E, Hesselman G, Besse T, de Graeff A. Palliatieve sedatie [Palliative sedation]. Ned Tijdschr Geneeskd 2005; 149:458-461. [in Dutch]
- 36. Rousseau P. Palliative sedation and sleeping before death: a need for clinical guidelines? J Pall Med 2003;6:425-427.
- 37. Rousseau P. Existential suffering and palliative sedation: a brief commentary with a proposal for clinical guidelines. Am J Hosp Palliat Care 2001;18:151-153.
- 38. Braun TC, Hagen NA, Clark T. Development of a clinical practice guideline for palliative sedation. J Pall Med 2003;6:345-350.
- 39. The Support Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand pronoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA 1995;274:1591-1598.
- 40. Winzelberg GS, Hanson LC, Tulsky JA. Beyond autonomy: diversifying end-of-life decision-making approaches to serve patients and families. J Am Geriatr Soc 2005;53:1046-1050.
- 41. Singer PA, Martin DK, Kelner M. Quality end-of-life care: patients' perspectives. JAMA 1999;281:163-168.
- 42. Detering KM, Silvester W. The impact of advance care planning on endof-life care in elderly patients: randomized controlled trail. BMJ 2010;340:c1345.
- 43. Blackford J, Strickland E, Morris B. Advance care planning in residential aged care facilities. Contemp Nurse 2007;27:141-151.
- 44. Bell C, Somogyi-Zalud E, Masaki K, et al. Factors associated with physician decision-making in starting tube feeding. J Palliat Med 2008;11:915-924.
- 45. Kuo S, Rhodes RL, Mitchell SL, et al. Natural history of feeding-tube use in nursing home residents with advanced dementia. J Am Med Dir Assoc 2009;10:264-270.

- 46. Dobalian A. Advance care planning documents in nursing facilities: results from a nationally representative survey. Arch Gerontol Geriatr 2006;43:193-212.
- 47. Manias E. Australian nurses' experiences and attitudes in the "Do Not Resuscitate" decision. Res Nurs Health 1998;21:429-441.
- 48. Crane MK, Wittink M, Doukas DJ. Respecting and-of-life treatment preferences. Am Fam Physician 2005;72:1263-1268.
- 49. van Wijnen MPS, Rurup ML, Pasman HRW, Kaspers PJ, Onwuteaka-Philipsen BD. Design of the Advance Directives Cohort: a study of end-oflife decision-making focusing on Advance Directives. BMC Public Health 2010;10:166.
- 50. Rosnick CB, Reynolds SL: Thinking Ahead: Factors Associated with Executing Advance Directives. J Aging Health 2003;15:409-429.
- 51. Tilden VP, Tolle SW, Nelson CA, Fields J: Family decision-making to withdraw life-sustaining treatments from hospitalized patients. Nurs Res 2001;50:105-115.
- 52. Torke AM, Moloney R, Siegler M, Abalos A, Alexander GC.Physicians' Views on the Importance of Patient Preferences in Surrogate Decision-Making. J Am Geriatr Soc 2010;58:533–538.
- 53. Perkin HS. Controlling death: the false promise of advance directives. Ann Intern Med 2007;147:51–7.
- 54. Fried TR, O'Leary J, Van Ness P, Fraenkel L: Inconsistency Over Time in the Preferences of Older Persons with Advanced Ilness for Life-Sustaining Treatment. J Am Geriatr Soc 2007;55:1007-1014.
- 55. Teno JM, Lynn J: Putting advance-care planning into action. J Clin Ethics 1996;7:205-213.
- 56. Barrio-Cantalejo IM, Molina-Ruiz A, Simón-Lorda P, Cámara-Medina C, Toral López I, del Mar Rodríguez del Aguila M, Bailón-Gómez RM: Advance Directives and Proxies' Predictions About Patients' Treatment. Nurs Ethics 2009;16:93-109.
- 57. Schneiderman LJ, Kronick R, Kaplan RM et al. Effects of offering advance directives on medical treatments and costs. Ann Intern Med 1992;117:599–606.
- 58. Teno JM, Lynn J, Phillips RS et al. Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J Clin Ethics 1994;5:23–30.

- 59. Teno JM, Stevens M, Spernak S et al. Role of written advance directives in decision making: Insights from qualitative and quantitative data. J Gen Intern Med 1998;13:439–446.
- 60. Teno JM, Lynn J, Connors AF Jr et al. The illusion of end-of-life resource savings with advance directives. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J AmGeriatr Soc 1997;45:513–518.
- 61. Teno JM, Lynn J, Wenger N et al. Advance directives for seriously ill hospitalized patients: Effectiveness with the patient self-determination act and the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997;45:500–507.
- 62. Teno JM, Licks S, Lynn J et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997;45:508–512.
- 63. Ditto PH, Danks JH, Smucker WD et al. Advance directives as acts of communication: A randomized controlled trial. Arch Intern Med 2001;161:421–430.
- 64. Degenholtz HB, Rhee Y, Arnold RM. Brief communication: The relationship between having a living will and dying in place. Ann Intern Med 2004;141:113–117.
- 65. Koninklijk besluit van 23 oktober 1964 tot bepaling van de normen die door de ziekenhuizen en de diensten moeten worden nageleefd - bijlagen. [Royal decree of October 23, 1964 concerning standards for hospitals and hospital wards – appendices]. Belgisch Staatsblad 7 november 1964 [Belgian Law Gazette of November 7, 1964], gewijzigd bij de Koninklijke besluiten van 12 april 1984 en 25 juni 1985 [changed by the Royal decrees of April 12, 1984 and June 25, 1985]. [in Dutch].
- De Gendt C, Bilsen J, Vander Stichele R, Lambert M, Van Den Noortgate N, Deliens L. Do-not-resuscitate policy on acute geriatric wards in Flanders, Belgium. Journal of the American Geriatrics Society 2005;53:2221-2226.
- 67. Melio M, Jenkinson C. Comparison of medical and nursing attitudes to resuscitation and patient autonomy between a British and an American teaching hospital. Soc Sci Med 1998;46:415-424.
- 68. Frank C, Heyland DK, Chen B, et al. Determining tesuscitation preferences of elderly inpatients: A review of the literature. Can Med Assoc J 2003;169:795-799.
- 69. Cherniack EP. Increasing use of DNR orders in the elderly worldwide: Whose choice is it? J Med Ethics 2002;28:303-307.

- 70. Dautzenberg PLJ, Hooyer C, Schonwetter RS, et al. Cardiopulmonary resuscitation policy in aged inpatients. Basic considerations when entering decisionmaking in the psychogeriatric field. Geriatrie Forsch 1993;3:175-183.
- Vervotte I. Antwoord op schriftelijke parlementaire vraag nr 111 van 16 maart 2007 [Answer to written parlementary question n 111 from March 16, 2007] [online]. http://jsp.vlaamsparlement.be/docs/schv/2006-2007/VERVOTTE/ 111/antw.111.doc (24 July 2008, date last accessed) [in Dutch].
- 72. Koninklijk Besluit van 21 september 2004 houdende vaststelling van de normen voor de bijzondere erkenning als rust- en verzorgingstehuis of als als centrum voor dagverzorging [Royal decree of September 21, 2004 concerning standards for additional recognition as a nursing home or as a day care centre]. Belgisch Staatsblad 28 Oktober 2004 [Belgian Law Gazette of October 28, 2004] [in Dutch].
- 73. De Lepeleire J, Leiman W. Poor effect of family prectice physician training at the organizational level in long-term care facilities in Flanders, Belgium. J Am Med Dir Assoc 2006;7:470.
- 74. Lemiengre J, Dierckx de Casterlé B, Verbeke G, et al. Ethics policies on euthanasia in nursing homes: a survey in Flanders, Belgium. Soc Sci Med 2008;66:376-386.
- 75. Verstraete AG, Vander Stichele R, Deliens L. Ethical issues in pharmacoepidemiological research in Belgium. Pharmacoepidemiol Drug Saf 2001;10:595-599.
- 76. Dillman DA. The design and administration of mail surveys. Annu Rev Sociol 1991;17:225-249.
- 77. Chambaere K, Bilsen J, Cohen J, et.al. A post-mortem survey on end-oflife decisions using a representative sample of death certificates in Flanders, Belgium: research protocol. BMC Public Health 2008;8:299.
- 78. van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007;356:1957–1965.
- 79. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 66:191–196.
- 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;338:1193–1201.
- 81. Bilsen J, Cohen J, Chambaere K, et.al. Medical end-of-life practices under the euthanasia law in Belgium. N Eng J Med 2009;361:1119-1121.
- 82. Haverkate I, van der Wal G. Policies on medical decisions concerning the end of life in Dutch health care institutions. JAMA 1996;275:435-439.

Part II

Medical end-of-life decision-making

and

terminal sedation

at the very end of life

Chapter 2

Medical end-of-life decision-making

and

terminal sedation

among very old patients

De Gendt C, Bilsen J, Mortier F, Vander Stichele R, Deliens L. End-of-life decision making and terminal sedation among very old patients. Gerontology 2009;55:99-105.

ABSTRACT

Background About half of the persons who die in developed countries are very old (aged 80 years or older) and this proportion is still rising. In general, there is little information available concerning the circumstances and quality of the end of life of this group.

Objective This study aims (1) to describe the incidence and characteristics of medical end-of-life decisions with a possible or certain life-shortening effect (ELDs) and terminal sedation among very old patients who died nonsuddenly, (2) to describe the characteristics of the preceding decision-making process, and (3) to compare this with the deaths of younger patients.

Methods A sample of 5,005 death certificates was selected from all deaths in Flanders (Belgium) in the second half of 2001 (before euthanasia was legalized). Questionnaires were mailed to the certifying physicians.

Results Response rate was 58.9%. An ELD was made for 53.6% very old (aged 80+) patients who died nonsuddenly (vs. 63.3% for the younger patients). Use of life-ending drugs occurred among 1.1% (six times less frequently than in younger patients), with no euthanasia cases, pain and symptom alleviation with a possible life-shortening effect among 27.3% (two times less frequently), and withholding or withdrawing life-prolonging treatments among 25.2% (slightly more frequently). Terminal sedation occurred among 6.9% of the cases, two times less frequently than for the younger patients. ELDs were not often discussed with very old patients. Among competent patients this was less than compared with younger patients.

Conclusion ELDs are less common for very old than for younger patients. Physicians seem to have a more reluctant attitude towards the use of lethal drugs, terminal sedation and participation in decision making when dealing with very old patients. Advance care planning should increase the involvement of very old competent and noncompetent patients in end-of-life decision-making.

Acknowledgments

This study was supported by a grant from the Fifth Framework Programme of the European Commission (contract QLRT-1999-30859) and a research grant from the Research Council of the Vrije Universiteit Brussel.

INTRODUCTION

Due to healthier lifestyles, advances in medical knowledge and technological innovation, people in Europe and other developed countries are now living longer than ever before. Life expectancy will continue to rise. Demographers expect that in Flanders (the Dutch-speaking part of Belgium, with six million inhabitants and 1% mortality) the population of very old people, aged 80 years or older, will triple by the year 2050 (from 212,816 in 2000 to 685,297) within a quite stable population total.^{1,2} Many of the very old have serious underlying comorbidities and die after a long period of chronic illness.³ Currently, about half of all persons who die in Flanders are very old (26,841 in 2001) and this proportion is still rising.^{4,5} In general, little information is available concerning the circumstances and quality of the end of life of this group.^{6,7}

Existing studies are restricted to elderly patients in specific care settings (hospitals or nursing homes) and to specific end-of-life decisions with a possible or certain life-shortening effect (ELDs).⁸⁻¹⁰ Studies on all ELD types in all kinds of settings have made no in-depth analysis about the incidence and characteristics of ELDs among very old patients and include all sudden and nonsudden deaths.^{4,11-17} Since an ELD is not likely to be made before sudden deaths and because there are substantial differences in the occurrence of sudden versus nonsudden deaths between age groups (very old patients more often die nonsuddenly),³ it is difficult to interpret differences in ELD incidence figures based on data with all deaths (sudden and non-sudden) as denominator. To investigate whether ELDs are as probable for very old patients as for younger patients, selecting only those patients for whom an ELD was a possibility (nonsudden deaths as denominator) is a more valid way of comparing these age groups. This approach has also been successfully applied when comparing cancer patients with non-cancer patients.¹⁸

Furthermore, nothing has ever been published about the end-of-life decisionmaking process specifically for very old patients. In this age group, decisionmaking is often complicated by patient noncompetence because of dementia or other final stage diseases.

This study aims (1) to describe the incidence and characteristics of ELDs and terminal sedation among very old patients in a nationwide representative sample of nonsudden deaths covering all care settings, (2) to describe the characteristics of the preceding decision-making process, and (3) to compare this with the deaths of younger patients.

METHODS

Design

This study is a subanalysis of a published study conducted in Flanders (Belgium) in 2001, the year before euthanasia was legalized in Belgium.⁴

In Flanders, all deaths are reported to the Health Care Division of the Ministry of Flanders, through death certificates. All deaths of those aged one year or older taking place between June and December 2001 (N = 26,229) were stratified for the likelihood that an ELD had preceded the patient's death. Larger samples were taken for the strata in which the cause of death had made an ELD more likely. A sample of 5,005 death certificates was randomly selected. For each sampled death certificate the certifying physician was sent an anonymous, structured questionnaire about the medical end-of-life decision-making which might have preceded death. To assure an appropriate response rate, the principles of the Total Design Method were used, including up to three follow-up mailings in cases of nonresponse.¹⁹

Questionnaire

The questionnaire for this study was based on those used in previous retrospective surveys of physicians identified as certifying physicians in a sample of death certificates.^{11,13,14}

One part of the questionnaire asked respondents in detail about actual medical practices at the end of the patient's life and whether they explicitly intended, cointended or did not intend to shorten the patient's life with this practice. Words such as 'euthanasia' and 'physician-assisted suicide' were avoided because of possible confusion and ethical connotations. Answers to these questions could be classified into three main categories of ELDs in accordance with robust previous studies on ELDs: (1) nontreatment decision: withholding or withdrawing a probable life-prolonging medical treatment while taking into account the possibility that this would hasten the patient's death or with the explicit intention of hastening the patient's death, (2) alleviation of pain and/or other symptoms: intensifying pain and/or symptom alleviation while taking into account the possibility that this would hasten the patient's death or with the co-intention of hastening the patient's death, and (3) physician-assisted dying: using life-ending drugs with the explicit intention of hastening the patient's death. A case was considered as euthanasia only when these drugs were administered by the physician at the patient's explicit request; as physician-assisted suicide, when the patient had taken the drug him/herself; or as life-ending acts without the patient's explicit request when drugs were administered without the explicit
request of the patient.^{11,13,14} If more than one ELD was reported for one patient, the decision with the most explicit life-shortening intention prevailed over the others, and in cases of similar intention, physician-assisted dying prevailed over alleviation of pain and/or symptoms, and the latter prevailed over non-treatment decisions.

When an ELD was made, respondents were asked to give more detailed information about the preceding decision-making process. Beside ELDs, physicians were finally asked whether the patient received drugs, such as barbiturates or benzodiazepines, to keep him/her continuously in deep sedation or coma until death (terminal sedation).²⁰

After data-collection, questionnaires were linked to information about the deceased patient on the death certificate (e.g. demographic data, place and cause of death) and were provided anonymously to the researchers.

Ethical considerations

A complex mailing procedure, approved by the Belgian National Disciplinary Board of Physicians and supervised by a legal attorney, was developed to assure anonymity for physicians and patients. The study was also approved by the Ethical Review Board of the Universitair Ziekenhuis Brussel (Belgium).

Analysis

Prior to the analysis, data were adjusted for disproportional stratification of the sample and weighted for patient characteristics (sex, age, place and cause of death) of all deaths in Flanders during the study period. Results are presented as unweighted numbers and weighted percentages. Because there was only one case of physician-assisted suicide reported, these results are presented together with the euthanasia cases.

To compare incidences and characteristics of the total proportion of ELDs and of all ELD types separately among very old patients versus younger patients, Fisher's exact tests were used. Logistic regression models (enter method) were performed to isolate the effect of the patient's age, adjusted for the patient's sex, educational level, living situation, cause and place of death. Analyses were performed using the statistical packages SPSS 15.0 (SPSS Inc., Chicago, III., USA) and StatXact 5 (Cytel Software Corporation, Cambridge, Mass., USA). p < 0.05 was considered statistically significant.

More details about the methodology are reported elsewhere.⁴

RESULTS

A total of 2,950 (58.9%) physicians returned their questionnaire. In two cases, the age of the deceased was missing and they were therefore excluded from analysis (N = 2,948). Since data were adjusted for disproportional stratification of the sample and weighted for patient characteristics (sex, age, place and cause of death) of all deaths in Flanders during the study period, figures are further presented as unweighted numbers and weighted percentages.

Of the studied deaths, 48.8% (N = 1,338) were very old (aged 80 years or older), and 51.2% (N = 1,610) were younger (aged between 1 and 79 years). Very old patients more often died nonsuddenly (81.1%) compared to younger patients (72.0%, p < 0.001).

For the purposes of this study only the nonsudden deaths were selected (N = 2,127), of which 52.7% (N = 998) were very old patients and 47.3% (N = 1,129) younger.

Demographic and Clinical Differences between Age Groups

The profile of very old patients was significantly different from that of younger patients. They were more often female (63.4 vs. 38.5%, p < 0.001), had in general received a low level of education (72.8 vs. 42.9%, p < 0.001) and were living more often in an institution (46.4 vs. 11.1%, p < 0.001) (Table 2.1). Cardiovascular disease (42.7 vs. 23.9%) and dementia (7.2 vs. 1.9%) were more frequently reported as main cause of death and malignant disease less frequently (18.3 vs. 50.8%, p < 0.001), and they died more frequently in a nursing home (37.6 vs. 7.8%, p < 0.001).

Incidence of End-of-Life Decisions and Terminal Sedation

Among 53.6% of very old patients at least one ELD was made (Table 2.2). In 1.1% drugs were used with the explicit intention of shortening the patient's life. Euthanasia/physician-assisted suicide was not found. Pain and symptom alleviation occurred among 27.3% (life shortening was rarely co-intended) and nontreatment decisions were made among 25.2%.

Terminal sedation was performed among 6.9%, mostly with administration of artificial food and fluids.

The total proportion of ELDs among very old patients was lower than among younger patients (53.6 vs. 63.3%), but not significantly different after multivariate logistic regression. Life-ending acts without the patient's explicit request (1.1 vs. 3.8%, adjusted odds ratio (OR) = 0.179, confidence interval (CI) = 0.071-0.452)

and alleviation of pain and symptoms with life-shortening effect co-intended (2.8 vs. 6.0%, OR = 0.533, CI = 0.291–0.976) occurred less frequently than among younger patients.

When correcting for the patient's cause of death, the higher incidence of nontreatment decisions among very old patients (25.2 vs. 18.9%) was no longer significant, with patients dying from cancer dying less frequently after a nontreatment decision than patients with another cause of death.

Terminal sedation with or without administration of artificial food and fluids was used less frequently among older patients than among younger patients (6.9 vs. 19.4%, OR = 0.424, CI = 0.292-0.616).

End-of-Life Decision-Making Process

Among all patients with at least one ELD (N = 1,344), 48.6% (N = 568) were very old and 51.4% (N = 776) were younger (Table 2.3). About four fifths of the very old patients for whom an ELD was made were noncompetent.

For the total proportion of ELDs and for pain and symptom alleviation with possible life-shortening effect this was significantly higher for very old patients than for younger patients (82.6 vs. 66,4%, p < 0.001, and 78.3 vs. 59,2%, p < 0.001, respectively).

Competent very old patients were involved in end-of-life decision-making in 56.1% of the cases. They were always involved in decision-making when lethal drugs were used, but in only 45.1% of the cases of pain and symptom alleviation with possible life-shortening effect. A quarter of all ELDs among competent very old patients were not discussed with the patient nor the patient's relatives.

Nurses were consulted in decision-making in about 60.1% of all ELDs for very old patients, most often for nontreatment decisions (71.9%). Another physician was consulted less frequently (34.9%). Compared to competent younger patients, competent very old patients were less frequently involved in end-of-life decision-making (56.1 vs. 71.9%, p = 0.017). ELDs among the oldest age group were less frequently discussed with another physician than in younger patients (34.9% vs. 53.9%, p = 0.003).

For noncompetent very old patients, different types of ELDs were usually discussed with the patient's relatives, and in about 30% of cases the physician had discussed the ELD with the patient or was aware of the patient's previous wish. Another physician was consulted in less than half of the cases of pain and symptom alleviation (41.5%) and nontreatment decisions (45.5%). With regard to nontreatment decisions, this is significantly less than for younger patients (64.3%, p = 0.001). Nurses were frequently consulted concerning the use of

lethal drugs (88.9%), alleviation of pain and symptoms (68.3%) and non-treatment decisions (69.5%). Regarding alleviation of pain and symptoms, this is significantly higher than for younger patients (55.6%, p = 0.013).

	1 - 79 years		>= 80 y	/ears	P-value*
	(N=1129)		(N=9	98)	
	Ν	%	Ν	%	
Sex					
Male	689	61.5	403	36.6	
Female	440	38.5	595	63.4	<.001
Educational level†					
Primary education or lower	347	42.9	548	72.8	
Lower secondary education	281	32.4	137	16.9	
Higher secondary education	175	18.1	48	6.1	
Higher education or university	64	6.6	32	4.3	<.001
Living environment‡					
Alone	163	15.5	172	18.2	
Private household	845	73.3	360	35.3	
Institution	112	11.1	453	46.4	<.001
Cause of death					
Cardiovascular diseases	126	23.9	281	42.7	
Malignant diseases	799	50.8	341	18.3	
Respiratory diseases	83	9.5	171	14.2	
Diseases of the nervous system	13	1.3	14	1.2	
Dementia	15	1.9	54	7.2	
Other/unknown	93	12.7	137	16.4	<.001
Place of death§					
Home	458	27.5	231	16.5	
Hospital	579	64.4	367	45.7	
Nursing home	88	7.8	397	37.6	
Other	3	0.3	2	0.2	<.001

Table 2.1 Characteristics of nonsudden deaths (N=2127)

Numbers are unweighted; percentages are weighted for stratification and nonresponse

* Fisher's exact test

† 495 missings

‡22 missings

§ 2 missings

Table 2.2 End-of-Life Decisions According to Patients' Age (N=2127)

	Tota	al	1 - 79 y	1 - 79 years		80 years and older		Odds Ratio [†]	
	Ν	%	N	%	N	%	P-value*	Adjusted	CI
Number of nonsudden deaths	2127		1129		998				
Nonsudden deaths with end-of-life decisions	1344	58.2	776	63.3	568	53.6	< .001	NS§	
Use of drugs with the explicit intention of shortening the patient's life	74	2.8	60	4.7	14	1.1	< .001	0.168	0.068 - 0.416
- Euthanasia/physician-assisted suicide	16	0.4	16	0.9	-	-	.002	11	
 Life-ending act without the patient's explicit request 	58	2.4	44	3.8	14	1.1	< .001	0.179	0.071 - 0.452
Alleviation of pain and symptoms with possible life-shortening effect	839	33.2	526	39.7	313	27.3	< .001	NS§	
 Taking into account life shortening 	724	28.9	447	33.7	277	24.6	< .001	NS¶	
- Life shortening co-intended	115	4.3	79	6.0	36	2.8	.001	0.533	0.291 - 0.976
Non-treatment decisions with possible life- shortening effect	431	22.2	190	18.9	241	25.2	.001	NS**	
- Taking into account life shortening	171	9.3	67	7.0	104	11.4	.001	NS**	
- Life shortening explicitly intended	260	12.9	123	11.9	137	13.8	.222		
Nonsudden deaths with terminal sedation‡	237	12.8	179	19.4	58	6.9	< .001	0.424	0.292 - 0.616
Without administration of food and fluids‡	117	4.9	89	7.4	28	2.7	< .001	0.473	0.264 - 0.847
With administration of food and fluids‡	120	7.9	90	12.0	30	4.1	< .001	0.427	0.269 - 0.679

Numbers are unweighted; Percentages are weighted for stratification and non-response.

* Fisher's exact test.

† Odds ratio of logistic regression with patients 1-79 years as reference group.

‡ 57 missings.

§ The only significant predictor is cause of death, with patients dying from cancer having higher odds of dying after this end-of-life decision.

|| Calculation of odds ratio for euthanasia/physician-assisted suicide was not possible because no occurrences were reported in the group of very old patients.

¶ The only significant predictors are educational level and cause of death, with the highest educated patients having lower odds and patients dying from cancer having higher odds of dying after this end-of-life decision.

** The only significant predictor is cause of death, with patients dying from cancer having lower odds of dying after this end-of-life decision

Table 2.3 Characteristics of the End-of-Life Decision-Making Process, 1-79 Years versus 80 Years or Older (N=1344)

End-of-Life Decisions*	PAD		APS		NTD		All ELDs	
	1-79y	>= 80y	1-79y	>= 80y	1-79y	>= 80y	1-79y	>= 80y
	N=60	N=14	N=526	N=313	N=190	N=241	N=776	N=568
	•	%	(%	Q	%	•	%
	37.2	18.2	<u>40.8</u>	<u>21.7</u>	18.9	13.1	<u>33.6</u>	<u>17.4</u>
Patient was competent †	N=28	N=4	N=199	N=64	N=43	N=40	N=270	N=108
-Decision discussed with patient ‡	87.5	100.0	<u>68.5</u>	<u>45.1</u>	76.7	72.7	<u>71.9</u>	<u>56.1</u>
-Not discussed, but patient had expressed a wish	6.3	0.0	6.5	7.7	10.0	9.4	7.4	8.6
 Decision discussed with patient's relatives ‡ 	93.8	100.0	69.7	61.2	80.0	81.3	73.7	69.9
-Decision not discussed with patient or relatives ‡	6.3	0.0	21.1	34.7	3.3	18.8	16.4	27.6
-Discussion with: - Other physician	56.3	0.0	<u>55.3</u>	<u>35.3</u>	46.7	34.4	<u>53.9</u>	<u>34.9</u>
- Nursing staff	50.0	0.0	59.7	53.8	46.7	71.9	56.2	60.1
- No other caregiver	13.3	0.0	7.3	5.8	10.0	15.6	8.8	9.5
	62.8	81.8	<u>59.2</u>	<u>78.3</u>	81.1	86.9	<u>66.4</u>	82.6
Patient was non-competent †	N=31	N=10	N=239	N=198	N=134	N=188	N=404	N=396
-Decision discussed with patient ‡	29.6	0.0	13.6	16.8	14.1	14.2	14.8	15.2
-Not discussed, but patient had expressed a wish	14.8	22.2	12.2	13.6	10.9	14.2	11.8	14.1
 Decision discussed with patient's relatives ‡ 	88.9	100.0	72.4	71.1	86.8	81.4	79.4	77.2
-Decision not discussed with patient or relatives ‡	7.4	0.0	26.0	27.2	13.2	17.6	19.2	22.6
-Discussion with: - Other physician ‡	66.7	66.7	46.9	41.5	<u>64.3</u>	<u>45.5</u>	<u>54.9</u>	<u>44.3</u>
- Nursing staff ‡	73.1	88.9	<u>55.6</u>	<u>68.3</u>	69.0	69.5	62.1	69.3
- No other caregiver ‡	3.7	11.1	8.3	10.4	10.9	13.2	8.9	12.1

Numbers are unweighted; percentages are weighted for stratification and non-response; significant differences in frequencies between patients aged between 1 and 79 years and very old patients are printed in bold and underlined (Fisher's Exact test)

* PAD= physician-assisted dying, including euthanasia, physician-assisted suicide and life-ending acts without the patient's explicit request; APS= alleviation of pain and symptoms with possible life-shortening effect, life-shortening not intended or co-intended; NTD= nontreatment decision with possible life-shortening effect, life-shortening effect, life-shortening not intended.

†Competence of the patient was unknown, because data missing for 1 PAD-case, 88 APS-cases and 13 NTD-cases in the group of patients aged between 1 and 79 years, and for 51 APS-cases and 13 NTD-cases in the group of very old patients.

[‡] The number of missing data for the different actors in discussion varied between 0 and 7 for both patient groups.

DISCUSSION

To our knowledge, this is the first nationwide study of ELDs and terminal sedation focusing on nonsudden deaths of very old patients across all care settings and disease groups, comparing them with younger patients. End-of-life decision-making among very old patients proved to be significantly different from that in younger patients. The death certificate study was judged a highly reliable method of estimating ELD incidences in a population.^{4,11-14}

There are some limitations related to this study. First, although the response rate was satisfactory, response bias remains a possibility, especially underreporting of ELD types that were illegal at the time of data collection (physician-assisted dying). However, since the weighted sample was representative for the population and anonymity was guaranteed, results can be considered as valid estimates of the true frequency of ELDs. Second, findings are based on self-reports of physicians and errors in the perceptions of their acts cannot be excluded, for example as a result of overestimating the actual life-shortening effect of symptom-alleviating medication such as opiods.²¹

Findings of this study are at some points different from those of previous studies where sudden, unexpected deaths were included in the denominator.^{4,11-14} In such studies, nontreatment decisions are found to be more frequent in the very old, while no differences in the prevalence of alleviation of pain and symptoms is found between age groups.

In the current study, with only nonsudden deaths in the denominator, the differences in frequency of nontreatment decisions disappears after correction for cause of death, while the incidence of alleviation of pain and symptoms and terminal sedation is lower among very old patients. One hypothesis to explain this difference is that there is poor recognition of pain and other suffering at the end of life of very old patients, due to dementia and poor diagnostic tools.^{8,22,23}

The finding that physician-assisted dying occurred less frequently among very old patients is a confirmation of previous results. After correction for other patient characteristics the difference between both age groups is even larger. In addition, euthanasia is not reported at all among very old patients. This reluctance to use euthanasia for very old patients suggests either that these older patients request euthanasia less often than younger patients, or it indicates that requests for euthanasia in this age group are not addressed, due to complicated or suboptimal end-of-life communication.²⁴

More than four of five very old patients who died after an ELD were judged as noncompetent. These patients are as rarely involved in end-of-life decisionmaking as younger noncompetent patients. Among competent patients with an ELD, the oldest are less frequently involved in decision making than younger patients. A substantial number of nontreatment decisions and alleviation of pain and symptoms with a possible life-shortening effect are not discussed with the patient, nor with the patient's relatives. Hence, values and wishes might not be taken into account in the end-of-life decision-making process, and possible unwanted interventions could not be avoided. In the future, it can be expected that elderly patients will become more involved since the educational level is rising and more highly educated patients are likely to be involved in end-of-life decision-making.

Nurses are more often consulted than other physicians before making an ELD for an older patient. This might be related to the fact that most very old patients die in an institution and are surrounded by nurses. In this situation, nurses have an important role in informing physicians about the patient's health status and wishes. Moreover, research shows that, in institutionalized care, nurses are more often consulted by physicians when the patient is less well educated.²⁵ Since very old patients are in general less well educated, nurses can act as intermediaries who can close the gap between patients and physicians.

In conclusion, this study demonstrates that physicians are more reluctant towards patient participation in end-of-life decision-making and the use of lethal drugs and terminal sedation when dealing with very old patients compared to younger patients. Actively consulting patients or their relatives and starting up advance care planning as early as possible might facilitate the involvement of competent as well as noncompetent patients in end-of-life decision-making.

REFERENCES

- Federale Overheidsdienst Economie [Federal Public Service Economy]: Mathematische demografie [Demographics]. http://www.statbel.fgov.be/figures/d23_nl.asp#4. Accessed January 14, 2008.
- Federale Overheidsdienst Economie [Federal Public Service Economy]: Mathematische demografie: Bevolkingsvooruitzichten [Demographics: Population prospects]. http://www.statbel.fgov.be/pub/d2/p231y2000– 2050_nl.pdf. Accessed January 14, 2008.
- 3. Lunney JR, Lynn J, Hogan C. Profiles of older Medicare decedents. J Am Geriatr Soc 2002;50:1108–1112.
- 4. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362:345–350.
- 5. Cohen J, Bilsen J, Hooft P, Deboosere P, van der Wal G, Deliens L. Dying at home or in an institution using death certificates to explore the factors associated with place of death. Health Policy 2006;78:319–329.

- 6. Lloyd-Williams M, Kennedy V, Sixsmith A, Sixsmith J. The end of life: a qualitative study of the perceptions of people over the age of 80 on issues surrounding death and dying. J Pain Symptom Manage 2007;34:60–66.
- De Gendt C, Bilsen J, Van Den Noortgate N, Lambert M, Vander Stichele R, Deliens L. Prevalence of patients with do-not-resuscitate status on acute geriatric wards in Flanders, Belgium. J Gerontol A Biol Sci Med Sci 2007;62:395–399.
- Somogyi-Zalud E, Zhong Z, Lynn J, Hamel MB. Elderly persons' last six months of life: findings from the Hospitalized Elderly Longitudinal Project. J Am Geriatr Soc 2000;48:S131–S139.
- 9. Somogyi-Zalud E, Zhong Z, Hamel MB, Lynn J. The use of life-sustaining treatments in hospitalized persons aged 80 and older. J Am Geriatr Soc 2002;50:930–934.
- 10. Hickman SE, Tolle SW, Brummel-Smith K, Carley MM. Use of the Physician Orders for Life-Sustaining Treatment program in Oregon nursing facilities: beyond resuscitation status. J Am Geriatr Soc 2004;52:1424–1429.
- 11. Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356:1806–1811.
- 12. van der Heide A, Onwuteaka-Philipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Engl J Med 2007;356:1957–1965.
- 13. van der Maas PJ, van Delden JJ, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. Lancet 1991;338:669–674.
- 14. van der Maas PJ, van der Wal G, Haverkate I, 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;335:1699–1705.
- 15. Kuhse H, Singer P, Baume P, Clark M, Rickard M. End-of-life decisions in Australian medical practice. Med J Aust 1997; 66:191–196.
- 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;338:1193–1201.
- 17. Mitchell K, Owens RG. National survey of medical decisions at end of life made by New Zealand general practitioners. BMJ 2003;327:202–203.
- Van den Block L, Bilsen J, Deschepper R, Van der Kelen G, Bernheim JL, Deliens L. End-of-life decisions among cancer patients compared with noncancer patients in Flanders, Belgium. J Clin Oncol 2006;24:2842– 2848.

- 19. Dillmann DA. The design and administration of mail surveys. Annu Rev Sociol 1991;17:225–249.
- 20. Miccinesi G, Rietjens JA, Deliens L, et al. Continuous deep sedation: physicians' experiences in six European countries. J Pain Symptom Manage 2006;31:122–129.
- 21. Bilsen J, Norup M, Deliens L, et al. Drugs used to alleviate symptoms with life shortening as a possible side effect: end-of-life care in six European countries. J Pain Symptom Manage 2006;31:111–121.
- 22. Davies E, Higginson I. Better Palliative Care for Older People. Milan, WHO, 2004, pp 1–40.
- 23. Roger KS. A literature review of palliative care, end of life, and dementia. Palliat Support Care 2006;4:295–303.
- 24. Vlaams Agentschap Zorg & Gezondheid [Flemish Agency for Care and Health]: Statistiek doodsoorzaken [Cause-of-death statistics]. http://www.zorg-en-gezondheid.be/statistiek-doodsoorzaken.aspx. Accessed January 14, 2008.
- 25. Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: a death certificate study. Int J Nurs Stud 2008;45:1022–1031.

Part III

Do-not-resuscitate decision-making

on acute geriatric wards

Chapter 3

Do-not-resuscitate policy

on acute geriatric wards

De Gendt C, Bilsen J, Vander Stichele R, Lambert M, Van Den Noortgate N, Deliens L. Do-not-resuscitate policy on acute geriatric wards in Flanders, Belgium. Journal of the American Geriatrics Society 2005;53:2221-2226.

ABSTRACT

Objectives To describe the historical development and status of a do-not-resuscitate (DNR) policy on acute geriatric wards in Flanders, Belgium, and to compare it with the international situation.

Design Structured mail questionnaires.

Setting All 94 acute geriatric wards in hospitals in Flanders in 2002 (the year Belgium voted a law on euthanasia).

Participants Head geriatricians.

Measurements A questionnaire was mailed about the existence, development, and implementation of the DNR policy (guidelines and order forms), with a request to return copies of existing DNR guidelines and DNR order forms.

Results The response was 76.6%, with hospital characteristics not significantly different for responders and nonresponders. Development of DNR policy began in 1985, with a step-up in 1997 and 2001. In 2002, a DNR policy was available in 86.1% of geriatric wards, predominantly with institutional DNR guidelines and individual, patient-specific DNR order forms. Geriatric wards in private hospitals implemented their policy later (P = .01) and more often had order forms (P = .04) than those in public hospitals. The policy was initiated and developed predominantly from an institutional perspective by the hospital. The forms were not standardized and generally lacked room to document patient involvement in the decision making process.

Conclusion Implementation of institutional DNR guidelines and individual DNR order forms on geriatric wards in Flanders lagged behind that of other countries and was still incomplete in 2002. DNR policies varied in content and scope and were predominantly an expression of institutional defensive attitudes rather than a tool to promote patient involvement in DNR and other end-of-life decisions.

Acknowledgements

The authors thank Annemie Van Hofstraeten, MSc, for participation in the study concept and design and acquisition of subjects and data.

INTRODUCTION

Cardiopulmonary resuscitation (CPR) was developed in the early 1960s as a simple and effective technique to treat cardiac arrest during anesthesia. In subsequent years, its application spread to almost every patient experiencing cardiopulmonary arrest, regardless of the underlying disease. This resulted in an increased rate of resuscitations and in reduced success rate of CPR. As a result, healthcare institutions and professionals started to consider CPR to be futile in certain cases. This led increasingly to decisions not to resuscitate patients or to perform a less-than-full resuscitation attempt^{1,2} and a growing trend to formalize the process of these decisions in a written policy, called a do-not-resuscitate (DNR) policy. Such a formal institutional policy is especially relevant for hospitals with acute geriatric patients, because they have a greater immediate risk of cardiopulmonary arrest, and many of them are less likely to benefit from CPR because of severe underlying comorbidity.³⁻⁶

In the United States, legislation has governed the use of DNR decisions since the 1970s and later on in Canada and Australia.⁷ In response to fear of potential litigation and to the professional need to determine the conditions under which DNR decisions are appropriate, U.S. hospitals began to describe their own DNR policies in 1974 as an institutional self-defense strategy.^{1,3,8–10} These policies also enhanced communication and accountability regarding DNR decisions.^{1,8,11} To minimize inappropriate CPR, due to nursing staff being unaware of patients' DNR status, some hospitals started to use individualized, preprinted DNR order forms to improve relevant patient communication between healthcare professionals.^{12–15} This even appeared to result in an increase in the frequency of DNR decisions.¹⁶

Since 1988, all acute care hospitals in the United States have been required to have DNR policies to meet accreditation standards, and since 1991, hospitals have been required to inform patients of their right to refuse medical treatment (Patient Self-Determination Act).¹⁰ Furthermore, they are obliged to document patients' or designated surrogates' consent in a written record before making a DNR decision.⁷

DNR policies are now commonplace in the United States, Canada, and Australia. In Europe, such policies are less widespread and exist almost exclusively at the institutional level.^{2,17–19} In the Netherlands, where the public debate concerning end-of-life decisions started much earlier than in the rest of Europe, 54% of hospitals had a DNR policy in 1995.²⁰ In Belgium, no information is available about the level of implementation of DNR policies. Although Belgium was the second country in the world to legalize euthanasia in 2002,²¹ there is still no legislation regarding DNR decision-making on geriatric wards or other settings in Flanders, except for a general section on futile treatments in the Belgian Medical Deontological Code.²² In 1997, the National Disciplinary Board of Physicians

issued a specific recommendation concerning communication about DNR decisions with patients, relatives, nurses, and colleagues; the (re)evaluation of DNR decisions; and the responsibility of the hospital's ethical council for the institutional policy regarding end-of-life care.²³

The aim of this study was to describe the existence, development, and implementation of DNR policies on acute geriatric wards in Flanders and to compare it with the international situation. The content of DNR guidelines and DNR order forms was also investigated. The hypothesis was that the implementation process was incomplete and institutionally driven.

The setting of this study is Flanders, the Dutch-speaking part of Belgium, where about 60% (6 million) of the Belgian population lives, with 16.5% elderly people (aged >=65). Within the healthcare system of the country, specialized acute geriatric wards are embedded in acute hospitals.²⁴ At the end of their hospitalization geriatric patients are triaged to home, a rehabilitation facility, or a home for older people - a geriatric residential long-term care facility where nurses provide supervision and assistance in activities of daily living and patients are eventually under the medical care of their general practitioner. In 2002, there were 4,072 acute geriatric beds in Flanders, with a yearly occupancy rate of 85.9%, serving 41,138 hospitalizations, with an average length of stay of 31 days (unpublished data). Certification criteria for acute geriatric wards are a minimum of 24 beds and supervision by a geriatrician (a specialist in internal medicine with a supplementary 1-year specialization in geriatric medicine).

METHODS

Design

This study was conducted in the spring of 2002 in Flanders, where there are 70 acute hospitals, 64 of which have an acute geriatric ward. Of these 64 hospitals with an acute geriatric ward, some had more than one hospital site, often with different policies. This situation resulted from previous administrative mergers between formerly independent hospitals. There were 94 hospital sites in Flanders with an acute geriatric ward, which were all included in this study. (Thirty-nine hospitals had one site with a geriatric ward, 21 had two sites, three had three sites, and one had four sites.) A list of these hospital sites was obtained from administrative hospital databases from the National and Regional Ministries of Health, including addresses and characteristics such as ownership (private/public), type of hospital (general/university), bed capacity of the hospital site, availability of an intensive care unit and a palliative support team, and bed

capacity of the geriatric ward. On each hospital site, the head geriatrician, identified as the respondent for that geriatric ward (N=94), was sent a structured mail questionnaire about the DNR policy in his or her institution. To assure an appropriate response rate, the Total Design Method was used.²⁵ One week before the first mailing of the questionnaire in April 2002, a recommendation letter from the Belgian Society of Gerontology and Geriatrics was sent to the geriatricians. A follow-up card was sent to all 1 week after the first mailing. Two weeks later, a follow-up letter was mailed to the nonrespondents with a copy of the questionnaire. After another 2 weeks, a telephone call was made to those who had still not responded. Another copy of the questionnaire was then sent to the physicians who indicated their intention to fill in the questionnaire.

Nonresponse analysis would only have been performed if response of less than 70% was reached. After data collection and linkage of the returned questionnaires to the databases of the ministries, the database was anonymized.

Questionnaire

The questionnaire consisted of 24 questions, all about the institutional DNR policy on the acute geriatric ward. Two possible aspects of this policy were explored: institutional DNR guidelines and individual, patient-specific DNR order forms, which were defined in the questionnaire as follows:

DNR guidelines: a protocol about the decision-making process, approved by the hospital, containing formalized agreements to guide physicians on how to approach the patient in case of a cardiopulmonary arrest.²⁰

DNR order form: a standardized form, or a section of it, on which fixed categories of DNR decisions and possible other nontreatment decisions could be registered for an individual patient.

Key questions were: "Is a DNR order form available on the (acute) geriatric ward? Yes/no/don't know" and "Are DNR guidelines available on the (acute) geriatric ward? Yes/no/don't know." When at least one of these documents was available, respondents were asked in what year it had been implemented and to return copies with their completed questionnaire to analyze their content. Questions were also asked concerning development and implementation of the DNR policy on the acute geriatric ward. With the consent of one of its authors, an existing questionnaire regarding policies and guidelines in medical decisions concerning the end of life in health care in the Netherlands inspired part of the questionnaire.²⁰

Two geriatricians thoroughly reviewed the questionnaire, which a group of 15 physicians then pilot tested, resulting in minor adaptations to avoid ambiguity and to improve understanding.

Data Analysis

Before the analysis, the response sample was tested for representativeness using the hospital and ward characteristics of the databases earlier mentioned. The geriatric ward on the hospital site was considered the unit of analysis. Descriptive results were presented in frequency tables and crosstabs, and differences in distribution (Fisher exact test) and variance (Kruskal-Wallis) were calculated using the statistical packages SPSS 12.0 (SPSS Inc., Chicago, IL) and StatXact 5 (Cytel Software Corporation, Cambridge, MA). Ninety-five percent confidence intervals were used.

RESULTS

Characteristics of Hospital Sites

Of all the head geriatricians from the 94 hospital sites with an acute geriatric ward, 72 completed and returned the questionnaire concerning DNR policy on the acute geriatric ward of their hospital site (76.6% response rate). Characteristics of hospital sites from the 72 returned questionnaires were compared with the nonresponse sample for ownership (private/public), type of hospital (general/university), bed capacity of the hospital site, availability of an intensive care unit and a palliative support team, and bed capacity of the geriatric ward. No significant differences were found.

Of the hospital sites in the response sample, 69.4% were private institutions, predominantly (all but 2) of Catholic denomination. Four percent were university hospitals. The mean bed capacity of the hospital sites was 285 (range 32–1359), with fewer than 200 beds in 41.7%, between 200 and 399 beds in 40.3%, and 400 beds or more in 18.1%. An intensive care unit (91.7%) and a palliative support team (95.8%) were available on almost every hospital site. In the geriatric wards, the mean bed capacity was 41 (range 24–96), with 31.9% at the minimum bed capacity (24 beds) and 27.8% having more than 48 beds.

Development of DNR Policy

On 86.1% of the geriatric wards, some kind of DNR policy was available (Table 3.1). In 61.1% of the institutions, the presence of an institutional DNR guideline as well as an individual, patient-specific DNR order form was observed. Only DNR guidelines were available in 22.2% of the wards, and 2.8% had only a DNR order form. At the time of the study, 13.9% had no DNR policy, but half of

those were developing one. Geriatric wards in private hospital sites had more DNR order forms, with or without DNR guidelines, than those in public hospital sites (P = .04), but no significant differences were found for other characteristics of the hospital site or acute geriatric ward. The first DNR guideline was implemented in 1985, and it took until 1990 before other geriatric wards followed (Figure 3.1). In 1995, when 14.3% of geriatric wards had implemented DNR policies, the first individual DNR order form was developed in a public institution. From then on, geriatric wards mostly implemented DNR guidelines together with a DNR order form. Private institutions lagged behind in the implementation process until 2000 but stepped up in 2001 and eventually surpassed the public institutions.

Of the geriatric wards with a DNR policy in 2002, more than half had implemented their DNR policy after 1998. Of the geriatric wards with a DNR policy, those in private hospital sites had had a DNR policy for 4 years, on average, whereas geriatric wards in public hospital sites had had such a policy on average for 7 years (P = .01).

Characteristics of Implementation

The hospital, and not patients or their next of kin, mostly initiated the development of DNR policies (Table 3.2). Until 1995, the initiative lay with individual members of the staff (sometimes involved directly in a problematic patient event). Later on, the staff or the medical ethical council (advisory body of the hospital concerning general or individual ethical aspects), the medical board (the delegation of physicians of the hospital in the management of the hospital), or both took the initiative to develop a policy in the institution. The majority of geriatric wards developed their policy in consultation with physicians (80.8%), the medical ethical council (63.5%), and nurses (57.7%) but not with patient organizations.

In 75.0% of wards, patients are informed about the existence and implementation of the DNR policy but not in a systematic way. Next of kin are almost always notified about the policy, as are physicians and nurses on the geriatric ward. Social workers (34.6%) and other caregivers (19.2%) are less informed. Caregivers from other wards in the hospital (physicians, nurses, and social workers) are notified somewhat less frequently. Physicians outside the hospital, mostly general practitioners, are informed in about one in 10 cases.

On 28.0% of the geriatric wards with a DNR policy, the head geriatrician reported dissatisfaction with this policy, requesting the introduction or adaptation of the individual DNR order form or, to a lesser extent, of the institutional DNR guidelines.

Description of DNR Guidelines and DNR Order Forms

Institutional guidelines were returned for 33 (55.0%) of the 60 geriatric wards with an available DNR guideline. They varied greatly in wording and in the nature and number of items treated.

Of the 46 geriatric wards that had a DNR order form available, 34 (73.9%) returned a copy with the completed questionnaire. Eighty-two percent of these documents were separate forms, and 17.6% were nursing notes with a specific section for DNR decisions. Twelve percent of the DNR order forms had DNR guidelines printed on the reverse, and 76.5% had a preprinted space for (re)evaluation of a DNR decision made earlier.

Except for one DNR order form, all provided a coding space for the formal confirmation of a DNR decision by the treating physician and, less often, by a second physician (17.6%) or head nurse (5.9%). On 61.8% of the DNR order forms, no space was left for information about consultation with others before a DNR decision was made. On about one quarter of the DNR order forms, it could be indicated whether a second physician, next of kin, the patient, (head) nurses, or the general practitioner had been consulted in DNR decision-making. Almost one third of the DNR order forms could also be used to explicitly request resuscitation attempts for a patient.

On 91.2% of the DNR forms, additional preprinted categories to order nontreatment decisions (antibiotics, hemodialysis) were present, and on 14.7%, there was a place to enter requests to withhold and withdraw artificial administration of food and fluids.

	Total	Ownership type		
		Private	Public	
		N = 50	N = 22	
	N (%)	N (%)	N (%)	
DNR policy	62 (86.1)	45 (90.0)	17 (77.3)	
DNR guidelines + DNR order form	44 (61.1)	34 (68.0)	10 (45.5)	
Only DNR guidelines	16 (22.2)	9 (18.0)	7 (31.8)	
Only DNR order form	2 (2.8)	2 (4.0)	0 (0.0)	
No DNR policy	10 (13.9)	5 (10.0)	5 (22.7)	
DNR policy in development	4 (5.6)	3 (6.0)	1 (4.5)	
No DNR policy at all	6 (8.3)	2 (4.0)	4 (18.2)	

Table 3.1 Do-Not-Resuscitate (DNR) Policy on Acute Geriatric Wards, 2002 (N=72)

Note: Differences in distribution of different forms of DNR policy were compared with characteristics of the hospital site using Fisher's exact test. Only for ownership type there was found a significant difference for the existence of a DNR order form (with or without guidelines) (P=.04).

Figure 3.1 Cumulative percentages of hospital sites with do-not-resuscitate (DNR) policy by year of implementation and by affiliation in Flanders, Belgium (private hospital sites, N=50 (year of implementation was not known for 4 cases with DNR policy); public hospital sites, N=22 (year of implementation was not known for 5 cases with DNR policy)).



	Ν	%
Initiative of development by * [§]		
Staff-members	20	39.2
Medical ethical council and/or the	19	37.3
medical board of the bospital	15	57.5
Staff involved in a problematic patient event	17	33.3
Patients	4	7.8
Next of kin	1	2.0
Others	11	2.0
Others	11	21.0
Persons involved in development ^{†,§}		
Physicians	42	80.8
Medical ethical council	33	63.5
Nurses	30	57.7
Members of the board	8	15.4
Social workers of the hospital	2	3.8
Others	6	11.5
Develope informed about implementation		
		75.0
Patients	39	75.0
In a systematic way	0	0.0
Sometimes	24	46.2
Only on request	15	28.8
Next of kin [†]	49	94.2
- +8		
Caregivers of the geriatric ward ^{1,9}	50	96.2
Physicians	47	90.4
Nurses	49	94.2
Paramedics	18	34.6
Other caregivers	10	19.2
Caregivers from other wards in the hospital ^{‡.§}	43	86.0
Physicians	40	80.0
Nurses	40	80.0
Social workers of the hospital	13	26.0
Other caregivers	8	16.0
	Ũ	1010
Physicians outside the hospital [†]	5	9.6
* 11 missing,		
10 missing,		
⁺ 12 missing,		
^a Multiple answers possible		

Table 3.2 Characteristics of Development and Implementation of Do-Not-Resuscitate (DNR) Policy (N=62)

DISCUSSION

To the best of the authors' knowledge, this study is the first to investigate DNR policy in Flanders and the first to describe the historical perspective of the implementation of DNR policy on acute geriatric wards in a whole district rather than in individual hospitals or wards.^{13–15,18,26,27} A high response of 76.6% was achieved, with no differences in structural characteristics between responders and nonresponders. The response sample was considered representative, with no need for nonresponse analysis on the content of the questionnaire. In the extreme case that all nonresponding geriatric wards had a DNR policy, the main result would have shifted from 86.1% to 89.4% of the wards, still an indication of incomplete implementation.

The main finding of this study is that the development of DNR policy in Flanders started late and was institutionally driven, not standardized, and incomplete.

Implementation started not earlier than 1985. Early adopters who implemented DNR guidelines before 1995 (predominantly public institutions) have not developed individual DNR order forms since. Implementations after 1995, particularly in private institutions, concerned most often a full DNR policy (institutional DNR guidelines and a patient-specific DNR order form). The incidence of DNR policy increased gradually, with a substantial increase in 2001, particularly in private institutions.

Nevertheless, in 2002, one in eight acute geriatric wards lacked a formal DNR policy, in contrast with the United States, where the implementation process of policies had long since been completed and formalized by law. The initial lag of implementation in private hospitals in Flanders was also observed in the United States.²⁸

DNR policies in Flanders were, as in other countries, developed as a selfdefense strategy for institutions, but as far as is known, and contrary to in the United States,^{1,29} no legal actions regarding DNR were undertaken against physicians in Flanders.

The international trend to formally document individual DNR decisions using DNR order forms was adopted in 1995, but not the trend to increase the involvement of patients in medical decision-making bv stimulating communication and the use of advance directives. Although a number of preprinted categories for other end-of-life decisions were found on the DNR order forms in Flanders, there was little room for registering consultation with patients and others. Hence, it is unlikely that these order forms were used as a tool to improve shared decision-making and to document communication regarding end-of-life decisions, as in other European countries.¹⁹

Little information about the implementation of DNR policies was systematically given to patients (e.g., by means of an information package on admission) and to a lesser extent to physicians outside the hospital, mostly general practitioners, who are more familiar with patients and could inform them more easily about possibilities regarding DNR when they are still healthy.

The fact that DNR policy documents on acute geriatric wards lacked standardization was probably the result of uncoordinated development and the absence of reference to a law or guidelines.

For a country with a law on euthanasia, it is peculiar that implementation of DNR policies was not completed or legally supported. To achieve full implementation, a legal initiative may be necessary. In addition, the structure of DNR order forms should be adapted to invite physicians to communicate better with patients, their next of kin, primary care physicians, and other healthcare providers. They should also be more standardized to improve decision making, as has previously been shown, especially when they are used on admission to explore patients' wishes.³⁰ In this way, the DNR policy will become a tool to avoid paternalism in patient–physician relations,³¹ and the DNR order form could turn from an instrument expressing a defensive institutional attitude to an instrument enabling communication between patients for the international evolution toward more attention to advance care planning on a more-extended range of end-of-life decisions in earlier stages of chronic and life-threatening diseases.

This study provided a snapshot of the status of DNR policy in Flanders at the moment of the introduction of the euthanasia law in Belgium. Further research is needed to investigate whether the enactment of the euthanasia law will have a profound influence on DNR policies and advance care planning in acute geriatric wards and long-term geriatric care facilities.

REFERENCES

- 1. Burns JP, Edwards J, Johnson J, et al. Do-not-resuscitate order after 25 years. Crit Care Med 2003;31:1543–1550.
- Vetsch G, Uehlinger DE, Zuercher Zenklusen RM. DNR orders at a tertiary care hospitalFare they appropriate? Swiss Med Wkly 2002;132:190–196.
- 3. Mello M, Jenkinson C. Comparison of medical and nursing attitudes to resuscitation and patient autonomy between a British and an American teaching hospital. Soc Sci Med 1998;46:415–424.

- 4. Frank C, Heyland DK, Chen B et al. Determining resuscitation preferences of elderly inpatients: A review of the literature. Can Med Assoc J 2003;169:795–799.
- 5. Cherniack EP. Increasing use of DNR orders in the elderly worldwide: Whose choice is it? J Med Ethics 2002;28:303–307.
- 6. Dautzenberg PLJ, Hooyer C, Schonwetter RS et al. Cardiopulmonary resuscitation policy in aged inpatients. Basic considerations when entering decisionmaking in the psychogeriatric field. Geriatrie Forsch 1993;3:175–183.
- 7. Hayes S, Stewart K. The role of audit in making do not resuscitate decisions. J Eval Clin Pract 1999;5:305–312.
- 8. Butler JV, Pooviah PK, Cunningham D, et al. Improving decision-making and documentation relating to do not attempt resuscitation orders. Resuscitation 2003;57:139–144.
- 9. Boyd K. Deciding about resuscitation. J Med Ethics 2001;27:291–294.
- 10. Manias E. Australian nurses' experiences and attitudes in the 'do not resuscitate' decision. Res Nurs Health 1998;21:429–441.
- 11. O'Toole EE, Youngner SJ, Juknialis BW et al. Evaluation of a treatment limitation policy with a specific treatment-limiting order page. Arch Intern Med 1994;154:425–432.
- Landon L.Amulree Essay Prize. CPRFwhen is it acceptable to withhold it? And a hospital survey of 'not for CPR' orders. Age Ageing 2000;29 Suppl 1:9–16.
- Castle N, Owen R, Kenward G et al. Pre-printed 'do not attempt resuscitation' forms improve documentation? Resuscitation 2003;59:89– 95.
- 14. Jacobson JA, Kasworm E.May I take your order? A user-friendly resuscitation status and medical treatment plan form. Qual Manag Health Care 1999;7:13–20.
- 15. Tolle SW, Tilden VP, Nelson CA et al. A prospective study of the efficacy of the physician order form for life-sustaining treatment. J Am Geriatr Soc 1998;46:1097–1102.
- 16. Dautzenberg PL, Bezemer PD, Duursma SA et al. The frequency of 'donotresuscitate' order in aged in-patients: Effect of patient- and non-patientrelated factors. Neth J Med 1994;44:78–83.
- Junod Perron N, Morabia A, de Torrente´ A. Evaluation of do not resuscitate orders (DNR) in a Swiss community hospital. JMed Ethics 2002;28:364–367.
- 18. O'Keeffe ST. Development and implementation of resuscitation guidelines: A personal experience. Age Ageing 2001;30:19–25.

- Richter J, Eisemann MR. Attitudinal patterns determining decision-making in the treatment of the elderly: A comparison between physicians and nurses in Germany and Sweden. Intensive Care Med 2000;26:1326– 1333.
- 20. Haverkate I, van der Wal G. Policies on medical decisions concerning the end of life in Dutch health care institutions. JAMA 1996;275:435–439.
- 21. Law Concerning Euthanasia. Belgian Law Gazette. June 22, 2002.
- National Disciplinary Board of Physicians. Belgian Medical Deontological Code. Revised edition. October 17, 1992 [on–line]. Available at http://www.ordomedic.be/web-ned/deonton.htm Accessed February 23, 2005.
- National Disciplinary Board of Physicians. Advice Concerning Do Not Resuscitate (DNR). January 18, 1997 [on-line]. Available at http://www.ordomedic.be/web-ned/adviezen.htm Accessed February 23, 2005.
- 24. Baeyens JP. Zorgstructuren [Health Care Organization] [on-line]. Available at www.geriatrie.be/doc/ger_pfizer/nl/deel01_hoofstuk06_nl.pdf Accessed June 21, 2005.
- 25. Dillman DA. The design and administration of mail surveys. Annu Rev Sociol 1991;17:225–249.
- 26. Diggory P, Cauchi L, Griffith D, et al. The influence of new guidelines on cardiopulmonary resuscitation (CPR) decisions. Five cycles of audit of a clerk proforma which included a resuscitation decision. Resuscitation 2003;56:159–165.
- 27. Combs PL, Stahl LD. Implementing a do-not-resuscitate order in an adult day center. Geriatr Nurs 2002;23:312–315.
- 28. Stolman CJ, Gregory JJ, Dunn D. Do not resuscitate policies of New Jersey hospitals. HEC Forum 1991;3:77–85.
- 29. Choudhry NK, Ma J, Rasooly I et al. Long-term care facility policies on lifesustaining treatments and advance directives in Canada. J Am Geriatr Soc 1994;42:1150–1153.
- 30. Page N, Morris D. Considering the 'do not resuscitate' decision. Age Ageing 1998;27:656–657.
- 31. Blondeau D, LavoieM, Valois P et al. The attitude of Canadian nurses towards advance directives. Nurs Ethics 2000;7:399–411.

Chapter 4

Prevalence of patients with do-not-resuscitate status on acute geriatric wards

De Gendt C, Bilsen J, Van Den Noortgate N, Lambert N, Vander Stichele R, Deliens L. Prevalence of patients with do-not-resuscitate status on acute geriatric wards in Flanders, Belgium. The Journals of Gerontology. Series A, Biological Scienses and Medical Sciences 2007;62:395-399.

ABSTRACT

Background Elderly hospitalized patients have low survival rates after cardiopulmonary resuscitation, especially in the long term. This study aims to investigate the prevalence of patients with do-not-resuscitate (DNR) status on acute geriatric wards and the characteristics of the preceding decision-making process.

Methods On all 94 geriatric wards in Flanders, Belgium (2002), the geriatrician who performed the bulk of clinical work was asked to fill in a retrospective structured mail questionnaire.

Results The response rate was 72.3%. A DNR status was attributed to 20.3% of patients. A significant higher prevalence of patients with DNR status was found on wards with a geriatrician who had been active in patient care for 15 years or less and on wards with a DNR policy. Mostly, DNR status was attributed when the patient's condition declined (34.0%) or became critical (29.0%). Geriatricians consulted at least one person in 81.0% of the cases: (head) nurses in 72.2%, next of kin in 61.9%, the patient's general practitioner in 22.6%, and the patient him- or herself in 15.7%. Reasons stated to make a DNR decision were the prognosis (68.1%) and the physical condition of the patient (62.2%). Age was mentioned in only 21.1% of the cases, always in combination with other reasons.

Conclusions One fifth of patients on acute geriatric wards in Flanders have DNR status. The decision to attribute DNR status is most often made late in the course of the disease. (Head) nurses and the patient's next of kin are often consulted, the patient and his or her general practitioner rarely.

Acknowledgements

This work was supported by a research grant from the Research Council of the Vrije Universiteit Brussel and by the Geriatric Departments of the Vrije Universiteit Brussel and the University of Ghent.

We thank Annemie Van Hofstraeten for participation in the study concept and design and for data collection. In addition, we thank Johan Vanoverloop for advice on statistical issues and Kate McDonald for linguistic advice.

INTRODUCTION

Because of advances in medical knowledge and technology, many people nowadays live to be very old, however, often with chronic and degenerative diseases which may result in poor quality of life (1,2). Many old and very old elderly persons, especially those admitted to acute geriatric wards, have serious underlying comorbidity decreasing their chance of survival after cardiopulmonary resuscitation (CPR), especially in the long term (2–6).

Although do-not-resuscitate (DNR) decisions are now common practice (7), no studies have been conducted to establish the prevalence of DNR status in elderly patients hospitalized on acute geriatric wards on a nationwide scale. The DNR status of patients on a single geriatric ward was studied in The Netherlands (8,9) and the United States (10). In other studies, this prevalence was studied in intensive care units or general wards (11,12).

This study aims to investigate the prevalence of patients with DNR status and the characteristics of the preceding decision-making process in the setting of acute geriatric wards in Flanders (the Dutch-speaking part of Belgium).

In Flanders, acute geriatric wards were installed since 1984 for specialized acute geriatric care, restricted in length of hospital stay, and with a multidisciplinary approach (13). In 2002, the total number of acute geriatric beds in Flanders was 4072, with a yearly occupancy rate of 85.9%, serving 41,138 hospitalizations, with an average length of stay of 31 days. In 86% of the wards, a DNR policy was available (14).

METHODS

Design

This study was conducted in spring 2002 in Flanders, the Dutch-speaking part of Belgium, where about 60% of the Belgian population lives. In this area, 64 acute hospitals had at least one acute geriatric ward. Due to administrative mergers, some hospitals had an acute geriatric ward at different hospital sites (39 hospitals had 1 site with a geriatric ward, 21 had 2 sites, 3 had 3 sites, and 1 had 4 sites). All 94 hospital sites were included in this study. The Ministry of Health provided a list of these sites which included addresses and institutional characteristics such as ownership (private or public), type of hospital (general or university), total bed capacity of the hospital site and the geriatric ward, and availability of an intensive care unit and a palliative support team.

A structured mail questionnaire was sent to the geriatrician (a specialist in internal medicine, with a supplementary 1-year specialization in geriatric medicine), who performed the bulk of clinical work on the geriatric ward (N = 94). To assure an appropriate response rate, the Total Design Method was used (15). One week before the first mailing of the questionnaire in April 2002, a recommendation letter from the Belgian Society of Gerontology and Geriatrics was sent to the geriatricians. A follow-up card was sent to all 1 week after the first mailing. Two weeks later, a follow-up letter was mailed with a copy of the questionnaire to the nonresponders.

Questionnaires

The first questions of the questionnaire inquire after the existence of a DNR policy, inspired by an existing questionnaire regarding this topic in The Netherlands (16). The two following questions asked geriatricians for the number of patients currently registered on the geriatric ward under their supervision, and for the number of these patients with DNR status at the time that the questionnaire was completed. The next five questions, based on international literature (17–19), investigated the characteristics of the preceding decision-making process, leading to the attribution of DNR status. Geriatricians were asked to register the moment of decision-making, who was consulted, whether this decision took place during the weekly team meeting or the daily ward visits, whether the decision (maximum three). Finally, gender, number of years active in patient care, and attendance at an intensive course on palliative care were recorded for all geriatricians.

The questionnaire was thoroughly reviewed by two geriatricians and then pilottested by a group of 14 geriatricians. This resulted in minor adaptations to the text to solve ambiguity and to improve understanding. In the questionnaire, a patient with DNR status was defined as "a patient for whom an anticipatory decision not to start resuscitation in case of a cardiac and/or respiratory arrest was made" (17).

Statistical Analysis

Hospital and ward characteristics of the response sample were compared with those of the nonresponse sample using Fisher's Exact test. The prevalence of patients with DNR status on geriatric wards was calculated as the proportion of the total number of patients with DNR status divided by the total number of treated patients at the moment of completing the questionnaire. Descriptive results were presented in frequency tables and cross-tabs, and differences in distribution and means were calculated by using, respectively, Fisher's Exact test and the independent samples t test. Multiple linear regression analysis was used to further investigate the significant relationships between characteristics of the geriatrician, the hospital site, and the geriatric ward, with the percentage of patients with a DNR status per geriatrician. For all these analyses, the statistical package SPSS 12.0 (SPSS Inc., Chicago, IL) was used. A p value less than .05 was considered statistically significant.

RESULTS

Description of Response and Nonresponse Sample

From the 94 hospital sites with an acute geriatric ward, 68 geriatricians returned their completed questionnaire (72.3% response rate). Response and non-response samples were compared for characteristics of the hospital site and the geriatric ward (Table 4.1). Except for bed capacity of the geriatric ward (p = .013), no significant differences were found. The observed underrepresentation of the smallest geriatric wards (24 beds) in the response sample and the results were weighted for bed capacity of the geriatric ward of all hospital sites with an acute geriatric ward in Flanders (2002).

Prevalence and Characteristics of DNR Decisions

The 68 responding geriatricians reported 393 patients with DNR status of a total of 1925 treated patients on acute geriatric wards, which represents 20.3% (data not shown in table). For each responding geriatrician, the proportion of patients with DNR status was calculated. The average percentage of this proportion was 19.6% (ranging from 0% to 62%) (Table 4.2). Eight geriatricians had no patients with DNR status at the time of this study, but they had all made (at least once) a DNR decision in the past. Female geriatricians had more patients with DNR status (25.9%) than did their male colleagues (15.6%, p = .022). The number of years that geriatricians were active in patient care was significantly related with the proportion of patients with a DNR status. Geriatricians who had been active in patient care for 15 years or less had more patients with DNR status (27.6%) than did those who had been active in patient care for 16-25 years (12.4%, p = .001) and those who had been active for more than 25 years (15.7%, p = .024). About half of the geriatricians had attended an intensive course on palliative care, but there was no significant relationship with the proportion of patients with DNR status.

On acute geriatric wards where a DNR policy was available, the average proportion of patients with a DNR status was higher (23.1%) than on wards without such a policy (5.8%, p = .000). No other characteristics of the hospital site and the geriatric ward were significantly associated with the proportion of patients with a DNR status per geriatrician.

Multiple linear regression analysis revealed that only the number of years active in patient care (β = -.298, p = .004) and the existence of a DNR policy (β = -.361, p = .000) (but not gender of the geriatrician) were significantly related with the proportion of patients with DNR status.

The DNR Decision-Making Process

The moment at which the last DNR decision was made was in 28.3% of patients before or at the time of admission, in 8.7% after diagnosis, in 34.0% when the patient's situation declined, and in 29.0% when the condition became critical (Table 4.3).

Geriatricians previously consulted at least one other person in 81.0% of the cases. In 72.2% the head nurse or another nurse of the geriatric ward was involved, in 61.9% the patient's next of kin, and in 36.0% a second specialist of the hospital site. The general practitioner of the patient was consulted in 22.6% of the cases and the patient him- or herself in 15.7%. In 69.2% of the cases, discussion took place during the weekly team meeting (38.5%) and/or during the geriatrician's daily ward visits (44.6%). The last DNR decision was documented in the patient's file by 93.7% of the geriatricians.

The most reported reason for the last DNR decision was prognosis of the disease (68.1%), followed by the physical condition of the patient (62.5%), the mental condition of the patient (45.6%), the expected quality of life after CPR (42.8%), and the probability of success of CPR (42.3%).

The geriatricians reported in 21.1% of the cases that the age of the patient was a reason to make the last DNR decision, always in combination with (at least) the physical and/or mental condition of the patient. One geriatrician considered economic aspects for his last DNR decision.

All characteristics of the DNR decision-making process were tested (Fisher's Exact test; not shown in table) for characteristics of the geriatrician, the hospital site, and the geriatric ward. Geriatricians who had been active in patient care for 15 years or less more often consulted general practitioners (43.3% vs 10.5%, p = .025) as well as the patient (33.3% vs 0.0%, p = .004) compared to those who had been active for more than 25 years. No other significant differences were found. There was also no significant relationship between consultation with different persons and the moment when the last DNR decision was made.

	Population	Response N = 68		Non- response	
	N = 94			N = 26	
		Unweighted	Weighted*		
		%)		
Ownership					
Private	66.0	69.1	71.3	73.1	
Public	29.8	30.9	28.7	26.9	
Type of hospital					
General	96.8	97.1	97.9	96.2	
University	3.2	2.9	2.1	3.8	
Bed capacity of the hospital site					
< 200	41.5	39.7	40.4	46.2	
200 → 399	41.5	41.2	40.4	42.3	
>= 400	17.0	19.1	19.1	11.5	
Availability of intensive care unit	91.5	91.2	91.5	92.3	
Availability of palliative support team	96.8	95.6	95.7	100.0	
Bed capacity of the geriatric					
2/	37.2	27.0	37.2	61 5	
27 $25 \rightarrow 48$	36.2	27.3 A1 2	36.2	23.1	
>= 49	26.6	30.9	26.6	15.4	

Table 4.1 Institutional Characteristics of Response and Nonresponse Sample

* Only difference in distribution between response and non-response sample was found for 'Bed capacity of the geriatric ward (p=.013). The response sample was weighted for this characteristic of all hospital sites with an acute geriatric ward in Flanders (2002)

	Ν	Average proportion	p- value [†]	Difference in average
		(Q1 - Q3)		proportions [95% confidence interval]
TOTAL	60	19.6 (6.7 - 30.0)		
CHARACTERISTICS OF THE GERIATRICIAN				
Gender				
Female	23	25.9 (12.0- 42.0)	.022	10,3 [1.6 - 19.0]
Male	37	15.6 (4.7 - 17.0)		
Number of years active in patient				
	25	27.6(12.0, 20.5)	001(1,2)	450 [60 040] ^(1,2)
1 - 15 years	20 18	27.0 (13.0 - 30.3) 12.4 (3.0 - 18.5)	$0.001^{(1,3)}$	15.2 $[0.3 - 24.2]^{(1,3)}$
> 25 years	17	15 7 (2 4 - 20 5)	.024 442 ^(2,3)	NS
Number of treated nationto	.,	10.7 (2.4 20.0)	.772	NO
<pre>Automation and a second and a second and a second and a second a secon</pre>	21	177(20 211)	207	NC
~ 30 patients	29	22 2 (9 7 - 30 7)	.307	NO
Attended an intensive course on palliative care	20			
Yes	29	16.52 (4.0 - 20.5)	.224	NS
No	31	22.68 (8.0 - 38.0)		
CHARACTERISTICS OF THE HOSPITAL SITE				
Ownership				
Private	41	20.0 (8.0 - 37.8)	.799	NS
Public	19	18.7 (4.5 - 20.7)		
Type of hospital				
General	58	19.2 (6.1 - 29.9)	.369	NS
University	2	32.5 (20.0 - 45.0)		
Bed capacity				
<200	25	18.8 (5.0 - 30.0)	.531 ^(1,2)	NS
200 - 399	24	21.9 (4.0 - 38.0)	$.660^{(1,3)}$	NS
>=400	11	16.7 (8.0 - 17.9)	.324(2,3)	NS
Availability of an intensive care unit				
Yes	55	19.4 (6.4 - 30.0)	.679	NS
No	5	22.7 (7.0 - 38.5)		
Availability of a palliative support				
team				
Yes	58	19.3 (6.1 - 29.9)	.563	NS
NO	2	31.0 (12.0 - 50.0)		

Table 4.2 Average Proportion of Patients with Do-Not-Resuscitate (DNR) Status per Geriatrician According to Characteristics of the Geriatrician, the Hospital Site and the Geriatric Ward $(N = 68)^{*}$
Table 4.2 Average Proportion of Patients with Do-Not-Resuscitate (DNR) Status per Geriatrician According to Characteristics of the Geriatrician, the Hospital Site and the Geriatric Ward $(N = 68)^{*}$ "Cont."

	N	Average proportion (Q1 - Q3)	p- value†	Difference in average proportions [95% confidence interval]
CHARACTERISTICS OF THE GERIATRIC WARD				
Availability of DNR policy				
Yes	48	23.1 (10.0 - 38.0)	.000	17.2 [11.4 - 23.0]
No	12	5.8 (0.0 - 12.3)		
Bed capacity				
=24	15	18.9 (8.0 - 38.0)	.759 ^(1,2)	NS
25 - 48	27	20.3 (6.0 - 29.0)	.936 ^(1,3)	NS
>48	18	19.4 (2.9 - 24.9)	.875 ^(2,3)	NS

Notes: All percentages are weighted for bed capacity of the geriatric wards of all hospital sites with an acute geriatric ward in Flanders (2002).

* The average proportion of patients with DNR status could not be computed for 8 cases.

† Independent Samples T Test, equal variances not assumed.

(1,2) Category 1 versus category 2.

(1,3) Category 1 versus category 3.

(2,3) Category 2 versus category 3.

DNR = do-not-resuscitate; Q1 = first quartile; Q3 = third quartile; NS = not significant.

Table 4.3 Characteristics of the Decision-Making Process, Preceding the Last Do-Not-Resuscitate (DNR) Decision (N=68)

	Ν	%
Moment of decision making*		
On admission	17	28.3
After diagnosis	5	8.7
When clinical situation declined	21	34.0
When situation became critical	18	29.0
Consultation of others†,‡	52	81.0
(Head) nurse	46	72.2
Next of kin	40	61.9
Second specialist of the hospital site	24	36.0
General practitioner	14	22.6
Patient	10	15.7
Social service of the hospital site	7	12.4
Physiotherapist	6	10.3
Occupational therapist	4	7.6
Others	7	11.6
Discussion during the weekly team meeting†	25	38.5
Discussion during geriatrician's daily ward visits†	29	44.6
DNR decision written down in patient's file§	59	93.7
Main reasons for DNR decision ^{+,‡}		
Prognosis of the disease	43	68.1
Physical condition	41	62.5
Mental condition	30	45.6
Expected quality of life	28	42.8
Probability of success of resuscitation	26	42.3
Age of the patient	13	21.1
Will of the patient	8	13.0
Will of the next of kin	4	6.1
Will of caregivers	1	2.1
Pain	1	1.4
Economical aspect	1	1.4

Notes: Percentages are weighted for bed capacity of the geriatric ward of all hospital sites with an acute geriatric ward in Flanders (2002)

* 7 missing cases

† 3 missing cases

‡ Multiple answers possible

§ 5 missing cases

DISCUSSION

To our knowledge, this study is the first to investigate the prevalence of patients with DNR status and the characteristics of the decision-making process preceding the attribution of such status on acute geriatric wards in a nationwide catchment area (Flanders), rather than on individual wards. No significant differences were found between response and nonresponse sample, except for bed capacity of the geriatric ward (small wards slightly underrepresented). Results were weighted for this difference. Hence, the study sample can be considered to be representative for the whole of Flanders.

There are some limitations to this study. First, because data on patients' characteristics were not obtained, their relationship with the characteristics of the decision-making process could not be investigated in this study. Second, situational circumstances might have had an influence on the point prevalence of DNR decisions.

The results of this study reveal that 1 of 5 patients hospitalized on acute geriatric wards in Flanders have DNR status. DNR decisions are most frequently made by younger geriatricians and on wards with a DNR policy, and are mostly made late in the course of the disease. The main reasons for such decisions are disease-related. Patients and their general practitioner are rarely consulted in the decision-making process.

The prevalence of DNR decisions on acute geriatric wards in Flanders is slightly higher than most international data regarding DNR decisions in hospitals or on specific wards,^{11,17,20-23} but these all concerned other patient populations. When comparing with results obtained in geriatric wards, the prevalence of patients with DNR status in Flanders is slightly higher than in the United States (16%)¹⁰ but substantially lower than in The Netherlands (55% and 79%).^{8,9} However, in Flanders there are also some wards where more than 50% of the patients had DNR status.

The finding that the proportion of patients with DNR status is higher among geriatricians who are younger¹⁸ or who work on a ward where a DNR policy is available²⁴ is supported in international literature. The fact that younger geriatricians, who graduated more recently, have more patients with a DNR status than do older geriatricians might be the result of a generational effect (different attitudes or value patterns). Efforts to integrate end-of-life care in the basic education program¹⁸ of the most recently graduated physicians might be another explanation, although less plausible because additional courses on palliative care seem to have no influence. Implementation of a DNR status to patients when appropriate.

As confirmed by international literature,^{11,17,18,25,26} DNR decisions are mostly made late in the course of the disease and the most important reasons for such decisions are disease-related. Age of the patient is only mentioned as a reason in combination with the underlying condition of the patient. Together with the finding that the prevalence of DNR decisions on acute geriatric wards in Flanders is only slightly higher than for nongeriatric patient populations, there is no evidence that age alone is used as rationale for DNR decisions. The contrary would be unethical.²⁵

On acute geriatric wards in Flanders, 4 of 5 DNR decisions are discussed with others. Nurses are most frequently consulted in decision-making, probably because they care for the patient on a daily basis and often have a confidential and close relationship with the patient and his or her next of kin.²⁶ Almost all DNR decisions (93.7%) were shared with the nursing team via the patient's file, which minimizes inappropriate CPR.^{14,27}

The low patient participation in DNR decision-making could be the result of many different factors such as the clinical condition (e.g., incompetence) of the patient at the (late) time of the decision-making, a paternalistic way of treating elderly patients, or the reluctance of patients to discuss this matter and pass this decision on to their family. The Patients' Rights Act,²⁸ which came into force after this study, intends to improve the level of patient involvement in medical decision-making. It is also surprising that the patients' general practitioners are not often consulted, although they usually have a longstanding relationship with their patients and a good knowledge of the patient's situation and social context.²⁹ Recently graduated geriatricians seem to involve more often the patient and the general practitioner; this might be explained by the earlier mentioned generational effect. Of course, it could also be a sign of the increasing autonomity of the patients and their families.

Although teamwork is very important in geriatric medicine,³⁰ discussion about attributing DNR status to a patient more often took place during the daily ward visits than during the weekly team meeting. Different explanations could be found. First, although consultation with different persons was not significantly related to the moment of decision-making, it is possible that the late phase of the patient's illness did not leave the opportunity to discuss DNR during the weekly team meeting. The daily ward visits of the geriatrician seem to be an alternative option in these cases. Second, anticipating end-of-life decisions was perhaps not possible due to unexpected deterioration of the patient's condition. Third, a physician's paternalistic views could obstruct the team from participating in decision-making.

Based on this study, different intervention strategies can be proposed to optimize DNR decision-making. First, DNR should be discussed with others in advance. Planning care in advance provides better opportunities to involve the still

competent patient and his or her next of kin and professional caregivers, and to collect better information about the patient's wishes.^{11,31} Nurses or other professional caregivers should discuss this matter as much as possible at the time of admission, because geriatric patients can lose competency later on, when the disease progresses. General practitioners should be more involved in DNR decision making, starting with information about the implemented DNR policy in general, and concerning individual patients when necessary. Second, the development and implementation of a clear and standardized DNR policy, accepted by all persons concerned and recognizing the important role of all professional caregivers (especially nurses), should be stimulated. Third, ongoing efforts should be made to change the knowledge, communication skills, and attitudes of professional health caregivers (physicians, nurses).³² In addition, the general public should be made more familiar with this matter, for example, by health information programs. Finally, further research is needed for more indepth information about the DNR decision-making process and on how this process could be optimized (e.g., format and content of DNR policies and education).

REFERENCES

- 1. Lorenz KA, Lynn J. Oregon's lessons for improving advance care planning. J Am Geriatr Soc 2004;52:1574–1575.
- 2. Weiss GL, Hite CA. The do-not-resuscitate decision: the context, process, and consequences of DNR orders. Death Stud 2000;24:307–323.
- 3. Vanpee D, Swine C. Scale of levels of care versus DNR orders. J Med Ethics 2004;30:351–352.
- 4. Gulati RS, Bhan GL, Horan MA. Cardiopulmonary resuscitation of old people. Lancet 1983;2:267–269.
- 5. Murphy DJ, Murray AM, Robinson BE, Campion EW. Outcomes of cardiopulmonary resuscitation in the elderly. Ann Intern Med 1989;111:199–205.
- Costello J. Do Not Resuscitate orders and older patients: findings from an ethnographic study of hospital wards for older people. J Adv Nurs 2002;39:491–499.
- 7. Burns JP, Edwards J, Johnson J, Cassem NH, Truog RD. Do-notresuscitate order after 25 years. Crit Care Med 2003;31:1543–1550.
- 8. Dautzenberg PL, Duursma SA, Bezemer PD, Van Engen C, Schonwetter RS, Hooyer C. Resuscitation decisions on a Dutch geriatric ward. Q J Med 1993;86:535–542.

- 9. Dautzenberg PL, Bezemer PD, Duursma SA, Schonwetter R, Hooyer C. The frequency of "do-not-resuscitate" order in aged in-patients: effect of patient- and non-patient-related factors. Neth J Med 1994;44:78–83.
- 10. Torian LV, Davidson EJ, Fillit HM, Fulop G, Sell LL. Decisions for and against resuscitation in an acute geriatric medicine unit serving the frail elderly. Arch Intern Med 1992;152:561–565.
- 11. Wenger NS, Pearson ML, Desmond KA, et al. Epidemiology of do-notresuscitate orders. Disparity by age, diagnosis, gender, race, and functional impairment. Arch Intern Med 1995;155:2056–2062.
- 12. Chan DK, Ong B, Zhang K, et al. Hospitalisation, care plans and not for resuscitation orders in older people in the last year of life. Age Ageing 2003;32:445–449.
- 13. Baeyens JP. Zorgstructuren [Health Care Organization] [on-line]. Available at www.geriatrie.be/doc/ger_pfizer/nl/deel01_hoofstuk06_nl.pdf. Accessed January 3, 2007.
- De Gendt C, Bilsen J, Vander Stichele R, Lambert M, Van Den Noortgate N, Deliens L. Do-Not-Resuscitate Policy on Acute Geriatric Wards in Flanders, Belgium. J Am Geriatr Soc 2005;53:2221–2226.
- 15. Dillman DA. The design and administration of mail surveys. Annu Rev Sociol 1991;17:225–249.
- 16. Haverkate I, van der Wal G. Policies on medical decisions concerning the end of life in Dutch health care institutions. JAMA 1996;275:435–439.
- 17. van Delden JJ, van der Maas PJ, Pijnenborg L, Looman CW. Deciding not to resuscitate in Dutch hospitals. J Med Ethics 1993;19:200–205.
- 18. Kelly WF, Eliasson AH, Stocker DJ, Hnatiuk OW. Do specialists differ on do-not-resuscitate decisions? Chest 2002;121:957–963.
- 19. Skerritt U, Pitt B. 'Do not resuscitate': how? why? and when? Int J Geriatr Psychiatry 1997;12:667–670.
- 20. de Vos R, Koster RW, de Haan RJ. Impact of survival probability, life expectancy, quality of life and patient preferences on do-not-attempt resuscitation orders in a hospital. Resuscitation Committee. Resuscitation 1998;39:15–21.
- 21. Junod Perron N, Morabia A, De Torrente A. Evaluation of do not resuscitate orders (DNR) in a Swiss community hospital. J Med Ethics 2002;28:364–367.
- 22. Youngner SJ, Lewandowski W, McClish DK, Juknialis BW, Coulton C, Bartlett ET. 'Do not resuscitate' orders. Incidence and implications in a medical-intensive care unit. JAMA 1985;253:54–57.

- 23. Jayes RL, Zimmerman JE, Wagner DP, Draper EA, Knaus WA. Do-notresuscitate orders in intensive care units. Current practices and recent changes. JAMA 1993;270:2213–2217.
- 24. WebsterGC,Mazer CD, PotvinCA, Fisher A, Byrick RJ. Evaluation of a "do not resuscitate" policy in intensive care. Can J Anaesth 1991;38:553–563.
- 25. Landon L. 2000 Amulree Essay Prize. CPR–when is it acceptable to withhold it? And a hospital survey of 'not for CPR' orders. Age Ageing 2000;29(suppl 1):9–16.
- 26. Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004;47:583–591.
- 27. Tolle SW, Tilden VP, Nelson CA, Dunn PM. A prospective study of the efficacy of the physician order form for life-sustaining treatment. J Am Geriatr Soc 1998;46:1097–1102.
- 28. Wet betreffende de rechten van de pati€ent [Patients' Rights Act]. Wet in Belgisch Staatsblad van 26 September 2002 [Law in Belgian Law Gazette of September 26, 2002]. [Dutch]
- 29. Bilsen J, Vander Stichele R, Mortier F, Bernheim J, Deliens L. The incidence and characteristics of end-of-life decisions by GPs in Belgium. Fam Pract 2004;21:282–289.
- Davies KN, King D, Silas JH. Professional attitudes to cardiopulmonary resuscitation in departments of geriatric and general medicine. J R Coll Physicians Lond 1993;27:127–130.
- 31. Vetsch G, Uehlinger DE, Zuercher-Zenklusen RM. DNR orders at a tertiary care hospital-are they appropriate? Swiss Med Wkly 2002;132:190–196.
- Gorman TE, Ahern SP, Wiseman J, Skrobik Y. Residents' end-of-life decision making with adult hospitalized patients: a review of the literature. Acad Med 2005;80:622–633.

Chapter 5

Nurses' involvement in

do-not-resuscitate decisions

on acute geriatric wards

De Gendt C, Bilsen J, Vander Stichele R, Van Den Noorgate N, Lambert M, Deliens L. Nurses' involvement in 'do not resuscitate' decisions on acute elder care wards. Journal of Advanced Nursing 2007;57:404-409.

Note: The use of 'acute elder care wards' in the original article has been replaced here by 'acute geriatric wards' for reasons of consistency.

ABSTRACT

Aim This paper reports the involvement of nurses in 'do not resuscitate' decision making on acute geriatric wards and their adherence to such decisions in the case of an actual cardiopulmonary arrest.

Background Previous literature showed that nurses are involved in half or less than half of 'do not resuscitate' decisions in hospitals, but their involvement in this decision-making on acute geriatric wards in particular has not been investigated.

Method A questionnaire was sent in 2002 to the head nurses of all acute geriatric wards in Flanders, Belgium (N = 94). They were asked whether nurses had been involved in the last 'do not resuscitate' decision-making process on their ward and whether nurses 'never', 'rarely', 'sometimes', 'often' or 'always' started resuscitation in case of cardiopulmonary arrest of patients with 'do not resuscitate' status and of those without.

Results The response rate was 86.2% (N = 81). In 74.7% of the last 'do not resuscitate' decisions on acute geriatric wards in Flanders, a nurse was involved in the decision-making process. For patients with 'do not resuscitate' status, 54.3% of respondents reported that cardiopulmonary resuscitation was 'never' started on their ward, 'rarely' on 39.5% and 'sometimes' on 6.2%. For patients without 'do not resuscitate' status, nurses started cardiopulmonary resuscitation 'rarely' or 'sometimes' on 22.2% of all wards, and 'often' or 'always' on 77.8%.

Conclusion To make appropriate 'do not resuscitate' decisions and to avoid rash decision-making in cases of actual cardiopulmonary arrest, nurses should be involved early in 'do not resuscitate' decision-making. If institutional 'do not resuscitate' guidelines were to stress more clearly the important role of nurses in all kinds of end-of-life decisions, this might improve the 'do not resuscitate' decision-making process.

Acknowledgements

This study was funded by a research grant from the Research Council of the Vrije Universiteit Brussel and financial support from the geriatric departments of the Vrije Universiteit Brussel and the University of Ghent.

We would like to thank Annemie Van Hofstraeten for participation in the study concept and design, Joachim Cohen for statistic advice, and Kate Macdonald for English language advice.

INTRODUCTION

The decision to attribute 'do not resuscitate' (DNR) status to a patient should take place after consultation with the patient, the patient's family and the multidisciplinary team (Stewart et al. 2003). Because nurses care for (frail older) hospitalized patients on a daily basis and spend more time with them than do physicians, they are mostly well informed about patients' total (physical and psychosocial) situation and preferences regarding the end of life (Hilden et al. 2004). Therefore, nurses are often the right people to initiate discussion about DNR and to fulfil a liaison role between physicians and patients (Manias 1998, Richter & Eisemann 1999, Anderson-Shaw 2003). They are able to convey a patient's preferences to the physician, and may also have a great influence on acceptance by the patient (or surrogate decision-maker) of the medical recommendation for attribution of DNR status (Eliasson et al. 1997).

Although nurses should participate in DNR decision making more and more, this is still not evident (Manias 1998, Holzapfel et al. 2002) and physicians remain responsible for the ultimate decision (Lofmark & Nilstun 1997, Anderson-Shaw 2003, Stewart et al. 2003), which needs to be communicated correctly among the nursing team of the ward. Nevertheless, when an actual cardiopulmonary arrest occurs in an institution, nurses are often the first at the scene, with an opportunity to influence the course of events. When nurses attend a cardiopulmonary arrest of a patient without DNR status they can still decide not to start cardiopulmonary resuscitation (CPR) because they consider it to be a futile procedure (potentially life-prolonging but not necessarily improving the patient's quality of life). On the other hand, nurses may also start CPR when the patient has DNR status. Research on what nurses and physicians would wish for themselves has shown that nurses would be more likely to forgo aggressive medical treatment than physicians (Gillick et al. 1993), but physicians are more likely to make a DNR decision for their current patients when compared with nurses (Eliasson et al. 1997).

Today, DNR decision making has become common in medical practice (van Delden et al. 2006). On acute geriatric wards in Flanders, of which 86% have an established DNR policy (De Gendt et al. 2005), one out of five patients is given DNR status (De Gendt et al. 2007). However, it is not known whether nurses on acute geriatric wards in Flanders are actually involved in DNR decision-making and how often they adhere to such decisions about whether or not to start CPR in case of cardiopulmonary arrest.

THE STUDY

Aim

The aim of the study was to establish the degree of involvement of nurses in DNR decision-making on acute geriatric wards and their adherence to such decisions in case of an actual cardiopulmonary arrest.

Design

A retrospective design was adopted, using a structured mailed questionnaire. The study was conducted in 2002 in Flanders, the Dutch-speaking part of Belgium where about 60% of the Belgian population lives.

Participants

At time of this study, there were 118 hospital sites (general or teaching) in Flanders, of which 94 had an acute geriatric ward. On each of these wards the head nurse (N = 94) was asked to complete the questionnaire.

Data collection methods

In the questionnaire, head nurses were asked to recall the last patient on their ward for whom a DNR decision was made. First, they were asked to report whether or not this DNR decision was made after consultation with at least one nurse. Secondly, they were asked to estimate how nurses perceived their involvement in DNR decision-making ('very involved', 'fairly involved', 'fairly uninvolved' or 'not involved'). Thirdly, they reported how the DNR decision was communicated among the nursing team. Fourthly, head nurses were asked in general whether nurses on their ward 'never', 'rarely', 'sometimes', 'often' or 'always' started CPR in case of a cardiopulmonary arrest in patients with DNR status and those without. Finally, they were asked if a DNR policy existed on the ward.

A patient with DNR status was defined in the questionnaire as 'a patient for whom an anticipatory decision not to start resuscitation in case of a cardiac and/or respiratory arrest was made' (van Delden et al. 1993).

In order to improve the response rate, the organization of the data collection was based on the Total Design Method (Dillman 1991). One week after the first mailing of the questionnaire, a follow-up card was sent to all head nurses, either to thank them for their response or to remind them to fill in and return the questionnaire. Two weeks later a follow-up letter with a copy of the questionnaire was mailed to non-respondents.

Returned questionnaires were linked to characteristics of the hospital site and geriatric ward, obtained from hospital databases at national and regional levels (availability of an intensive care unit and palliative support team, type of hospital and bed capacity of the hospital site and geriatric ward).

Ethical considerations

Approval for the study was received from the Medical Ethics Council of the Academic Hospital of the Vrije Universiteit Brussel. Participants were assured in a covering letter that data would be analysed anonymously. Return of the completed questionnaire was considered as consent to participate. After data collection and linkage of the returned questionnaires to the databases, the study data were anonymized.

Data analysis

Descriptive results were presented in frequency tables. Differences in distribution were tested using Fisher's Exact test and the Sign test (differences between two related variables), and differences in means were tested using the independent samples t-test (equal variances not assumed). The statistical package SPSS 12.0 (SPSS Inc., Chicago, IL, USA) was used for these calculations and a P-value <0.05 was considered statistically significant.

RESULTS

Response

From the 94 hospital sites with an acute geriatric ward, 81 head nurses returned a completed questionnaire (86.2% response rate). Characteristics of the hospital site and the acute geriatric ward from the response sample were compared with the non-response sample (Table 5.1). No statistically significant differences were found.

Nurses' involvement in DNR decision-making

The last DNR decision on the acute geriatric ward had been discussed with at least one nurse in 74.7% of the cases (Table 5.2). Most head nurses thought that their nursing team felt sufficiently involved by the physician in the last DNR decision-making, but 28.2% of head nurses estimated that nurses felt that they were only (fairly) uninvolved.

DNR status of the patient was always communicated among the nursing team (not shown in table), most often in writing and accompanied with an oral explanation at a formal meeting (multidisciplinary meeting and/or briefing). In 8.9% of cases, the DNR status was communicated orally on an informal basis. In one case this informal communication was the only way that the DNR status of the patient was communicated among the nursing team (not shown in table).

No statistically significant differences in distribution were found between acute geriatric wards with a DNR policy and those without.

Nurses' adherence to DNR decisions

When a cardiopulmonary arrest occurred among patients with a DNR status, nurses' actions were mostly in accordance with this status (CPR 'never' started in 53.0% and 'rarely' in 39.5% of cases; Table 5.3). For patients without DNR status, nurses started CPR 'rarely' or 'sometimes' on 22.2% of wards, and 'often' or 'always' on 77.8%. Nurses' actions in case of an actual cardiopulmonary arrest differed statistically significantly depending on whether or not patients had been given DNR status ($P \le 0.001$).

Nurses' adherence to DNR decisions was tested for the availability of a DNR policy on the acute geriatric ward and the way of communicating DNR status of a patient among the nursing team (not shown in table). No statistically significant differences were found.

	Population	Response	Non-	P-value*
			response	
	% (N = 94)	% (N = 81)	% (N = 13)	
HOSPITAL SITES				
Ownership				0.197
Private	66.0	72.8	53.8	
Public	29.8	27.2	46.2	
Type of hospital				1.000
General	96.8	96.3	100.0	
Teaching	3.2	3.7	0.0	
Bed capacity				0.193
< 200	41.5	40.7	46.2	
200 → 399	41.5	39.5	53.8	
>= 400	17.0	19.8	0.0	
Availability of intensive care unit	91.5	92.6	84.6	0.305
Availability of palliative support	96.8	97.5	92.3	0.364
team				
ACUTE GERIATRIC WARDS				
Bed capacity				0.931
24	37.2	37.0	38.5	
25 → 48	36.2	37.0	30.8	
>= 49	26.6	25.9	30.8	

Table 5.1 Characteristics of hospital sites and acute geriatric wards: response vs. non-response

* Differences in distribution of characteristics between response and non-response sample was tested by the Fisher's Exact test.

	Total	DNR policy		P-value *
		Available	Not	
			available	
	% (N=81)	% (N=63)	% (N=18)	
Discussion with nurses before				0 535
attribution of DNR status †				0.000
Yes	74.7	76.2	68.8	
No	25.3	23.8	31.3	
Degree of nurses' involvement				0.393
according to the head nurse ‡				
Very involved	26.9	25.8	31.3	
Fairly involved	44.9	48.4	31.3	
Fairly uninvolved	25.6	24.2	31.3	
Uninvolved	2.6	1.6	6.3	
Way of communicating DNR status				
of a patient among the nursing				
team †,§				
Written, in the patient's file	86.1	87.3	81.3	0.686
Written, other than the patient's file	6.3	7.9	0.0	0.577
Oral, on a formal meeting	68.4	66.7	75.0	0.764
Oral, on an informal basis	8.9	7.9	12.5	0.625

Table 5.2 Nurses' involvement in the last 'do not resuscitate' (DNR) decisionmaking according to existence of a DNR policy

* Differences in nurses' involvement in DNR decision-making between cases in acute geriatric wards with a DNR policy and those without, was tested by Fisher's Exact test

† Two missing cases

‡ Three missing cases

§ Multiple answers possible

Table 5.3 Cardiopulmonary resuscitation (CPR) in case of a cardiopulmonary arrest for patients with 'do not resuscitate' (DNR) status and those without $(N=81)^*$

	Patients sta	Patients with DNR status		ithout DNR tus
	Ν	(%)	Ν	(%)
CPR is started				
Never	44	(54.3)	-	
Rarely	32	(39.5)	4	(4.9)
Sometimes	5	(6.2)	14	(17.3)
Often	-		35	(43.2)
Always	-		28	(34.6)

* Differences in starting CPR between patients with DNR status and those without was tested by the Sign test (P<=0.001).

DISCUSSION

This study is the first to investigate nurses' involvement in DNR decision-making on acute geriatric wards in Flanders, and the first to examine their adherence to these decisions in case of an actual cardiopulmonary arrest. All acute geriatric wards in Flanders were included in this study and a high response of 86.2% was reached, with no statistically significant differences between response and nonresponse samples concerning characteristics of the hospital site and geriatric ward.

There are some limitations to this study. First, head nurses were asked to report for their nursing team, and members of the nursing team were not directly questioned about their involvement in DNR decision-making or about their actions in case of an actual cardiopulmonary arrest. Secondly, head nurses were not asked for the reason(s) for not involving nurses in the last DNR decisionmaking process. Thirdly, nurses' adherence to the resuscitation status of patients was only asked for at an aggregated level and not for specific cases.

Nevertheless, our findings give a first insight into the daily practice of nurses' involvement in DNR decision-making on acute geriatric wards in Flanders. They show that nurses are often but not always consulted in these decisions. Nevertheless, the DNR status of a patient is always communicated among the nursing team, mostly in writing. Actual decisions to forgo CPR when an arrest occurs are mostly in accordance with the DNR status of the patient but also occur for patients without such status.

The involvement of nurses in DNR decision-making on acute geriatric wards in Flanders seemed to be higher than in other countries. An American study in three hospitals found that only 26.9% of the DNR decisions were made after consulting the patient's nurse (Jacobson & Kasworm 1999). One French study reported that nurses were always consulted in DNR decision-making on an intensive care unit, but other studies in France, the United Kingdom and Canada reported that nurses were involved in about half or less than half of the decisions (Holzapfel et al. 2002). Nurses in Finland participated in 46% of the cases (Hilden et al. 2004). Dutch figures for nurses' involvement by several specialists are more comparable, ranging from 66% (internal medicine specialists and surgeons) to 83% (lung specialists) (van Delden et al. 1993). All these studies concerned different healthcare settings from those in our study (different hospital wards and countries).

For Flanders, one study investigated nurses' involvement, not in DNR decisionmaking as such, but in all kinds of medical end-of-life decisions. Physicians reported that 51.4% of all non-treatment decisions (including DNR) made in institutional care were made after discussion with nurses (Bilsen et al. 2004). This result is in line with figures for nurses' involvement in DNR decision-making in other European countries, but is still lower than the participation rate for nurses found in this study. It is possible that head nurses, who were asked to report for their nursing team, gave a slightly exaggerated description of current practices at the ward. Another explanation might be the specific character of DNR decisions vs. all non-treatment decisions. Not starting CPR in case of a cardiopulmonary arrest has an immediate effect on the time of death, which is not true for other non-treatment decisions (e.g. withholding antibiotics). A final explanation might be found in the specific setting of our study. Death is rather common on acute geriatric wards, which might lead to more open discussion about the end of life and DNR on these wards than on others. In addition, geriatricians may be more inclined to forgo futile treatments and may be more familiar with multidisciplinary teamwork in general, and with communicating with nurses in particular.

An important finding is that nurses almost always forgo CPR in case of cardiopulmonary arrest in patients with DNR status and that they do not start CPR in case of cardiopulmonary arrest for a substantial number of patients without such status. This is supported by international literature (Hakim et al. 1996, Goodlin et al. 1999, Lee et al. 2000). The fact that nurses sometimes decide on the spot (without prior discussion with the physician) that CPR would be futile for patients without DNR status might be explained by the possibility that DNR had not yet been considered by the physician but that nurses thought it was appropriate, or that nurses were not properly acquainted with the DNR status of the patient (e.g. DNR status was not written in the patient's file). Timely, well-discussed and communicated decision-making with the nursing team should prevent conflict situations and inadequately considered actions in acute moments of medical emergency with great emotional stress.

CONCLUSION

Nurses are often consulted in DNR decision-making on acute geriatric wards in Flanders. Nevertheless, as nurses can be seen as gatekeepers for the care of hospitalized patients, their involvement by physicians in the DNR decision-making process might still be increased, perhaps by implementing institutional guidelines recognizing nurses' important role in all end-of-life decisions. Further research is needed to investigate the circumstances of those decisions to forgo CPR when no DNR status was attributed to a patient. To make appropriate DNR decisions and to avoid rash decision-making in case of an actual cardiopulmonary arrest, DNR decisions should be made in advance and nurses should be involved early.

REFERENCES

Anderson-Shaw L. The unilateral DNR order – one hospital's experience. JONA'S Healthcare Law, Ethics and Regulation 2003;5:42–46.

Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. Journal of Advanced Nursing 2004;47:583–591.

De Gendt C, Bilsen ., Vander Stichele R, Lambert M, Van Den Noortgate N, Deliens L. Do-not-resuscitate policy on acute geriatric wards in Flanders, Belgium. Journal of the American Geriatrics Society 2005;53:2221–2226.

De Gendt C, Bilsen J, Van Den Noortgate N, Lambert M, Vander Stichele R, Deliens L. Prevalence of patients with do-not-resuscitate status on acute geriatric wards in Flanders, Belgium. Journals of Gerontology. Series A, Biological Sciences and Medical Sciences 2007; ;62:395-399.

van Delden JJ, van der Maas PJ, Pijnenborg L, Looman CW. Deciding not to resuscitate in Dutch hospitals. Journal of Medical Ethics 1993;19:200–205.

van Delden JJ, Lofmark R, Deliens L, Bosshard G, Norup M, Cecioni R, van der Heide A. Do-not-resuscitate decisions in six European countries. Critical Care Medicine 2006;34:1686–1690.

Dillman D.A. The design and administration of mail surveys. Annual Review of Sociology 1991;17:225–249.

Eliasson AH, Howard RS, Torrington KG, Dillard TA, Phillips YY. Do-notresuscitate decisions in the medical ICU: comparing physician and nurse opinions. Chest 1997;111:1106–1111.

Gillick MR, Hesse K, Mazzapica N. Medical technology at the end of life. What would physicians and nurses want for themselves? Archives of Internal Medicine 1993;153:2542–2547.

Goodlin SJ, Zhong Z, Lynn J, Teno JM, Fago JP, Desbiens N, Connors AF Jr, Wenger NS, Phillips RS. Factors associated with use of cardiopulmonary resuscitation in seriously ill hospitalized adults. The Journal of the American Medical Association 1999;282: 2333–2339.

Hakim RB, Teno JM, Harrell FE Jr, Knaus WA, Wenger N, Phillips RS, Layde P, Califf R, Connors AF Jr, Lynn J. Factors associated with do-not-resuscitate orders: patients' preferences, prognoses, and physicians' judgments. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. Annals of Internal Medicine 1996;125:284–293.

Hilden HM, Louhiala P, Honkasalo ML, Palo J. Finnish nurses' views on end-oflife discussions and a comparison with physicians' views. Nursing Ethics 2004; 11:165–178.

Holzapfel L, Demingeon G, Piralla B, Biot L, Nallet B. A four-step protocol for limitation of treatment in terminal care. An observational study in 475 intensive care unit patients. Intensive Care Medicine 2002;28:1309–1315.

Jacobson JA, Kasworm E. May I take your order: a userfriendly resuscitation status and medical treatment plan form. Quality Management in Health Care 1999;7:13–20.

Lee MA, Brummel-Smith K, Meyer J, Drew N, London MR. Physician orders for life-sustaining treatment (POLST): outcomes in a PACE program. Program of all-inclusive care for the elderly. Journal of the American Geriatrics Society 2000;48: 1219–1225.

Lofmark R, Nilstun T. Deciding not to resuscitate. Responsibilities of physicians and nurses – a proposal. Scandinavian Journal of Caring Sciences 1997;11: 207–211.

Manias E. Australian nurses' experiences and attitudes in the 'Do Not Resuscitate' decision. Research in Nursing & Health 1998;21:429–441.

Richter J, Eisemann MR. The compliance of doctors and nurses with do-not-resuscitate orders in Germany and Sweden. Resuscitation 1999;42:203–209.

Stewart K, Spice C, Rai GS. Where now with do not attempt resuscitation decisions? Age and Ageing 2003;32:143–148.

Part IV

Advance care planning

in nursing homes

Chapter 6

Nursing home policies

regarding

advance care planning

De Gendt C, Bilsen J, Vander Stichele R, Deliens L. Nursing home policies regarding advance care planning in Flanders, Belgium. European Journal of Public Health 2010;20:189-194.

ABSTRACT

Background The aim of this study is to discover how many nursing homes (NHs) in Flanders (Belgium) have policies on advance care planning (ACP) and their content regarding different medical end-of-life decisions.

Methods A structured mail questionnaire was sent to the NH administrators of all 594 NHs in Flanders (Belgium) at the end of 2006. The questionnaire asked about the existence, timing of implementation and content of ACP policy documents (guidelines and patient-specific planning forms), and on NH characteristics related to end-of-life care.

Results The response rate was 58.1%. The development of ACP policy documents began in 1989 with major increases in implementation taking place from 2000. In 2006, ACP policy documents were available in 95.1% of NHs. Most of these NHs had ACP guidelines as well as ACP patient-specific planning forms. Almost all patient-specific planning forms included anticipatory do-not-hospitalize (90.0%) and do-not-resuscitate decisions (83.2%). Anticipatory decisions about terminal sedation (29.2%) and euthanasia (19.7%) were mentioned less often and these decisions were not permitted to be made in all NHs. One out of three NHs had policies on the appointment of a patient's representative.

Conclusion By the end of 2006, almost all NHs in Flanders (Belgium) had an ACP policy. The implementation of ACP policies in Flemish NHs lagged behind other countries, but has developed rapidly since 2000. However, some NHs appear to ban some end-of-life options which are actually legal in Belgium. Further research is needed to investigate whether ACP policies have much impact on the quality of end-of-life care in NHs.

Acknowledgements

This article has been presented orally on the 9th Public Health Symposium 'Public Health at the End of Life' in Brussels (Belgium), 14 December 2007. The authors thank the four umbrella organizations for nursing homes (Vereniging van Vlaamse Steden en Gemeenten, Verbond der Verzorgingsinstellingen, Federatie Onafhankelijke Seniorenzorg and the Federatie van Rustoorden van Belgie"), Crataegus and the Federation Palliative Care Flanders for their support given to this study by signing the recommendation letter enclosed with the questionnaire. Different research grants from the Research Council of the Vrije Universiteit Brussel [OZR1517, OZR1146].

INTRODUCTION

During the last century the process of dying became more and more institutionalized with increasing numbers of people dying in hospitals and in nursing homes (NHs).¹ However, in recent years the proportion of deaths in hospitals has decreased slightly in contrast to NHs.^{1–6} In 2002, in Flanders, Belgium, a quarter of people aged >=65 years died in a NH (about 13 000), while the degree of NH institutionalization among persons aged >=65 years is only 5.6% (almost 60 000), meaning that yearly one out of four NH residents also had died in the NH.^{7–9}

Recently, advance care planning (ACP) at the end of life has become more important, especially in NHs where residents often lack competence at the end of life.¹⁰ ACP involves the discussion with patients and/or their representatives of the goals and desired direction of the patient's care, particularly end-of-life care, in the event that the patient loses the capacity to make decisions themselves (MeSH Database). The aim is that the patient's wishes can thereby be taken into account as much as possible by health care workers.

In the USA the Patient Self-Determination Act of 1991 obliges health care institutions, including NHs, to inform patients of their right to accept or reject medical treatments and to appoint a representative, and to encourage patients to write advance directives. If it concerns incompetent patients, institutions should give this information to the patient's relatives and later on to the patient when he/she is no longer incompetent. More recently, patients in some other countries (e.g. Australia) have been enabled by law to participate actively in medical decision making.¹¹

In Belgium the Patients' Rights Act (2002) also gives patients the right to accept or reject medical treatments and to appoint a representative,¹² but in contrast to some other countries Belgian legislation does not regulate how health care institutions need to implement these rights in practice. Because implementation of ACP policy in Flanders is not driven by law and little is known about ACP policies in NHs in Flanders, this study aims to discover how many NHs have a policy on ACP (institutional ACP guidelines and individual patient-specific planning forms), and for how long they have had one. The study also looks at the content of ACP policy documents regarding the different types of medical end-oflife decisions (i.e. do-not-hospitalize, do-not-resuscitate and other non-treatment decisions, pain and symptom alleviation which may shorten life, terminal sedation, euthanasia and physician-assisted suicide).

METHODS

Design

This study was conducted at the end of 2006 in Flanders, the Dutch-speaking part of Belgium which contains about 60% of the Belgian population (six million). Professional residential care for elderly people in Flanders is organized in 745 care homes for elderly people (in total 63 003 beds). These care homes can be divided into care homes not recognized as a NH (N= 151)—usually residing less elderly and less dependent people-and into care homes that are also recognized as a NH (N= 594). Only the latter subset of institutions was included in this study. These NHs provide skilled nursing care to elderly people who have serious problems in activities of daily living and/or lack mental capacity, but who do not need daily medical supervision or full-time specialized medical treatment as in hospitals. They serve in total 57 858 beds (a mix of 31 551 NH beds and 26 307 traditional care home beds) and each institute has on average 97 elderly residents.^{13,14} The medical care in Flemish NHs (including end-of-life care) is provided by general practitioners (GPs) chosen by the individual resident. These GPs are not part of the management of the institution. Each NH is also obliged by law to have one coordinating and advisory physician, also a GP, who participates in the management of the NH. This coordinating and advisory physician has the task of facilitating the cooperation between the NH management and the visiting GPs, coordinating and streamlining medical care, and organizing training for GPs and nurses. He/she can also be consulted for a second opinion by the other GPs and can intervene in care-related conflicts (e.g. a conflict between resident, next of kin and professional caregivers concerning decisions at the end of life).^{15,16}

The addresses of the 594 NHs included in this study, their characteristics such as ownership ('public'/'private, nonprofit'/' private, profit') and bed capacity were obtained from the Flemish Ministry of Health. The NH administrator of each NH was sent a structured mail questionnaire requesting information about the ACP policy of his/her institution, together with a letter of recommendation signed by six relevant organizations for this setting. About 1 month later a follow-up letter was mailed to the non-responders. A telephone call was made after another three weeks to those who had still not responded.

Questionnaire

The first part of the four-page questionnaire was about NH characteristics related to end-of-life care: (i) How much time per week did the coordinating and advisory

physician visit the NH (excluding any time spent acting as the treating GP of an individual resident)? (ii) How many full-time equivalent (FTE) reference nurses for palliative care are there? (iii) How many residents died in the past 12 months? (iv) How many residents who died in the past 12 months received palliative care in the NH? (e.g. palliative care delivered in the NH by a multidisciplinary palliative support team or by the resident's GP) (v) How many residents who died in the past 12 months care unit? To make useful comparisons between NHs, the answer to question (iii) was reassessed per 100 beds, and to questions (iv) and (v) per 100 deaths.

The second part of the questionnaire explored two possible aspects of the ACP policy of the NH namely (i) written institutional ACP guidelines and (ii) individual, patient-specific planning forms. These were defined in the questionnaire as follows:

- Written institutional ACP guidelines: generally accepted agreements of the NH to guide physicians and nurses in advance care planning regarding the end-of-life of patients;
- (ii) Individual patient-specific planning forms: standardized forms to document anticipatory instructions from the physician and/or the patient (regarding hospitalization, treatments and other medical end-of-life acts) concerning the individual patient.

Key questions were: 'Are written institutional ACP guidelines regarding the end of life available in the NH' ('Yes'/'No') and 'Are individual patient-specific planning forms available in the NH' ('Yes'/'No'). When these documents were available, respondents were asked at what stage they were enacted and about their content differentiating several medical end-of-life decisions. The questionnaire was partly inspired by an existing questionnaire on policies and guidelines on medical end-of-life decision making in health care in The Netherlands¹⁷ and by another regarding do-not-resuscitate policies on acute geriatric wards in Flanders.¹⁸

The questionnaire was pilot-tested by 10 NH administrators in all five provinces of Flanders, resulting in minor adaptations to avoid ambiguity and to improve understanding.

Data analysis

To test the representativity of the response sample, it was compared with the non-response sample using the NH characteristics of the database from the Flemish Ministry of Health (ownership and number of beds). For characteristics with significant differences in distribution, the response sample was weighted to the distribution of the population. The NH was considered the unit of analysis.

Descriptive results were presented in frequency tables and crosstabs, and differences in distribution (Chi-square and Rao-Scott Chi-square tests taking into account design correction) were calculated using the statistical package SPSS 16.0 (SPSS Inc., Chicago, IL) and SAS Enterprise Guide 4.1 (SAS Institute Inc., Cary, NC). Confidence intervals of 95% were used.

RESULTS

Nursing home characteristics

In total 345 of the 594 NH administrators (58.1%) completed and returned the questionnaire; 189 (31.8%) were returned after sending the original questionnaire, 91 (15.3%) after the follow-up letter was sent and 65 (10.9%) after the follow-up telephone call. Ownership ('public'/'private, non-profit'/ 'private, profit') and number of beds of the 345 responding NHs were compared with the non-response sample. Since there was an overrepresentation of public NHs in the response sample (41.7 vs. 30.1% in the non-response sample; P = 0.006), results were weighted for ownership of all NHs in Flanders (Table 6.1).

In 25.9% of the NHs the coordinating and advisory physician spent <=1 h per week in the NH, 26.5% spent between 1 and 2 h, 20.4% between 2 and 3 h and 27.2% >3 h. This was positively related to the bed capacity of the NH (P < 0.001; not shown in Table 6.1). Most NHs (41.4%) had one FTE reference nurse for palliative care and 23.5% had less than one FTE.

Dying and care for the dying in nursing homes

The mean proportion of NH residents per 100 beds who died in the past year was 28 (Table 6.1). Of the residents who had died in the last year, NHs had been given palliative care on average to 53 per 100 and had transferred on average 1 per 100 to a palliative care unit in the last phase of life. In the majority of NHs (86.9%) no transfers to a palliative care unit had taken place.

Development of ACP policy

At the end of 2006, 95.1% of the NHs had a policy regarding ACP (Figure 6.1). Institutional ACP guidelines were available in 66.6% of NHs and individual patient-specific planning forms in 93.0%. Both institutional guidelines and individual patient-specific planning forms were available in 64.5% of NHs. No

significant differences were found for NH characteristics (not shown in the table or figure).

The first ACP policy documents were implemented in 1989 in two NHs, and it took until 1993 before other NHs began to implement institutional ACP guidelines and/or individual patient-specific planning forms. Since 1998, more than half of the NHs with ACP policy documents had institutional guidelines as well as an individual patient-specific planning form available. After a major increase of 17.8% in 2002, more than half of Flemish NHs had one or both ACP policy documents enacted. From 2003 to 2005 the number of NHs who implemented ACP policy documents increased each year by about 10% to attain near completion in 2006.

Content of institutional ACP guidelines regarding different medical end-oflife decisions

Anticipatory decisions about whether or not to transfer a resident to hospital at the end of life were the most (59.2%) common medical end-of-life decisions covered by institutional ACP guidelines (Table 6.2). These guidelines make it possible to make do-not-hospitalize decisions in 58.6% of the NHs, more often according to legal criteria (38.0%) as according to legal as well as additional institutional criteria (20.6%).

Institutional guidelines about anticipatory do-not-resuscitate decisions (not to start resuscitation in case of a cardiopulmonary arrest) were somewhat less frequently found (55.1%). About the same figures were found concerning institutional guidelines for anticipating decisions to withhold or withdraw artificial food and fluids, antibiotics or other treatments.

Intensifying pain and symptom alleviation, in the knowledge that this might shorten the patient's life, was mentioned less often in the institutional ACP guidelines (47.4%). In 29.4% of NHs this was allowed according to legal criteria and in 17.7% there were additional institutional criteria.

Institutional guidelines about terminal sedation or euthanasia were found in one third of NHs, and in respectively 2.3 and 6.2% of the NHs these guidelines did expressly not allow these medical decisions in the institution.

Physician-assisted suicide was mentioned in institutional ACP guidelines in one to five NHs. In 15.2% of the NHs this practice was explicitly prohibited in their guidelines.

About a quarter (26.2%) of NHs had institutional guidelines about the appointment of a representative for the resident (not shown in the table).

Institutional guidelines about euthanasia were more frequently (but not significantly, P = 0.064) implemented in private, non-profit NHs which are mostly of Catholic denomination (42.0 vs. 34.7% in public and 27.8% in private, for profit NHs). These institutions were also significantly more likely to have guidelines allowing euthanasia according to legal as well as institutional criteria (17.6 vs. 9.7% in public and 2.8% in private, for profit NHs; P = 0.043; not shown in the table).

Content of individual patient-specific planning forms regarding different medical end-of-life decisions

In 90.0% of the NHs anticipatory do-not-hospitalize decisions could be documented on individual patient-specific planning forms (Table 6.3). In 82.1–84.6% of NHs other kinds of non-treatment decisions could be documented on individual patient-specific planning forms. A space to document anticipatory instructions about intensifying pain and symptom alleviation which might shorten the patient's life (56.4%), terminal sedation (29.2%) and euthanasia (19.7%) was provided less often.

In 29.4% of the NHs a standardized document was available for the appointment of a representative (not shown in the table).

	Response	
	Unweighted	Weighted ^a
	N (%)	%
NURSING HOME CHARACTERISTICS		
Ownership		
Public	144 (41.7)	36.9
Private, non-profit	171 (49.6)	52.2
Private, profit	30 (9.7)	10.9
Number of beds		
<= 60	72 (20.9)	21.4
61 → 90	113 (32.8)	32.6
91 → 120	74 (21.4)	21.8
> 120	86 (24.9)	24.2
Average time spent per week in the nursing home by the coordinating and advisory physician ^b		
<= 1h	85 (25.9)	25.9
$1h \rightarrow 2h$	88 (26.8)	26.5
$2h \rightarrow 3h$	66 (20.1)	20.4
> 3h	89 (27.1)	27.2
FTE reference nurse for palliative care ^c		
< 1 FTE	75 (23.4)	23.5
1 FTE	131 (40.9)	41.4
1.01 FTE → 2 FTE	60 (18.8)	18.4
> 2 FTE	54 (16.9)	16.6
DYING AND CARE FOR THE DYING IN NURSING HOMES		
Number of deaths per year (per 100 beds) ^d		
<= 20	53 (15.6)	15.7
21 → 25	80 (23.5)	23.5
26 → 30	98 (28.8)	28.3
31 → 35	48 (14.1)	14.4
> 35	61 (17.9)	18.1
Mean 28 (Sd 8) ; Median 27; Range 2 – 60		
Number of deaths with palliative care per year (per 100 de	eaths) ^e	
<= 40	107 (31.8)	32.0
41 → 60	99 (29.5)	29.3
61 → 80	93 (27.7)	27.4
> 80	37 (11.0)	11.3
Mean 53 (Sd 23) ; Median 52; Range 0 – 100	£	
Number of transfers to a palliative care unit per year (per	100 deaths) '	
0	298 (87.1)	87.1
	24 (7.0)	6.9
	9 (2.6)	2.6
> IU Moon $= 1$ (Sd $= 5$): Modion (): Dongo () = 40	11 (3.2)	3.4
(50 = 5), we dan 0; Range 0 – 40		

Table 6.1 Description of NHs, dying and care for the dying (N = 345)

SD: standard deviation

a: Percentages are weighted for ownership of all NHs in Flanders; b: 17 missing cases; c: 25 missing cases, d: 5 missing cases; e: 9 missing cases; f: 3 missing cases

Figure 6.1 Cumulative percentages of NHs with ACP policy documents by year of implementation (N=345)



Note: Percentages are weighted for ownership of all nursing homes in Flanders ^a year of implementation was not known for 9 nursing homes with guidelines and for 12 nursing homes with patient-specific planning forms

Table 6.2 Availability and content of institutional ACP guidelines regarding different medical end-of-life decisions (N=345)

	Available	Content of available institutional ACP guidelines		
		Decision allowed according to legal criteria	Decision allowed according to legal as well as additional institutional criteria	Decision not allowed
	%		%	
Institutional ACP guidelines (total)	66.6			
Institutional ACP guidelines regarding decisions concerning ^a				
do-not-hospitalisation	59.2	38.0	20.6	0.6
do-not-resuscitation	55.1	36.7	17.5	0.9
withholding or withdrawing artificial food and fluids	56.9	36.8	20.1	0.0
withholding or withdrawing antibiotics	57.7	37,3	20.3	0.0
withholding or withdrawing other treatments	57.1	37.4	19.5	0.3
pain and symptom alleviation, which may shorten the patient's life	47.4	29.4	17.7	0.3
terminal sedation	33.5	20.9	10.3	2.3
euthanasia	37.7	18.4	13.1	6.2
physician-assisted suicide	19.7	3.5	0.9	15.2

Note: Percentages are weighted for ownership of all NHs in Flanders.

a: From 4 to 9 missing cases

Table 6.3 Availability of individual patient-specific planning forms concerning different medical end-oflife decisions (N=345)

	%
Individual patient-specific planning form available (total)	93.0
Individual patient-specific planning form available to	
document decisions concerning ^a	
do-not-hospitalisation	90.0
do-not-resuscitation	83.2
withholding or withdrawing artificial food and fluids	84.6
withholding or withdrawing antibiotics	82.3
withholding or withdrawing other treatments	82.1
pain and symptom alleviation, which may shorten the patient's life	56.4
terminal sedation	29.2
euthanasia	19.7
Note: Percentages are weighted for ownership of all purging homes in Flo	adara

Note: Percentages are weighted for ownership of all nursing homes in Flanders

a: From 4 to 17 missing cases

DISCUSSION

The development of ACP policy in NHs in Flanders, Belgium, started gradually in 1989 and increased more rapidly from 2000. At the end of 2006, almost all NHs had an ACP policy, consisting predominantly of individual patient-specific planning forms often accompanied by institutional guidelines. Anticipatory do-not-hospitalize and do-not-resuscitate decisions are almost always included in these policy documents, while anticipatory decisions about terminal sedation and euthanasia are often not mentioned, and when mentioned often specifically excluded. In addition, this study shows that about half of residents who had died had previously received palliative care in the NH and that 1 out of 100 was transferred to a palliative care unit in the last phase of life.

This is the first nationwide study in Flanders to investigate ACP policies regarding different kinds of medical end-of-life decisions in NHs rather than focussing on euthanasia alone, and the first to describe both individual patient-specific planning forms and institutional guidelines. Furthermore, it gives for the first time some insight into the existence of palliative care initiatives in NHs. Results were weighted for the slight overrepresentation of public NHs in the response sample and can be considered to be representative for all NHs in Flanders.

Nevertheless, there are some limitations related to this study. First, in spite of the satisfactory response rate (58.1%) and weighted figures, possible non-response bias cannot be totally ruled out. It remains possible that NH with ACP policies were more likely to respond to the questionnaire, resulting in an overestimation of NH with ACP policies. Second, although a substantial impact of ACP on actual practices in the NHs can be expected, this is currently debated in literature^{19,20} since medical crisis often can not be predicted in detail, making most prior instructions difficult to use, irrelevant or even misleading. The current study does not provide information on this issue.

The development of ACP policies in NHs in Flanders has recently expanded rapidly. This might be an indirect consequence of the public debate about the laws on euthanasia and patients' rights (both enacted in 2002) which formally began in 2000.^{12,21}

There is little information available about ACP policies in other European countries. In The Netherlands, where the public debate on end-of-life decisions began much earlier than in Belgium and the rest of Europe, an important step towards policy development on euthanasia and physician-assisted suicide was taken in 1995 (in 74% of the Dutch NHs), but on DNR and the withholding or withdrawing of other life-sustaining treatments to a lesser degree (in about 20% of the Dutch NHs).¹⁷

In short, one can say that the development of ACP policy in NHs in Europe is still incomplete and lags behind the situation in the USA. Almost half of the US NHs had implemented an ACP policy before enactment of the Patient Self-Determination Act (1991) and the rest did so shortly afterwards.^{22,23} ACP policies, especially those

concerning do-not-resuscitation and living wills, are also commonplace in health care institutions in Canada and Australia. $^{\rm 24}$

For a country like Belgium which has had a law on euthanasia since 2002, it seems strange that by 2006 only 37.7% of NHs in Flanders had guidelines on euthanasia in their ACP policies. An earlier study of 2003 showed that about 30% of Catholic NHs in Flanders had guidelines on euthanasia.²⁵ Since the current study has not found any relationship between the ownership of a NH and the inclusion of euthanasia in its ACP guidelines, only a slight increase of this specific kind of policy is assumed in a 3year period after enactment of the euthanasia law. However, as euthanasia is only performed in 0.6% of deaths in NHs, it might be necessary to put into perspective the lower prevalence of guidelines on euthanasia.²⁶ Perhaps more remarkable is the fact that in 6.2% of NHs euthanasia is not allowed, although it is not possible to discover from this study whether this means that euthanasia requests from residents of these NHs will be ignored, or that these NHs will refer to another institution in the event of such a request. It is also not clear whether existing additional institutional criteria (besides the legal ones) allowing euthanasia, more often imposed in private nonprofit NHs, are actually intended to improve carefulness in decision making or rather to deter such decisions. This may possibly be a leftover from the so-called palliative filter procedure. During the public hearings in the Belgian Senate before the enactment of the euthanasia law, there was a lot of discussion about whether or not to include an obligatory palliative filter procedure in the law. This procedure would require the consultation of a specialized palliative care team before a euthanasia request could be honoured (from a point of view that palliative care can forestall such requests), but in the end this obligation was not included in the law. Although the law stipulates that patients requesting euthanasia must be informed of the possibilities of palliative care, the palliative filter procedure might still persist in some health care institutions.^{25,27,28}

Less than one-third of NHs had policy documents on the appointment by the resident of a representative. Since NH residents are often lacking in capacity due to dementia or other illness, it is important to investigate further whether and how this could be encouraged e.g. by obliging NHs under law to draw up guidelines and formalized documents.

Finally, this study showed that only half of residents who had died in NHs had previously received palliative care and that very few were transferred to palliative care units in order to get adequate care. Because of the high mortality rate in NHs and since the majority of NH residents die non-suddenly, it can be assumed that palliative care delivery in the NH has not yet reached the optimal quality of end-of-life care for these residents. This might be subject for improvement by placing more financial means and manpower at their disposal.

In conclusion, this study provides an insight into the present state of ACP policies regarding the different kinds of end-of-life decisions in NHs in Flanders, Belgium. By
the end of 2006, almost all NHs in Flanders had an ACP policy. Compared with other countries, implementation had started rather slowly but developed rapidly during recent years. Further research is needed to investigate actual ACP practices and the extent to which the existence of ACP policy documents impacts on actual medical practice at the end-of-life and on the quality of end-of-life care in NHs. Differences in legal regulations, organization of care and cultural factors should be taken into account in international comparisons.

REFERENCES

- 1 Teno JM, Clarridge BR, Casey V, et al. Family perspectives on end-of-life care at the last place of care. JAMA 2004;291:88–93.
- 2 Mezey M, Dubler NN, Mitty E, Brody AA. What impact do setting and transitions have on the quality of life at the end of life and the quality of the dying process? Gerontologist 2002;42(Spec No 3):54–67.
- 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 Hunt RW, Bond MJ, Groth RK, King PM. Place of death in South Australia. Patterns from 1910 to 1987. Med J Aust 1991;155:549–53.
- 5 Bickel H. The last year of life: a representative study of deceased patients. Living arrangement, place of death and utilization of health resources. Z Gerontol Geriatr 1998;31:193–204.
- 6 Flory J, Yinong YX, Gurol I, et al. Place of death: U.S. trends since 1980. Health Aff (Millwood) 2004;23:194–200.
- 7 van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362:345–50.
- 8 Pacolet J, Delie`ge D, Artoisenet C, et al. Vergrijzing, gezondheidszorg en ouderenzorg in Belgie[–]. Rapport voor de FOD Sociale Zekerheid Directie-Generaal Sociaal Beleid, 2006.
- 9 Cohen J, Bilsen J, Hooft P, et al. Dying at home or in an institution. Using death certificates to explore the factors associated with place of death. Health Policy 2006;78:319–29.
- 10 Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. Arch Fam Med 1998;7:417–23.
- 11 Manias E. Australian nurses' experiences and attitudes in the "Do Not Resuscitate" decision. Res Nurs Health 1998;21:429–41.

- 12 Wet betreffende de rechten van de patie nt [Patients' Rights Act]. Belgisch Staatsblad van 26 september 2002 [Belgian Law Gazette of September 26, 2002] [in Dutch].
- 13 Koninklijk Besluit van 21 september 2004 houdende vaststelling van de normen voor de bijzondere erkenning als rust- en verzorgingstehuis of als centrum voor dagverzorging [Royal decree of September 21, 2004 concerning standards for additional recognition as a nursing home or as a day care centre] Belgisch Staatsblad 28 Oktober 2004 [Belgian Law Gazette of October 28, 2004] [in Dutch].
- 14 Vervotte I. Antwoord op schriftelijke parlementaire vraag nr 111 van 16 maart 2007 [Answer to written parlementary question n 111 from March 16, 2007] [online]. http://jsp.vlaamsparlement.be/docs/schv/2006-2007/VERVOTTE/ 111/antw.111.doc (24 July 2008, date last accessed) [in Dutch].
- 15 De Lepeleire J, Leirman W. Poor effect of family practice physician training at the organizational level in long-term care facilities in Flanders, Belgium. J Am Med Dir Assoc 2006;7:470.
- 16 Lemiengre J, Dierckx dC, Verbeke G, et al. Ethics policies on euthanasia in nursing homes: a survey in Flanders, Belgium. Soc Sci Med 2008;66:376–86.
- 17 Haverkate I, van der Wal G. Policies on medical decisions concerning the end of life in Dutch health care institutions. JAMA 1996;275:435–39.
- 18 De Gendt C, Bilsen J, Stichele RV, et al. Do-not-resuscitate policy on acute geriatric wards in Flanders, Belgium. J Am Geriatr Soc 2005;53:2221–6.
- 19 Perkin HS. Controlling death: the false promise of advance directives. Ann Intern Med 2007;147:51–7.
- 20 Dobbins EH. End-of-life decisions: influence of advance directives on patient care. J Gerontol Nurs 2007;33:50–6.
- 21 Wet betreffende euthanasie [Law concerning euthanasia]. Belgisch Staatsblad van 22 juni 2002 [Belgian Law Gazette of June 22, 2002] [in Dutch].
- 22 Kapp MB. Nursing home compliance with the patient self-determination act: does Jewish affiliation make a difference? HEC Forum 1993;5:223–36.
- 23 Bradley EH, Blechner BB, Walker LC, Wetle TT. Institutional efforts to promote advance care planning in nursing homes: challenges and opportunities. J Law Med Ethics 1997;25:150–9.
- 24 Hayes S, Stewart K. The role of audit in making do not resuscitate decisions. J Eval Clin Pract 1999;5:305–12.
- 25 Gastmans C, Lemiengre J, van der Wal G, et al. Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders). Health Policy 2006;76:169–78.
- 26 Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356:1806–11.

- 27 Bernheim JL, Deschepper R, Distelmans W, Mullie, et al. Development of palliative care and legislation of euthanasia: antagonism or synergy? BMJ 2008;336:864–7.
- 28 Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003;362:1239–40.

Chapter 7

Advance care planning and dying

In nursing homes

Based on:

De Gendt C, Bilsen J, Vander Stichele R, Deliens L. Advance care planning in nursing homes in Flanders, Belgium. A nationwide survey. (submitted)

ABSTRACT

Objectives To describe (1) the demographic, clinical and care characteristics of dying in nursing homes (NHs) in Flanders, and (2) the prevalence and characteristics of documented advance care plans (advance directives and physician's orders) and the authorization of a legal representative by the NH resident.

Design Sampling of all deaths of NH residents in a retrospective period of two months.

Setting All 594 NHs in Flanders (Belgium).

Participants NH administrators and nurses involved in care for NH residents deceased during September and October 2006.

Measurements Structured mail questionnaires about the resident's characteristics, hospital transfers, palliative care delivery, advance care plans and authorization of legal representatives.

Results Of all NHs (N=594) 318 NH administrators (53.5%) reported 1303 deaths. Nurses reported about 1240 (95.2%) of these deaths. At the end of life NH residents often had dementia (65.2%) and were severely dependent (76.1%). Almost half (43.1%) had at least one hospital transfer and two thirds received palliative care. Half of the residents had an advance care plan, predominantly a physician's order and less often an advance directive, positively related to palliative care delivery. Residents with physician's orders more often died in the NH. Fewer residents with dementia had advance directives. Nine percent had authorized a legal representative.

Conclusion Prevalence of advance care plans and formal authorization of a legal representative is low among deceased NH residents in Flanders. The emphasis is on physician's orders, established after the resident became incompetent. Initiatives should be developed to stimulate more advance discussion on care options and end-of-life decision making with residents while they still have the competence.

Acknowledgements

The authors thank the four umbrella organizations for nursing homes (Vereniging van Vlaamse Steden en Gemeenten, Verbond der Verzorgingsinstellingen, Federatie Onafhankelijke Seniorenzorg and the Federatie van Rustoorden van België), Crataegus and the Federation Palliative Care Flanders for their support given to this study by signing the recommendation letter enclosed with the questionnaire.

Different research grants from the Research Council of the Vrije Universiteit Brussel funded this study.

INTRODUCTION

In Belgium and other Western countries the population is ageing due to better living conditions, changing lifestyles and advances in medical knowledge and technology leading to improved early diagnoses and treatment of chronic conditions. Many people now live to be very old and die after a long period of chronic and degenerative disease,¹ whereas before deaths occurred more suddenly, often caused by infectious diseases.² During recent decades awareness has grown that palliation and improvement of the quality of life of the patient and family may be preferable to futile life-prolonging treatment at the end of life.³

This has resulted in increasing attention being paid to advance care planning (ACP), especially in nursing homes (NHs) where residents often lack competence at the end of life.⁴⁻⁶ ACP is defined as the discussion with patients and/or their representatives about the goals and the desired direction of the patient's care, particularly end-of-life care, in the event that the patient is or becomes incompetent to make decisions (MESH Database). This way the patient's values, attitudes and wishes can be taken into account as much as possible by healthcare workers and unwarranted, often burdensome, interventions can be avoided.⁷⁻⁹

In Belgium the Patients' Rights Act¹⁰ (2002) gives patients the legal right to reject medical treatments and to authorize a legal representative to speak for them when they are unable to speak for themselves, similar to the Patient Self Determination Act (1991) in the US.^{11,12} Advance care plans outlining the patient's preferences concerning care and medical treatments can be either patient-driven (advance directives) or physician-driven (physician's orders).¹³ Advance directives are declarations by patients, made in advance of a situation in which they may be incompetent to make decisions about their own care, stating their treatment preferences or authorizing a third party to make decisions for them (MESH Database). Physician's orders, on the other hand, are written by the physician with the consent and input of the NH resident or his/her representatives.

In the US, the prevalence of advance care plans among NH residents has increased since the Patient Self Determination Act, but is still low,¹¹ with the exception of the anticipatory decision not to hospitalize the resident (83.8% of NH residents).¹⁴

In Belgium, no data on ACP practice in NHs and related factors are available so far, and international results cannot be generalized to this setting. This study aims to describe (1) the demographic, clinical and care characteristics of those dying in NHs in Flanders, and (2) the prevalence and characteristics of documented advance care plans (advance directives and physician's orders) and of the authorization of a legal representative by the NH resident.

Within the healthcare system of Belgium, NHs provide skilled nursing care to elderly people who have serious problems undertaking the activities of daily living and/or lack mental capacity, but who do not need daily medical supervision or full-time specialized medical treatment as in hospitals.¹⁵ However, since NHs in this country developed out of care homes for elderly people, it is still possible that some of their residents are less dependent, but this number is diminishing. At the end of 2006 these institutions serve in total 57,858 beds (a mixture of NH beds and traditional care home beds) and each institution has on average 97 residents.¹⁶⁻¹⁷

Most residents are still supervised by their former general practitioner (GP).¹⁸ At the end of life of NH residents palliative care can be provided by these GPs and/or by others. On the one hand it is possible to receive palliative support from other individual regular caregivers with specialized palliative care training. (1) Since 2000, NHs are legally bound to have a coordinating and advisory physician (CAP).¹⁹ This is a GP, preferably with training in gerontology, who has some tasks related to individual end-of-life care situations (consultancy, taking charge of care or conflict mediation).¹⁶ (2) It is also obligatory for each NH to appoint a palliative reference nurse, together with the CAP, responsible for embedding a culture of palliative care in the NH, to sensitize the NH staff for palliative care, to formulate advice on individual palliative care situations and to organize training on palliative care.¹⁶ (3) Life End Information Forum (LEIF) physicians offer a wide forum for information and support for both professional caregivers and patients of all care settings who have questions about the end of life, including palliative care, and they help physicians confronted with euthanasia requests in finding a specifically trained, accessible, and independent physician for a formal consultation as required by the euthanasia law.^{20,21} On the other hand palliative support can be given by multidisciplinary palliative care teams: (1) the multidisciplinary palliative task group from the NH or (2) by multidisciplinary teams of other care settings (chosen mostly for their experience with specialized palliative treatment techniques), ie a palliative home care team, a palliative support team from the hospital or a palliative care unit from the hospital.

METHODS

Design

This study was conducted at the end of 2006 in Flanders, the Dutch-speaking part of Belgium where about six million people (60% of the Belgian population) live. All those care homes for elderly people recognized as high care nursing homes (N=594) were included.

Addresses of these NHs were obtained from the Flemish Ministry of Health. The NH administrator of each NH was sent a package of identical structured mail questionnaires with the request to report the number of residents who had died during September and October 2006 and to pass a questionnaire for each of these residents to the nurse most involved in their care, or to the head nurse in cases where it was not possible to identify this nurse.

To improve the response rate a letter of recommendation signed by six organizations relevant to this setting was enclosed with the mailing. About one month after the first mailing a follow-up letter was mailed to the NH administrator of non-responding institutions. A telephone call was made after another three weeks to the NH administrators who had still not responded and to those who reported more deceased residents during September and October 2006 than the researchers had received completed questionnaires for.²²

Approval for this study was received from the Medical Ethical Commission of the UZ Brussel (University Hospital of Brussels).

Questionnaire

The first part of the four-page questionnaire contained questions about characteristics of the resident at time of death, for example sex, age, level of dependency in daily living. The level of dependency was defined by means of a five category scale (O – independent, A – little dependent, B – dependent, C – severely dependent and Cd – severely dependent and demented), based on the KATZ ADL scale,²³ indicating the resident's overall level of independency in performing the six functions of bathing, dressing, toileting, transferring, continence and feeding, and orientation in place and time.

The second part of the questionnaire asked for the number of hospital transfers during the last three months of life and whether palliative care had been delivered and by whom. The last part of the questionnaire explored whether the resident's file contained documented advance care plans (advance directives and/or physician's orders) and whether the resident had formally authorized a legal representative.

The questionnaire was pilot-tested by 13 nurses working in 12 different nursing homes. This resulted in minor adaptations to avoid ambiguity and to improve understanding.

Analysis

The deceased NH resident was considered the unit of analysis. Descriptive results were presented in frequency tables and crosstabs and differences in distribution (Chi²) were calculated. Logistic regression models (stepwise conditional) were fitted to determine the relation between demographic, clinical and care characteristics of dying in NHs and documentation of advance care plans. The covariates 'diagnosis of dementia' and 'level of dependency' were found to be related. Therefore 'level of dependency' was withdrawn from further analyses. 'Delivery of palliative care' was considered as a dichotomous variable (yes/no) in these models.

The statistical package PASW 17.0 (SPSS Inc., Chicago, IL) was used and p-values of less than 0.05 were considered statistically significant.

RESULTS

Response

The administrators of 345 (58.1%) NHs reported a total number of 1,357 NH residents dying during September and October 2006. Nurses from 318 different NHs (53.5% of the total number of NHs) returned a questionnaire for 1,240 of these residents (95.2% of the 1,303 deceased residents reported in these 318 NHs; 91.4% of total reported number of deceased NH residents). Characteristics of those residents were compared with sex and age data of in-NH deaths from a representative death-certificate study $(2001)^{24}$ with no significant differences (data not shown in tables).

Characteristics of Deceased Nursing Home Residents

Two out of three deceased NH residents were female and 80% were 80 years or older (mean: 86 years - Table 7.1). Nurses reported cardiovascular (34.8%) and specific neurological (31.8%) diseases as the most frequently diagnosed problems, followed by respiratory diseases (20.1%) and malignancies (18.6%). More than 75% were severely dependent and 65.2% suffered from dementia (24.3% moderate and 40.9% severe). Twenty-two percent had a length of stay of less than six months and more than half of three years or more. Most (94.7%) still had a support person and in less than 20% of cases the treating GP was the CAP of the NH.

For most of the NH residents (80.6%) death was (rather) expected. One out of five died in a hospital with less than 1% in a palliative care unit.

Hospital Transfers at the End of Life and Palliative Care Delivery

In the last three months of life, 31.1% of residents were transferred once to hospital and 12.0% more than once (Table 7.1).

Palliative care was delivered to 67.2% of the dying NH residents: sixty percent of these residents received palliative care from regular caregivers with a palliative care training (mostly their treating GP and/or the palliative reference nurse of the NH) and 45.6% from a multidisciplinary palliative care team (mostly from the NH). In 38.5% of cases both regular and specialized palliative care were involved. Residents whose death was expected more often received palliative care (80.2%;p<0.001) than those whose death was only partially expected (17.4%) or was unexpected (2.4%). (Data not shown in table)

Prevalence and Characteristics of Documented Advance Care Plans

Documented advance care plans (advance directives and/or physician's orders) were available for 51.8% of the NH residents (Table 7.2).

Advance Directives

Five percent of the residents had documented advance directives (Table 7.2). Four percent had an advance directive not to be hospitalized and 2.9% not to be resuscitated in case of a cardiopulmonary arrest. The wish not to receive artificial food or fluids was documented by 2.4% of the residents. Two residents (0.2%) documented their potential wish for terminal sedation and eight residents (0.7%) for euthanasia.

Bivariate analysis revealed that those residents diagnosed with malignancies had significantly more documented advance directives (8.6% vs 4.2%;p=0.010) and those with dementia had significantly fewer documented advance directives (p<0.001 – Table 7.3).

Six percent of residents whose death was expected had documented their wishes in advance directives compared with 1.7% (p=0.018) of those who died unexpectedly. Residents who received palliative care significantly more often had advance directives than those who did not (6.5% vs 2.6%;p=0.005), especially those receiving palliative care from the CAP (9.6%), the palliative task group from the NH (7.7%) and their treating GP (6.8%).

After multivariate logistic regression, having an advance directive remained significantly different with regard to suffering from dementia and to palliative care delivery (not shown in table). Residents with severe dementia six times less frequently had documented advance directives (adjusted odds ratio(OR) =0.182, confidence interval (CI) =0.088-0.377) and those with moderate dementia had half as many (OR=0.516;CI=0.270-.988) as did those without dementia. Residents who received palliative care four times more often had documented advance directives (OR=4.160;CI=1.933-8.950).

Physician's Orders

According to nurses, half of the residents who died in this period had one or more physician's orders concerning end-of-life care documented in their file (Table 7.2). For 37.2% of the residents an order not to hospitalize was documented and for 28.6% an order not to resuscitate in case of a cardiopulmonary arrest. Withholding or withdrawing artificial food and fluids were each documented for almost one out of four residents. For 5.4% there was an order concerning terminal sedation with administration of artificial food and fluids, and for 12.0% without administration of food and fluids. For nine residents (0.7%) a physician had documented agreements concerning euthanasia.

Physician's orders were documented significantly more often for residents with malignancies (63.2%;p=<0.001), a neurologic diagnosis (57.2%;p=0.007) and severe dementia (59.6%;p<0.001 - Table 7.3). More dependent residents (p<0.001) and those with a longer length of stay (p=0.018) more often had physician's orders. Residents whose death was expected (p<0.001) and who were not transferred to the hospital during the last three months of life (p<0.001) and died in the NH (p<0.001) were more likely to have physician's orders, as were residents who received palliative care at the end of life (68.7% vs 18.5%;p<0.001).

Multivariate logistic regression showed that residents whose deaths were expected more than twice as often had physician's orders as did those who died suddenly (OR=2.351;CI=1.422-3.888) and residents who died in the NH had physician's orders almost three times more often than those who died in the hospital (OR=2.751;CI= 1.796-4.213 – not shown in table). Residents who received palliative care five times more often had physician's orders documented than did those who did not (OR=4.957;CI=3.322-7.396).

Prevalence of Authorization of a Legal Representative

Nurses reported that 8.6% of the residents had authorized a legal representative (Table 7.2).

This was more often the case for residents with malignancies (13.0% vs 7.8%;p=0.021) and for those who received palliative care from a multidisciplinary palliative care team (10.6% vs 6.9%;p=0.032 – Table 7.3).

After multivariate logistic regression, this difference remained for residents with malignancies (OR=1.706;CI=1.064-2.734 – not shown in table).

CHARACTERISTICS OF DECEASED NURSING HOME RESIDENTS							
Sex							
Male		384	31.1				
Female		852	68.9				
	missing cases	4					
Age							
	Mean = 86						
< 80		237	19.4				
80-84		283	23.2				
85-89		303	24.9				
90-94		249	20.4				
>= 95		147	12.1				
	missing cases	21					
Diagnosed diseases/disorders*							
Cardiovascular		413	34.8				
Neurological		377	31.8				
Respiratory		238	20.1				
Malignant tumor		221	18.6				
Urogenital system		100	8.4				
Metabolic disorder		56 115	4.7				
Other	missing cases	54	9.7				
	iniconig cacco	01					
Diagnosis of dementia							
No		408	34.8				
Yes, moderate dementia		285	24.3				
Yes, severe dementia		479	40.9				
	missing cases	68					
Level of dependency							
O: independent		47	4.1				
A: little dependent		58	5.0				
B: dependent		172	14.9				
C: severely dependent		265	22.9				
Cd: severely dependent and demented		615	53.2				
	missing cases	83					
Length of stay							
<= 6 months		267	21.7				
0,5 - 2 years		286	23.3				
3 - 4 years		281	22.9				
> 4 years		395	32.1				
	missing cases	11					

Table 7.1 Characteristics of deceased nursing home residents, number of hospital transfers at the end of life and palliative care received (N=1240)

Ν

%

		Ν	%
Having a support person		4407	047
Yes		1167 65	94.7 5 3
	missing cases	8	0.0
	the states		
nursing home as treating general practitione	er of the		
Yes		229	18.6
No		1002	81.4
	missing cases	9	
Type of death			
Expected		723	58.8
Neither expected nor unexpected		268	21.8
Unexpected	missina casas	239	19.4
,	missing cases	U	
Place of death			
Nursing home		981	79.2
Hospital		244	19.7
Palliative care unit		10	0.8
Other	minaina anna	3	0.2
,	nissing cases	2	
NUMBER OF HOSPITAL TRANSFERS DURIN	IG THE		
0		696	56.9
1		381	31.1
>= 2		147	12.0
	missing cases	16	
PALLIATIVE CARE DELIVERED AT THE END	OF LIFE*	789	67.2
 by individual regular caregiver, with pallis care training 	ative	705	60.1
Treating general practitioner		546	46.5
Palliative reference nurse		461	39.3
Coordinating and advisory physician		115	9.8
LEIF-physician		1	0.1
- by multidisciplinary palliative care team		535	45.6
Failialive lask group Palliative home care team		494 2 <i>1</i>	42.1 2 0
Palliative support team of the hospital		34	2.9
Palliative care unit of the hospital		17	1.4
	missing cases	68	

Table 7.1 Characteristics of deceased nursing home residents, number of hospital transfers at the end of life and palliative care received (N=1240) "Cont."

* multiple answers possible

Table 7.2 Prevalence of Advance Care Plans and Authorization of a Legal Representative for Nursing Home Residents (1240)

	Ν	%
ADVANCE CARE PLANS*	637	51,8
Advance directives	61	5,0
Do-not-hospitalise	48	3,9
Do-not-resuscitate	36	2,9
Withholding or withdrawing administration of artificial food and/or fluids	29	2,4
Withholding or withdrawing antibiotics	12	1,0
Withholding or withdrawing other treatments	21	1,7
Terminal sedation	2	0,2
Euthanasia	8	0,7
Physician's orders	622	50,6
Do-not-hospitalise	458	37,2
Do-not-resuscitate	352	28,6
Withholding or withdrawing artificial food	292	23,7
Withholding or withdrawing artificial fluids	291	23,7
Withholding or withdrawing antibiotics	211	17,2
Withholding or withdrawing chemo therapy	204	16,6
Withholding or withdrawing haemodialysis	155	12,6
Withholding or withdrawing blood transfusion	162	13,2
Alleviation of pain and symptoms knowing that this might shorten the patient's life	337	27,4
Terminal sedation, with administration of artificial food and fluids	66	5,4
Terminal sedation, without administration of artificial food and fluids	148	12,0
Euthanasia	9	0,7
AUTHORIZATION OF A LEGAL REPRESENTATIVE†	102	8,6

* 10 missing cases; multiple answers possible † 59 missing cases

Table 7.3 Prevalence of Advance Care Plans According to Deceased Resident's Characteristics, Number of Hospital Transfers at the End of Life and Palliative Care Delivery (N=1240)

		Total	Advance Directive†		Physician's Orders†		Authorization of a Legal Representative‡	
			Documented	p-value§	Documented	p-value§	Documented	p-value§
		N	%		%		%	
Sex				0,479		0,295		0,654
Male		384	4,2		48,2		8,0	
Female		852	5,3		51,4		9,0	
	missing cases	4						
Age	-			0,543		0,504		0,670
< 80		237	6,0		52,8		9,8	
80-84		283	5,3		46,6		9,2	
85-89		303	3,3		52,8		9,3	
90-94		249	4,9		49,0		8,0	
>= 95		147	6,2		52,7		5,6	
	missing cases	21						
Diagnosed diseases/disorders	-							
Malignant tumor		221	8,6	0,010	63,2	<0,001	13,0	0,021
Cardiovascular		413	5,1	0,890	50,7	0,760	9,2	0,740
Respiratory		238	4,6	0,869	56,1	0,110	11,1	0,187
Neurological		377	2,9	0,031	57,2	0,007	8,3	0,736
Urogenital system		100	4,0	0,812	53,0	0,755	11,3	0,346
Metabolic disorder		56	1,8	0,522	53,6	0,785	5,7	0,617
Other		115	2,6	0,361	46,5	0,280	8,2	1,000
	missing cases	54						
Diagnosis of dementia				<0,001		<0,001		0,341
No		408	8,4		41,4		8,2	
Yes, moderate dementia		285	4,9		51,8		10,5	
Yes, severe dementia		479	2,1		59,6		7,4	
	missing cases	68						

Table 7.3 Prevalence of Advance Care Plans According to Deceased Resident's Characteristics, Number of Hospital Transfers at the End of Life and Palliative Care Delivery (N=1240) "Cont."

	Total	Advance Directive†		Physician's Orders†		Authorization of a Legal Representative‡	
		Documented	p-value§	Documented	p-value§	Documented	p-value§
	Ν	%		%		%	
Level of dependency			0.005		<0.001		0.440
O: independent	47	6,5	,	23,9	,	4,7	,
A: little dependent	58	8,6		34.5		10,9	
B: dependent	172	6,4		34,3		7,2	
C: severely dependent	265	7,6		48,9		10,2	
Cd: severely dependent and demented	615	2,8		58,1		7,0	
missing cases	83						
Length of stay			0,478		0,018		0,774
<= 6 months	267	5,7		49,1		10,0	
0,5 - 2 years	286	5,7		43,3		8,7	
3 - 4 years	281	5,3		54,1		8,5	
> 4 years	395	3,6		54,5		7,7	
missing cases	11						
Having a support person			0,069		0,518		0,005
Yes	1167	5,3		50,8		9,2	
No	65	0,0		46.0		0,0	
missing cases	8	,					
Treating general practitioner is the coordinating and advisory physician of the nursing home			1,000		0,106		0,187
Yes	229	4.8		55.5		6.4	
No	1002	5.0		49.3		9,2	
missing cases		0,0		,.		0,-	
Type of death	C C		0.018		< 0.001		0.179
Expected	723	6.0	-,	65.2	,	9.3	-,
Neither expected nor unexpected	268	4.9		41.4		9.8	
Unexpected	239	1.7		16.5		5.7	
missing cases	10	- , -		-,-		- , -	

Table 7.3 Prevalence of Advance Care Plans According to Deceased Resident's Characteristics, Number of Hospital Transfers at the End of Life and Palliative Care Delivery (N=1240) "Cont."

	Total	Total Advance Directive†		Physician's Orders†		Authorization of a Legal Representative‡	
		Documented	p-value§	Documented	p-value§	Documented	p-value§
	N	%		%		%	
Place of death			0,205		<0,001		0,435
Nursing home	981	5,6		59,1		8,6	
Hospital	244	2,5		18,1		8,8	
Palliative care unit	10	0,0		22,2		0,0	
Other	3	0,0		0,0		33,3	
missing	cases 2						
Number of transfers to the hospital during the last 3 months of life			0,173		<0,001		0,550
0	696	4,8		56,8		8,8	
1	381	4,2		42,4		7,8	
>= 2	147	8,2		46,3		10,7	
missing	cases 16						
Palliative care delivered at the end of life*		6,5	0,005	68,7	<0,001	9,2	0,363
 by individual regular caregiver, with palliative car training 	re	7,0	0,001	71,3	<0,001		
Tara tinan ana analana atiti anan	540		0.005	74 7	0.004	9,0	0,586
Preating general practitioner	540	6,8	0,025	71,7	<0,001	9,7	0,202
Palliative reference nurse	461	6,5	0,138	72,0	<0,001	6,7	0,081
	115	9,6	0,042	11,2	<0,001	12,0	0,203
LEIF-physician	.1	0,0	1,000	100,0	1,000	0,0	1,000
- by multidisciplinary pallative care team	10.1	7,3	0,004	67,9	<0,001	10,6	0,032
Palliative task group	494	7,7	0,001	69,1	<0,001	10,5	0,052
Palliative home care team	34	5,9	0,697	76,5	0,005	12,1	0,520
Palliative support team of the hospital	34	0,0	0,254	41,2	0,224	10,3	0,732
Palliative care unit of the hospital	17	0,0	1,000	52,9	1,000	12,5	0,641
missing	cases 66						

* multiple answers possible

† 10 missing cases; ‡ 59 missing cases; § Chi² test

DISCUSSION

At time of death residents of NHs in Flanders often have a diagnosis of dementia, and are often severely dependent. During the last three months of life almost half had been transferred to hospital at least once, and one out of five died in hospital. Most deaths were expected or partially expected and two thirds of all deaths received palliative care. Half of residents had an advance care plan (mostly physician's orders and rarely advance directives). Delivery of palliative care was positively related to having an advance care plan (either a physician's order or an advance directive). Dying in the nursing home, expected death and suffering from dementia were associated with having physician's orders. Residents with dementia less often had advance directives. Nine percent had authorized a legal representative.

This study is the first in Flanders, Belgium, to describe the dying conditions and actual practice of ACP in NHs. Deceased NH residents were used as the denominator of the study because this population provided a more accurate estimate of ACP for those who really needed it. The characteristics of deceased NH residents in this study were compared with sex and age data of in-NH deaths from a representative death-certificate study (2001)²⁴ with no significant differences.

The study has some limitations. First, response bias cannot be ruled out, as no direct comparison with a cohort of dying patients in this setting is available. Second, this study did not investigate the quality of the process preceding documentation of advance care plans (timing, communication) nor the quality of the palliative care delivered and the decisions made at the end of life, and how far these decisions complied with the advance care plans.

Findings of this study confirm that the profile of NH residents at time of death makes them most eligible to have made anticipating decisions concerning end-of-life care issues. More than 80% were found to be very old (aged 80 years or older) - with one out of three being 90 years or older – and to have died relatively expected, which is a much higher proportion than among the general public. In previous studies including all deaths of those aged one year or older in Flanders, only half were found to be 80 years or older and two thirds died non-suddenly.^{2,25,26}

In Flanders, 28% of NH residents were found to die each year¹⁵ of which 65% had dementia. Because of the degenerative character of dementia, those suffering from this disease can benefit especially from anticipating discussion about their values, attitudes and wishes concerning the end of life. Although dementia is one of the most frequent reasons for NH admission in Flanders²⁷ the possibility of some kind of communication might be expected at time of admission or shortly afterwards, before progress of the disease. Moreover, more than half of the deceased NH residents had lived in the NH for more than three years before death (which is longer than in other countries^{28,29}), and it might be expected that during this time NH staff would have been in a position to stimulate advance communication about the resident's preferences concerning end-of-life care.

Despite the growing interest in ACP in general and more specifically for NH residents, documented advance care plans were found in only half the cases of deceased NH residents in Flanders at the end of 2006. This is rather low since ACP can be of great benefit for qualitative end-of-life care,³⁰ particularly for NH residents who often became incompetent and impaired near the end of life and whose death can largely be expected.

Documentation of advance directives by NH residents in Flanders (5%) lags far behind that in other countries like the US,³¹ where (in contrast with the Belgian Patients' Rights Act) the Patient Self Determination Act obliges health care institutions, including NHs, to give patients information about advance directives at the time of admission and to encourage them to write them.⁵ Most alarming is that none of the NH residents without a support person (5.3% of deceased residents) has an advance directive, implying that there was no one apart from the health care professionals to advocate in their best interests when they became incompetent.

The fact that physician's orders occurred more often when death was expected and that residents with dementia less often had advance directives seems to confirm other studies stating that formal discussions about end-of-life care often do not occur before the onset of dementia or incompetence due to serious illness near the end of life.^{11,30}

Most advance care plans (advance directives and physician's orders) concern anticipatory decisions about non-hospitalization and/or to withholding or withdrawing treatments. This should not be a surprise because previous research has shown that of all end-of-life decisions preceding deaths in NHs, non-treatment decisions are the most frequent.^{2,25,26} Euthanasia, which is performed in 0.6% of all deaths in NHs,²⁵ was rarely documented in advance care plans (0.7%). However, based on this study no conclusions can be made about levels of concordance between advance care plans and actual end-of-life decisions made at the very end of life.

Delivery of palliative care seems to be a very important factor in the documentation of advance care plans (physician's orders and advance directives). This finding could be expected since discussion of goals of care is inherent in palliation.^{3,4,8} However, in one third of all deceased NH residents or in one fifth of NH residents whose death was expected, no palliative care initiatives were taken. There seems to be room for improvement in palliative care delivery in nursing homes, although previous research in Flanders shows that decedents in nursing homes received twice as much specialist palliative care as those dying at home.³²

When palliative care was delivered by the coordinating and advisory physician (CAP), independently of whether or not s/he was the resident's treating physician, this resulted in a higher rate of documented advance care plans. While the same trend was seen when palliative care was delivered by the resident's treating general practitioner (not necessarily the CAP), documentation of advance directives by the NH resident was clearly higher for those who received palliative care from the CAP

(9.6%) than for those who received it from their treating general practitioner (6.8%). Since no difference in documentation of advance directives (or physician's orders) was found related to whether or not the resident's treating general practitioner was the CAP of the NH, it seems as if the specific training of the CAP has mainly impact on stimulating residents to write advance directives when care is defined as palliative care and not in non-palliative care situations.

Almost half of the deceased NH residents in the study had been transferred to hospital during the last three months of life and one in five died in the hospital; those residents were less likely to have had physician's orders limiting life-sustaining treatments, though it remains unclear whether these transfers were aimed at curative treatment or at receiving adequate palliative care that was not available in the NH.

The authorization of a legal representative was documented by fewer than one in ten NH residents. A person who is familiar with the resident's preferences regarding the end of life could be involved in end-of-life discussions about specific problems that were difficult to foresee in drawing up advance directives. Although there is discussion in the literature about whether relatives have an adequate understanding of the wishes of a dying person, it has been shown that authorizing a representative can avoid burdensome treatments at the end of life.^{9,33}

In conclusion, considering the profile of NH residents at the end of life, there are very few advance care plans documented. Increased awareness of the role played by advanced care planning in achieving a dignified dying process in line with a person's wishes can stimulate specialized palliative care workers as well as regular healthcare workers (especially GPs¹¹ and nurses³⁴) to the timely discussion of the direction of care at the end of life with NH residents. As many residents become incompetent during their stay, it is also important to encourage people to communicate their wishes, values and worries to their care givers and to write advance directives as early as possible, before or soon after NH admission, and/or to appoint a legal representative.

REFERENCES

- 1. Lunney JR, Lynn J, Hogan C. Profiles of older medicare decedents. J Am Geriatr Soc 2002;50:1108-1112.
- 2. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362:345-350.
- 3. World Health Organization. Better Palliative Care for Older People. Copenhagen, Denmark: 2004.

- 4. Boockvar KS, Meier DE. Palliative care for frail older adults: "there are things I can't do anymore that I wish I could . . . ". JAMA 2006;296:2245-2253.
- 5. Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. Arch Fam Med 1998;7:417-423.
- 6. Givens JL, Kiely DK, Carey K, et al. Healthcare proxies of nursing home residents with advanced dementia: decisions they confront and their satisfaction with decision-making. J Am Geriatr Soc 2009;57:1149-1155.
- 7. Bell C, Somogyi-Zalud E, Masaki K, et al. Factors associated with physician decision-making in starting tube feeding. J Palliat Med 2008;11:915-924.
- 8. Blackford J, Strickland E, Morris B. Advance care planning in residential aged care facilities. Contemp Nurse 2007;27:141-151.
- 9. Kuo S, Rhodes RL, Mitchell SL, et al. Natural history of feeding-tube use in nursing home residents with advanced dementia. J Am Med Dir Assoc 2009;10:264-270.
- Wet betreffende de rechten van de patient [Patients' Rights Act]. Belgisch Staatsblad van 26 september 2002 [Belgian Law Gazette of September 26, 2002]. [in Dutch]
- 11. Crane MK, Wittink M, Doukas DJ. Respecting end-of-life treatment preferences. Am Fam Physician 2005;72:1263-1268.
- 12. Manias E. Australian nurses' experiences and attitudes in the "Do Not Resuscitate" decision. Res Nurs Health 1998;21:429-441.
- 13. Dobalian A. Advance care planning documents in nursing facilities: results from a nationally representative survey. Arch Gerontol Geriatr 2006;43:193-212.
- 14. Lamberg JL, Person CJ, Kiely DK, et al. Decisions to hospitalize nursing home residents dying with advanced dementia. J Am Geriatr Soc 2005;53:1396-1401.
- 15. De Gendt C, Bilsen J, Vander Stichele R, et al. Nursing home policies regarding advance care planning in Flanders, Belgium. Eur J Public Health 2010;20:189-194.
- 16. Koninklijk Besluit van 21 september 2004 houdende vaststelling van de normen voor de bijzondere erkenning als rust- en verzorgingstehuis of als centrum voor dagverzorging [Royal decree of September 21, 2004 concerning standards for additional recognition as a nursing home or as a day care centre] Belgisch Staatsblad 28 Oktober 2004 [Belgian Law Gazette of October 28, 2004]. [Dutch]
- 17. Vervotte I. Antwoord op schriftelijke parlementaire vraag nr 111 van 16 maart 2007 [Answer to written parlementary question n° 11 1 from March 16, 2007]

[online]. Available at <u>http://jsp.vlaamsparlement.be/docs/schv/2006-</u>2007/VERVOTTE/111/antw.111.doc. Accessed on June 6, 2010. [Dutch]

- 18. Lemiengre J, erckx de CB, Verbeke G, et al. Ethics policies on euthanasia in nursing homes: a survey in Flanders, Belgium. Soc Sci Med 2008;66:376-386.
- 19. De Lepeleire J, Leirman W. Poor effect of family practice physician training at the organizational level in long-term care facilities in Flanders, Belgium. J Am Med Dir Assoc 2006;7:470.
- 20. Van Wesemael Y, Cohen J, Onwuteaka-Philipsen BD, et al. Role and Involvement of Life End Information Forum Physicians in Euthanasia and Other End-of-Life Care Decisions in Flanders, Belgium. Health Serv Res 2009;44:2180-2192.
- 21. Wet betreffende euthanasie [Law concerning euthanasia]. Belgisch Staatsblad van 22 juni 2005 [Belgian Law Gazette of June 22, 2002]. [in Dutch]
- 22. Dillman DA. The design and administration of mail surveys. Annu Rev Sociol 1991;17:225-249.
- 23. Katz S, Akpom CA. A measure of primary sociobiological functions. Int.J Health Serv 1976;6:493-508.
- 24. Cohen J, Bilsen J, Hooft P, et al. Dying at home or in an institution using death certificates to explore the factors associated with place of death. Health Policy 2006;78:319-329.
- 25. Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356:1806-1811.
- 26. Bilsen J, Cohen J, Chambaere K, et.al. Medical end-of-life practices under the euthanasia law in Belgium. N Eng J Med 2009;361:1119-1121.
- 27. Devroey D, Van Casteren V, and De Lepeleire J. Placements in Psychiatric Institutions, Nursing Homes, and Homes for the Elderly by Belgian General Practitioners. Aging Ment.Health 2002;6:286-292.
- 28. Brandt H, Dleiens L, Ooms ME, van der Steen JT, van der Wal G, Ribbe MW. Symptoms, signs, problems, and diseases of terminally ill nursing hame patients: a nationwide observational study in the Netherlands. Arch Intern Med 2005;165:314-320.
- 29. Minnesota Department of Health. Nursing home length of stay. Calendar Years 2002-2006. Available at <u>http://www.health.state.mn.us/divs/fpc/profinfo/nhlengthofstay.pdf</u>. Accessed on June 6, 2010.
- 30. Daaleman TP, Williams CS, Preisser JS, et al. Advance care planning in nursing homes and assisted living communities. J Am Med Dir Assoc 2009;10:243-251.

- Resnick HE, Schuur JD, Heineman J, Stone R, Weissman JS. Advance directives in nursing home residents aged > or =65 years: United States 2004. Am J Hosp Palliat Ware 2008;25:476-482.
- 32. Van den Block L, Deschepper R, Bossuyt N, et al. Care for patients in the last months of life: the Belgian Sentinel Network Monitoring End-of-Life Care study. Arch Intern Med 2008;168:1747-1754.
- 33. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes ofsurrogate decision making before death. N Eng J Med 2010;362:1211-1218.
- 34. Jeong SY, Higgins I, McMillan M. Advance care planning (ACP): the nurse as 'broker' in residential aged care facilities. Contemp Nurse 2007;26:184-195.



General discussion

Chapter 8

General discussion

INTRODUCTION

In our current society, the majority of deaths concern old or very old people who often die non-suddenly and are likely to receive some type of end-of-life care. The aim of this dissertation was to increase information and knowledge about care at the end of life of older people in Flanders, Belgium. It focused on end-of-life decision-making and terminal sedation at the very end of life of older people in general, and on advance care planning among older people in institutionalised care (policy and actual practice of do-not-resuscitate decision-making on acute geriatric wards and of advance care planning in general in nursing homes).

First, this chapter concisely describes the main findings on the research questions of this dissertation. Second, some strengths and limitations of the different studies are considered. Third, findings are discussed, and finally, recommendations for healthcare policy, practice and further research are made.

MAIN FINDINGS

Medical end-of-life decision-making and terminal sedation at the very end of life

Chapter 2 described the frequency and characteristics of end-of-life decision-making and terminal sedation among very old patients (aged 80 years or older) who died non-suddenly, and compared this with younger patients (research question 1). The preceding decision-making process was considered as an essential aspect of this matter since this might often be complicated by non-competency in very old patients.¹

1) What is the frequency and what are the characteristics of end-of-life decisionmaking and terminal sedation among very old patients who die non-suddenly, what are the characteristics of the preceding decision-making process, and is there a difference with younger patients? (Chapter 2)

Medical end-of-life decision-making among very old patients proved to be significantly different from that in younger patients. At least one end-of-life decision was made for 53.6% of very old patients who died non-suddenly (vs. 63.3% for the younger patients). Life-ending drugs were used with the explicit intention of shortening the patient's life among 1.1% of these patients (six times less frequently than in younger patients), and no euthanasia cases were found in very old patients (vs. 16 cases or 0.9% in younger patients). Intensified pain and symptom alleviation with a possible life-shortening effect occurred among 27.3% of very old patients (half

as frequently as in younger patients), and withholding or withdrawing life-prolonging treatments among 25.2%, which is somewhat (but not significantly) more frequent than in younger patients. Terminal sedation was performed in 6.9% of cases, half as frequently as in younger patients.

An important finding of this study is that communication on all types of end-of-life decisions with very old patients is not optimal. More than four out of five very old patients who died after an end-of-life decision were judged as non-competent. These patients are as rarely involved in end-of-life decision-making as younger non-competent patients (about 15%). Among competent patients with an end-of-life decision, the oldest are less frequently involved in decision-making than younger patients (56.1% vs. 71.9%).

Nurses are consulted more often than a second physician before making an end-oflife decision for an older patient (69.3% vs. 44.3%).

Do-not-resuscitate decision-making on acute geriatric wards

Chapters 3, 4 and 5 gave a description of the status of do-not-resuscitate decisionmaking on acute geriatric wards in 2002. Institutional policies (research question 2), actual practice (research question 3) and nurses' involvement and adherence to the patients' resuscitation status (research question 4) were successively highlighted.

2) How many acute geriatric wards have a policy on do-not-resuscitate decisionmaking, since when was this implemented, what are the characteristics of the development and implementation of such policies, and what is their global content? (Chapter 3)

In 2002, 86.1% of acute geriatric wards in Flanders had implemented a do-notresuscitate policy, most often consisting of institutional do-not-resuscitate guidelines as well as a patient-specific do-not-resuscitate order form. Implementation of these policies started in 1985, rather late compared to other countries, with a substantial increase in 2001. Geriatric wards in private hospitals implemented their policy later, but had more often implemented order forms than those in public hospitals.

The policy had been initiated and developed predominantly from an institutional perspective by the hospital, with little or no involvement of patients or patient organisations. Do-not-resuscitate policy documents varied in content and scope. The do-not-resuscitate policy documents were not standardised and the order forms generally lacked room to document patient involvement in the decision-making process.

3) What is the prevalence of patients with do-not-resuscitate status on acute geriatric wards and what are the characteristics of the preceding decision-making process? (Chapter 4)

One out of five patients on acute geriatric wards had been given a do-not-resuscitate status by the geriatrician. Geriatricians who had had fewer years of experience in patient care and those who worked on a geriatric ward with a do-not-resuscitate policy had a higher prevalence of patients with a do-not-resuscitate status.

Do-not-resuscitate status is attributed late in the course of the disease of patients on acute geriatric wards and the main reasons are disease-related. Age alone is never a rationale for such decisions. In four out of five cases the geriatrician's decision is based on consultation with others, mainly nurses and the patient's relatives. Patients and their general practitioner are rarely involved in the decision-making process. Attribution of do-not-resuscitate status to a patient more often took place during the daily ward visits than during the weekly multidisciplinary team meeting and was documented in the patient's file by 93.7% of the geriatricians.

4) Are nurses involved in do-not-resuscitate decision-making (Chapter 4 and 5) and how often do they adhere to the resuscitation status of patients? (Chapter 5)

Nurses are often but not always consulted in do-not-resuscitate decision-making on acute geriatric wards; they are consulted in three quarters of cases. Though, a status not to resuscitate a patient is always communicated among the nursing team, mostly in writing.

Nurses almost always forgo cardiopulmonary resuscitation in case of an actual cardiopulmonary arrest in patients with do-not-resuscitate status and they do not start cardiopulmonary resuscitation in case of an actual cardiopulmonary arrest for a substantial number of patients without such status.

Advance care planning in nursing homes

Chapters 6 and 7 of this dissertation gave a description of the status of advance care planning at the end of 2006 in nursing homes in Flanders, a long-term care setting for older people. First, the existence, historical development and global content of institutional policies were investigated (research question 5). Second, and after an exploration of the demographic, clinical and care characteristics of dying in nursing homes, the practice of advance care planning was investigated, including the prevalence and related characteristics of documented advance care plans and authorisation of a legal representative by nursing home residents (research question 6).

5) How many nursing homes have a policy on advance care planning, since when was this implemented, and what is their global content? (Chapter 6)

Development of nursing home policies regarding advance care planning in Flanders started rather slowly in 1989, but has expanded rapidly since 2000 to attain near completion in 2006 (95.1% of nursing homes). These policies consist predominantly of individual patient-specific planning forms, often accompanied by institutional guidelines. Policy documents regarding advance care planning (institutional guidelines as well as patient-specific planning forms) often concern several medical end-of-life decisions. Anticipatory decisions not to hospitalise the nursing home resident were almost always mentioned, closely followed by anticipatory decisions not to resuscitate in case of a cardiopulmonary arrest and to withhold or withdraw other treatments like administration of artificial food and/or fluids and antibiotics. Almost half of nursing homes had specified intensification of pain and symptom alleviation which might shorten the resident's life in institutional and/or patientspecific planning forms. Anticipatory decisions about terminal sedation and euthanasia were mentioned less often and in some nursing home guidelines euthanasia was expressly not allowed although it is legal. Less than one third of the nursing homes had mentioned authorisation of a representative in institutional guidelines and/or patient-specific planning forms.

6) How many nursing home residents have documented advance care plans at time of death and how many had authorised a legal representative, and is this related to the demographic, clinical and care characteristics of dying in the nursing home? (Chapter 7)

At time of death, more than 80% of nursing home residents in Flanders are very old (aged 80 years or older) - with one out of three being 90 years or older. They often have a diagnosis of dementia (65.2%), and are often severely dependent (76.1%). Four out of five nursing home residents died expectedly or partially expectedly. During the last three months of life almost half (43.1%) had been transferred to hospital at least once, and one out of five died in hospital. Two thirds received palliative care at the end of life.

Half of deceased nursing home residents have an advance care plan (51.8%), predominantly physician's orders (50.6%) and less often advance directives (5.0%). Most advance care plans (advance directives and physician's orders) concern anticipatory decisions not to be hospitalised and/or to withhold or withdraw potentially life-prolonging treatments. Euthanasia and terminal sedation are rarely included in these plans. Delivery of palliative care was positively related to having an advance care plan (physician's orders and advance directives). Dying in the nursing home, expected death and suffering from dementia were associated with having physician's orders. Residents with dementia less often had advance directives.

Less than one in ten had authorised a legal representative. Residents with malignancies more often had authorised a legal representative.

STRENGTHS AND LIMITATIONS OF THE STUDIES

Study 1: Death certificate study among physicians

In chapter 2 a secondary analysis was made based on a death certificate study with a quantitative and retrospective study design. In 2001 a random sample of all death certificates in Flanders (of patients aged one year or older) was taken and structured mail questionnaires were sent to the certifying physicians.

This method has been judged a highly reliable way to make epidemiological estimates of the incidence of end-of-life decisions for an entire population, including all care settings.²⁻⁸ Linkage to the information of the death certificates (e.g. sex, age, place and cause of death) made it possible to weight data for patient characteristics for all deaths in Flanders. This also enabled shortening the questionnaire, which contributed to the achievement of a satisfying response rate. Full anonymity was guaranteed via a complex mailing procedure involving a legal attorney. We selected for our analyses only the non-sudden deaths and made meaningful comparisons between very old and younger patients (similar to previous comparisons between cancer and non-cancer patients⁹). This resulted in findings that were at some points different from those of previous studies where sudden and non-sudden deaths were included.^{2,3} The hypothesis that, in the past, this methodology might have caused misinterpretation of analyses comparing medical end-of-life decision-making between age groups - because older patients more often die non-suddenly and are consequently more likely to have had an end-of-life decision - was confirmed by our study and should be taken into account in future comparisons between patient groups.

There are also some limitations related to this study. First, although the response rate was satisfactory, non-response bias remains a possibility, for example underreporting of types of medical end-of-life decisions that were illegal at the time of data collection (euthanasia, physician-assisted suicide and the use of life-ending drugs without the explicit request of the patient). To minimise this kind of underreporting, anonymity was guaranteed. Second, findings are solely based on self-reports of physicians; resulting errors in the perceptions of their acts cannot be excluded, for example as a result of overestimating the actual life-shortening effect of symptom-alleviating medication such as opiods.¹⁰ Third, due to the retrospective design of the study, some recall bias is possible, although the patient's death was not too long ago and the physician was advised to consult the patient's file during

completion of the questionnaire. Finally, this study does not give all relevant information about the patient (e.g. changing clinical situation at the end of life, degree of incompetence) or the broader context of end-of-life care (e.g. palliative care, advance care planning).

Study 2: Do-not-resuscitate decision-making on acute geriatric wards

This study consisted of three sub-studies concerning do-not-resuscitate decisionmaking on acute geriatric wards in Flanders that were conducted in 2002. Each of the sub-studies used a different quantitative, structured mail questionnaire, respectively sent to the head geriatricians of acute geriatric wards, geriatricians who perform the bulk of clinical work on these wards and to head nurses.

All acute geriatric wards in Flanders were included in this study, in contrast to other studies where individual hospitals or wards were adressed.¹¹⁻¹⁶ It was the first study concerning do-not-resuscitate decision-making on acute geriatric wards in Flanders, a highly relevant setting to explore this topic. This study provides information on several aspects of do-not-resuscitate decision-making on acute geriatric wards, i.e. development and status of institutional do-not-resuscitate policy Cchapter 3), prevalence of patients with do-not-resuscitate status (Chapter 4), characteristics of the preceding decision-making process including the involvement of nurses (Chapter 4 and 5) and adherence to the resuscitation status of patients in case of an actual cardiopulmonary arrest (Chapter 5). A strength of all sub-studies is the high response rate, which is indicative of a high level of interest in this topic in the field and the need for information. Study results are representative for the whole of Flanders.

Each of the sub-studies has its own limitations: (1) Findings on the existence of donot-resuscitate policy are based on self-reporting of head geriatricians. It was only possible to verify their responses when copies of the policy documents were enclosed with the completed questionnaire. Content analysis was based on these returned copies only. (2) In the sub-study concerning actual practice of do-notresuscitate decision-making, no data were obtained on patients' characteristics. Hence, the relationship with the characteristics of the decision-making process could not be investigated in this study. Furthermore, unknown situational circumstances (such as the average severity of the clinical situation of admitted patients is higher or lower than usual) might have had an influence on the point prevalence of patients with do-not-resuscitate status. (3) Results concerning nurses' involvement in the donot-resuscitate decision-making process and adherence to these decisions in case of a cardio-pulmonary arrest are based on head nurses' reporting for their nursing team. Members of the nursing team were not directly questioned about their individual involvement or actions in case of an actual cardiopulmonary arrest which might have caused some bias. Furthermore, no reasons were asked for non-involvement in the decision-making process, leading to an incomplete picture of the situation. Finally,

nurses' adherence to the resuscitation status of patients was only asked for at an aggregated level and not for specific individual cases.

It is inherent in the design used in sub-study 2 and 3, where geriatricians and head nurses had to report about the last do-not-resuscitate decision-making process on their ward, that some selection bias could have occurred. It is possible that geriatricians and head nurses did not respond about their most recent cases, but in fact reported about a more memorable case or about a case in which the decision-making process was considered as 'good practice' by the respondent. Furthermore, it could not be guaranteed that geriatricians and head nurses of the same geriatric ward reported about the same case, making it impossible to test the concordance between the perception of the decision-making process of both respondents.

Study 3: Advance care planning in nursing homes

Chapters 6 and 7 of this dissertation concern a study on advance care planning in nursing homes in Flanders. Findings resulted from two different quantitative, structured mail questionnaires. The first investigated the status of the development of policy documents regarding advance care planning at the end of 2006, and was sent to the nursing home administrators (Chapter 6). The second questionnaire retrospectively questioned the dying conditions and actual practices of advance care planning in nursing homes, and was addressed to the nurses most involved in care for deceased residents (Chapter 7).

This study was the first nationwide study to describe advance care planning, (policy and actual practices) in nursing homes in Flanders, regarding different kinds of endof-life decisions, i.e. non-treatment decisions, intensified alleviation of pain and/or other symptoms knowing that this might shorten the patient's life, the use of lifeending drugs with the explicit intention to end life and terminal sedation. Other studies in Flanders had mainly focused on policies regarding euthanasia,¹⁷⁻²⁰ though this remains a quite rare practice in nursing homes,³ and did not describe both institutional guidelines and patient-specific planning forms. No data were available concerning anticipatory end-of-life decision-making in nursing homes. This was considered as a major gap, since little discussion about end-of-life decisions at the very end of life had previously been found in patients in general, and is even more complex, and might even become impossible in nursing home residents who often lack competence at the end of life. Furthermore this study gave for the first time some insights into the existence and use of palliative care initiatives in nursing homes and clearly describes the characteristics of nursing home residents at time of death, which is very important in interpreting findings concerning several end-of-life care issues in this care setting. All nursing homes in Flanders were included in this study and findings can be considered as representative for the whole of Flanders.
There are some limitations related to this study. First, possible non-response bias cannot be totally ruled out. It remains possible that nursing homes with policies regarding advance care planning were more likely to respond, especially to the questionnaire concerning advance care planning policies, resulting in overestimation of nursing homes with policies. Specifically for the findings concerning actual practice of advance care planning in nursing homes, non-response bias also remains possible; no direct comparison with a cohort of dying nursing home residents was available. However, since no differences were found between in-nursing home deaths of a representative death-certificate study²¹ and the in-nursing home deaths in our study, it is reasonable to assume representativeness. Second, self-reporting of nursing home administrators also might have caused an overestimation of nursing homes with policies. Third, for studying actual practice of advance care planning a retrospective study design was used, which might result in recall bias. To minimise this, the delay between death of the nursing home resident and completion of the questionnaire was kept to a maximum of four months (from the beginning of the inclusion period until the end of data collection). Finally, this study did not investigate the process preceding documentation of advance care plans (e.g. timing, communication), the actual decisions made at the end of life of nursing home residents and compliance of these decisions with advance care plans, neither the impact of advance care planning on actual practices.

Timing of the studies

The three studies, chronologically discussed in this dissertation, were spread over several years under differing legal frameworks. The study on advance care planning in nursing homes, the most recent study, was conducted at the end of 2006 when the laws on patients' rights,²² euthanasia²³ and palliative care²⁴ had been effective for four years. The other two studies concerning do-not-resuscitate decision-making (2002) and end-of-life decision-making at the very end of life (2001) were conducted shortly before these laws became effective.

Enactment of the laws on patients' rights, euthanasia and palliative care in 2002 and the preceding public debates should be considered as influential in issues concerning the end of life. This was clearly shown in our policy studies concerning do-not-resuscitate decision-making on acute geriatric wards (Chapter 3) and advance care planning in nursing homes (Chapter 6) which both showed major step-ups in the prevalence of institutional policy documents in this period. The same kind of influence might also be assumed in the actual practice of advance care planning (including do-not-resuscitate decision-making) were conducted in different care settings and were not aimed at trend analysis of actual practices as such, they can only be considered as indicative for higher rates of advance care planning in 2006 than in 2002. This needs to be verified with further research.

Concerning medical end-of-life decision-making at the very end of life and institutional policies regarding do-not-resuscitate decision-making, more recent figures (2007, after enactment of the laws on patients' rights, euthanasia and palliative care) became available after publication of the manuscripts in chapters 2 and 3, and will be discussed further in this chapter.

GENERAL DISCUSSION

In this section we first discuss our findings on medical end-of-life decision-making at the very end of life of very old patients. Second, we discuss the eligibility of advance care planning for older people in institutional care. Third, institutional policies regarding do-not-resuscitate decision-making on acute geriatric wards and advance care planning in nursing homes will be considered together, for both care settings. Finally, the actual practice of do-not-resuscitate decision-making on acute geriatric wards and of advance care planning in general in nursing homes are discussed successively.

1 Medical end-of-life decision-making at the very end of life of older people

Chapter 2 described the frequency and characteristics of medical end-of-life decision-making and terminal sedation at the very end of life of very old people (aged 80 years or older) who died non-suddenly, and compared this with younger patients. The preceding decision-making process was considered as an essential aspect of this matter since this might often be complicated by loss of competence in very old people.¹

Incidence

Medical end-of-life decision-making among very old patients proved to be a common medical practice (53.6%), though significantly different from that in younger patients (63.3%). Physicians showed themselves to be more reluctant to the use of lethal drugs, intensified pain and symptom alleviation with a possible life-shortening effect and terminal sedation in very old patients (Chapter 2). The fact that euthanasia is not reported at all among very old patients suggests either that they request euthanasia less often than younger patients, or indicates that requests for euthanasia in this age group are not addressed due to complicated or suboptimal end-of-life communication.²⁵ The latter might also be an explanation for the fact that the incidence of intensified alleviation of pain and symptoms and terminal sedation is lower among very old patients than in younger patients (27.3% vs. 39.7% - Chapter 2); there is probably poor recognition of pain and other suffering at the end of life of very old patients, often exacerbated by dementia and poor diagnostic tools.²⁶⁻²⁸

In 2007, a follow-up study was performed on medical end-of-life decision-making in Flanders, using the same methodology as the 2001-study which was the basis for our secondary analysis about medical end-of-life decision-making.²⁹ Euthanasia, intensification of pain and/or symptom alleviation with a possible life-shortening effect, withholding and withdrawing of life-prolonging treatments and terminal sedation increased between 2001 and 2007. In-depth comparison between non-sudden deaths in the very old and in younger patients has not yet been performed, but in general there was no shift found in patients' characteristics (including age) for euthanasia or the use of life-ending drugs without the explicit request of the patient.

Communication about medical end-of-life decision-making

Communication concerning all types of medical end-of-life decisions with very old patients in general was found to be not optimal (Chapter 2). It is remarkable that among competent patients with an end-of-life decision, the very old are less frequently involved in decision-making than are younger patients. Consequently, age can be considered as an influential factor in whether or not end-of-life decision-making is discussed with the patient.

A substantial number of non-treatment decisions and intensified alleviation of pain and symptoms with a possible life-shortening effect are not discussed with the patient, nor with the patient's relatives (Chapter 2). Hence, a patient's values and wishes might not be taken into account in the end-of-life decision-making process. and possible unwanted interventions may not be avoided. Among very old patients this is an important problem. First, because the very old are more likely to be noncompetent at the end of life than are younger people, it is often too late to involve them in decision-making. Second, among competent patients the oldest are less frequently involved in decision-making than younger patients. Plausible explanations for this might be their lower level of education, that they might be less assertive and that end-of-life discussion may have a higher level of taboo for their generation. In the future, it can be expected that older patients will become more involved since the educational level is rising and it is plausible that more highly educated patients are more likely to be involved in end-of-life decision-making. Actively consulting patients or their relatives and starting up advance care planning as early as possible might facilitate the involvement of competent as well as non-competent patients in end-oflife decision-making. In general, but most specifically in older people, this should become a golden standard in our society in which more and more attention is being given to autonomy and self-determination of patients.³⁰

Nurses are more often consulted than other physicians before making a medical endof-life decision for very old patients (Chapter 2). This might be related to the fact that most very old patients die in an institution, where they are surrounded by nurses. In this situation, nurses have an important role in informing physicians about a patient's health status and wishes. Moreover, research shows that, in institutionalised care, nurses are consulted more often by physicians when the patient is less well educated.³¹ Since very old patients are in general less well educated, nurses can act as intermediaries to close the gap between patients and physicians.

2 Older people in institutionalised care: an eligible group for advance care planning

Since remaining life expectancy decreases when people become older, the usefulness of advance end-of-life care planning increases with age; older people often have serious underlying comorbidity, die after a long period of chronic and degenerative diseases, and often lack competence at the end of life. Advance care planning is even more important in institutionalised care for older people (nursing homes, acute geriatric wards). Because the majority of older people die in

institutionalised care,²¹ death is quite a frequent event in this setting. Consequently, reflection about one's own preferences concerning the end of life should not be too far away for many when admitted to such a care setting at older age.

Our findings show that 28% of nursing home residents in Flanders die each year (Chapter 6), while there is a 1% mortality rate among the general public. The majority of deceased nursing home residents are aged 80 years or older (80%) and die more or less expectedly (80%) (Chapter 7), which is a much higher proportion than among the general public (about 50%).^{2,3,29} Most suffer from several conditions, 65% from dementia (Chapter 7). Because of the degenerative character of dementia those suffering from it can particularly benefit from anticipatory discussions about their values, attitudes and wishes concerning the end of life. Since nursing homes in Flanders provide long-term care, with most residents having a length of stay of several months or even years, residents and their family can be guided by their general practitioner and nursing home staff through the process of advance care planning at the time of admission and afterwards.

Patients admitted to acute geriatric wards also have serious underlying comorbidity,³²⁻³⁵ but suffer from more acute conditions compared with nursing home residents. Unfortunately, the studies discussed in this dissertation do not give detailed information about their profiles. However, it is known that in general these patients have a decreased chance of survival after cardiopulmonary resuscitation, especially in the long term,³⁶⁻⁴⁰ which is therefore often considered as a futile treatment for these patients. Hence, it might be decided, in advance of an actual cardiopulmonary arrest, not to resuscitate the patient in this situation. In the acute geriatric ward setting it is more difficult to discuss do-not-resuscitate orders than in nursing homes, because the length of stay on acute geriatric wards is shorter and it is not easy to start a conversation concerning end-of-life issues with patients who have an acute illness, or with their families.⁴¹ However, communication difficulties should not be a reason to avoid this topic.

3 Policies regarding advance care planning in institutionalised care for older people

To enhance the process of advance care planning in health care institutions, policies can be developed and implemented. These policies can consist of general institutional guidelines to guide healthcare workers in the process of advance care planning, as well as patient-specific planning forms to document anticipatory decision-making, which are easy to refer to and remain a permanent record for future medical decision-making at the very end of life.⁴² However, when the patient is still competent at that time, the physician should always verify whether the patient still has the same views and wishes.

Although policies regarding advance care planning cannot cover every clinical situation and no one guideline can be considered to be the golden standard,⁴¹ availability of these policies can be of benefit to the patient as well as the physician and other healthcare workers. It explicitly gives patients the opportunity to plan their medical care in the future, in the event that they may lose capacity. For healthcare workers, these policies create a clear framework, define responsibility and enhance the exploration of the patients' wishes.

Prevalence and historical development

Currently, in Flanders, institutionalised care settings for older people considered in this dissertation (acute geriatric wards and nursing homes) seem to have recognised the usefulness of advance care planning for their population. Implementation of donot-resuscitate policies (a specific kind of advance care planning policy) on acute geriatric wards started rather slowly in 1985, but has expanded rapidly since 2000. At the time of our study, in 2002, 86% of acute geriatric wards had implemented a donot-resuscitate policy (Chapter 3). Because some of those without a policy had already started to develop one, and because of the ongoing debate on euthanasia and other end-of-life issues at that time, it could be expected that the implementation of do-not-resuscitate policies would near completion in the years following this study. A more recent study concerning end-of-life policies, including do-not-resuscitate policies, in acute hospitals confirmed this; 98% of acute Flemish hospitals, including acute geriatric wards, had a do-not-resuscitate policy in 2007.⁴³ Findings of our study on nursing home policies regarding advance care planning showed a similar trend. In 2006, 95% of nursing homes had implemented such a policy. Implementation of these policies started somewhat later than do-not-resuscitate policies on acute geriatric wards, but also had a substantial increase after the year 2000 (Chapter 6).

The timing of the increasing development of these policies in institutionalised care for older people is possibly related to the public debate about the legalisation of euthanasia²³ and the laws concerning palliative care²⁴ and patients' rights²² (three laws enacted during 2002) that formally began in 2000. None of these laws stipulated how health care institutions should integrate them into their daily practice, though it seems like they have had an important effect on the development of policies in these care settings.

Development of these policies in healthcare is aimed at increasing communication, transparency, consistency and accountability and is an important step towards improvement of quality of end-of-life care and decision-making.⁴³⁻⁴⁸ The patient should be central in this process. However, patients and general practitioners, who often have a longstanding confidential relationship with their patients, were often not consulted during development and not systematically informed about the implementation of do-not-resuscitate policies on acute geriatric wards (Chapter 3). Because development and implementation was predominantly institutionally driven, it

is plausible to assume that policies regarding advance care planning were not solely developed out of a professional need to regulate this decision-making process, but also as an institutional self-defensive strategy for potential litigation caused by an expanding legal framework. This might also be the basis for the development of the many patient-specific planning forms, a kind of permanent record in case of later disputes. The impact of legislation on the prevalence of advance care planning policies has also been seen in healthcare institutions in other countries like the US, Canada and Australia.^{25,32,46,47,49-52} In the US this was seen much earlier than in Flanders, probably because of the big difference in 'litigation culture' between the two.

In the Netherlands, where the public debate on end-of-life decisions began much earlier than in Belgium and the rest of Europe, an important step towards policy development on euthanasia and physician-assisted suicide was taken in 1995 (in 69% of the Dutch hospitals and 74% of the Dutch nursing homes), but on do not resuscitation and the withholding or withdrawing of other life-sustaining treatments to a lesser degree (in 27% of the Ditch hospitals and 18% of the nursing homes).⁵³ Although little information is available about institutional policies regarding advance care planning in other European countries, it can be said that the development of these policies in Flanders and the rest of Europe lags behind the situation in the US. For example, almost half of US nursing homes had implemented a policy regarding advance care planning before enactment of the Patient Self-Determination Act (1991), with the remaining institutions following shortly thereafter.^{25,51}

Global content regarding different medical end-of-life decisions

Unlike other countries (e.g. the US) where implementation of policies regarding donot-resuscitate and other advance care planning decisions is driven by law, healthcare institutions in Flanders took the initiative individually. This resulted in a large variation in institutional guidelines and patient-specific planning forms. Nevertheless, most of the planning forms were based on the same coding structure, which gradually decreased the number of treatments to perform and gradually increases the level of comfort care. Within the setting of acute geriatric wards an anticipatory decision not to resuscitate the patient in case of a cardiopulmonary arrest was usually found to be a condition for actually withholding or withdrawing other treatments like the administration of antibiotics. Withholding or withdrawing administration of food and fluids was usually mentioned separately as the last step (Chapter 3).

In nursing homes, anticipatory decision-making about whether or not to hospitalise a nursing home resident is an extra end-of-life care issue (not relevant in an in-hospital setting) and might be considered as withholding technically more advanced potentially life-prolonging treatments. Together with anticipatory decision-making about withholding or withdrawing treatments in general, these decisions were

obviously most often taken into consideration in nursing home policy documents (Chapter 6). They were also the most frequent decisions included in documented advance care plans for nursing home residents (Chapter 7). This should not come as a surprise since previous research has shown that of all deaths in nursing homes with a preceding medical end-of-life decision, non-treatment decisions are the most frequent.³ It is probably the medical end-of-life decision which most respects the natural course of the end of life and is, when accompanied by good palliation, probably the most accepted in this long-term care setting.

For a country like Belgium which has had a law on euthanasia since 2002, it seems strange that by 2006 only 38% of nursing homes in Flanders had guidelines on euthanasia in their policies regarding advance care planning (Chapter 6). Based on an earlier study in 2003¹⁷ only a slight increase (8%) of this specific kind of policy is assumed in a 3-year period after enactment of the euthanasia law. As euthanasia is only performed in 0.6% of deaths in nursing homes,³ it might be necessary to put into perspective the lower prevalence of guidelines on euthanasia; however, the possibility remains that the lack of institutional policies slows down the occurrence of euthanasia for these older patients. Perhaps more remarkable is the fact that in 6.2% of nursing homes euthanasia is not allowed (Chapter 6). However, we do not know from this study how occurring euthanasia requests from residents of these nursing homes are handled; whether euthanasia requests are ignored or whether these nursing homes refer to another institution in the event of such a request. It is also not clear whether existing additional institutional criteria (on top of the legal criteria) allowing euthanasia - more often imposed in private non-profit nursing homes (Chapter 6) - are actually intended to improve carefulness in decision-making or rather to deter such decisions. This may possibly be a leftover from the so-called palliative filter procedure. During the public hearings in the Belgian Senate before the enactment of the euthanasia law, there was a lot of discussion about whether or not to include an obligatory palliative filter procedure in the law. This procedure would require the consultation of a specialised palliative care team before a euthanasia request could be honoured (from a point of view that palliative care can forestall such requests), but in the end this obligation was not included in the law. Although the law stipulates that patients requesting euthanasia must be informed of the possibilities of palliative care, the palliative filter procedure might still persist in some health care institutions.^{17,54,55}

Other studies performed in Flanders in 2004^{17} and 2007^{43} show that policies on euthanasia were much more often available in a hospital setting (79% of Catholic hospitals in 2004 and 97% of all hospitals in 2007) than in nursing homes. Since euthanasia at the very end of life occurs almost twice as much in hospitals (1%) than in nursing homes (0.6%),³ and in-hospital deaths also concern more younger people (who are more likely to ask for euthanasia – Chapter 2) than in-nursing home deaths, this difference in the prevalence of euthanasia policies is not so surprising. But again, a higher or lower prevalence of institutional policies in the different care settings

might respectively increase or slow down the occurrence of euthanasia in these settings.

Policy documents focus too little on discussion with still competent older people

The process of advance care planning is focussed on making anticipatory decisions about end-of-life care consistent with the patient's wishes. Inherently, it should enable discussion with patients when they still have competency. In institutionalised care for older people the prevalence of dementia and other incapacitating conditions increases when death is nearing, but at the time of admission many people will still have some level of competency to discuss these kind of issues. However, do-notresuscitate policy documents on acute geriatric wards proved to be predominantly an institutional instrument, rather than a tool for patient involvement in do-not-resuscitate and other end-of-life decision-making. All patient-specific planning forms about resuscitation were physician's order forms (Chapter 3). Consequently, the will of the patient was not often mentioned by geriatricians as a reason to make a do-notresuscitate decision (Chapter 4). The study in chapter 6 on nursing home policy documents regarding advance care planning did not present information about whether these documents actually enable involvement of patients, but this study did collect these policy documents for further analysis, which was performed in 2009-2010.⁵⁶ Unfortunately, this analysis showed that institutional guidelines mainly focus on how to act when residents have lost capacity and hardly at all on enabling discussion with still competent residents around the time of admission to the nursing home. Furthermore, less than 10% of analysed patient-specific planning forms were standardised documents which residents could use to draw up advance directives; most of them were aimed at the authorisation of a legal representative.⁵⁶

These findings show that advance care planning policies at the time of these studies could be improved in order to become more an instrument enabling communication between patients and their different healthcare workers. Otherwise they ignore the most essential condition of advance care planning, namely discussion with patients (and/or their relatives) about the desired direction of patient care.

4 Actual practice of advance care planning in institutionalised care for older people

Most of the nursing homes are shown to have developed and implemented policies regarding advance care planning in general and most acute geriatric wards regarding do-not-resuscitate decision-making. But to what extent is advance care planning also used in actual practice in these settings?

4.1 Do-not-resuscitate decision-making on acute geriatric wards

Prevalence of patients with a do-not-resuscitate order

In 2002, one out of five patients on acute geriatric wards had a do-not-resuscitate status (Chapter 4). Whether or not this is high or low is difficult to interpret since no patient characteristics were available in the study. However, when compared with international data, this result is slightly higher than in hospitals in general⁵⁷⁻⁶⁰ When comparing with results obtained in geriatric wards, the prevalence of patients with do-not-resuscitate status in Flanders is slightly higher than in the United States (16%),⁶¹ identical to the United Kingdom,⁴² but substantially lower than in The Netherlands (55% and 79%).^{62,63} However, in Flanders we also found some wards with more than 50% of the patients with do-not-resuscitate status.

It is not possible to compare the prevalence of do-not-resuscitate orders between acute geriatric patients and nursing home residents based on our studies (in chapter 4 and 7 respectively) because of differences in timing (2002 versus 2006) and inclusion criteria (acute geriatric patients who are alive versus deceased nursing home residents) used in both studies. However, the literature shows that the prevalence of do-not-resuscitate decisions seems higher among deceased nursing home residents than among deceased acute geriatric patients.⁶⁴ A possible explanation might be that an acute hospital setting generally has a more curative goal and hospitalised patients are therefore more likely to receive life-prolonging treatment, although within the acute hospital setting in general it has also been found that geriatricians are more likely than other specialties to make do-not-resuscitate decisions.⁴² Variations between physicians may relate to a number of factors such as their personal or religious views,⁴² but also geriatricians are typically trained to provide holistic care for older people⁴² and are probably therefore more sensitive to clinical situations in which a do-not-resuscitate order might be suitable. The fact that geriatricians who had fewer years of activity in patient care (younger and of another generation) and those who worked on a geriatric ward with a do-not-resuscitate policy had a higher prevalence of patients with do-not-resuscitate status (chapter 4) shows that do-not-resuscitate decision-making is related to the geriatrician's age and the availability of an institutional policy. This creates the opportunity to familiarise physicians in general with do-not-resuscitate decision-making, for example by implementation of do-not-resuscitate policies, education and training. Especially the introduction of a patient-specific do-not-resuscitate order form seems to promote this type of anticipatory decisions; on a geriatric ward in the UK this intervention has doubled the number of do-not-resuscitate orders in a two-year period.⁴²

Timing of do-not-resuscitate decision-making

Anticipatory physician's orders not to resuscitate a patient on an acute geriatric ward are made late in the course of the disease, and disease-related factors are mostly given as the most important reasons for these orders, e.g. prognosis of the disease, physical or mental condition of the patient (Chapter 4).

Decision-making should start as early as possible after admission, before deterioration of the patient's situation. Ideally, discussion on resuscitation and other end-of-life decisions should take place before acute hospitalisation of the patient, because it is much easier to discuss end-of-life issues with patients when there is an absence of disease.

Discussion about do-not-resuscitate decision-making

International guidelines on do not resuscitation all emphasise the importance of patient autonomy and the patient's right to informed choice,⁴² but our results showed low patient participation in do-not-resuscitate decision-making (Chapter 4). This could be the result of many different factors such as the clinical condition (e.g., incompetence) of the patient at the late time of decision-making, a paternalistic way of treating older patients or the reluctance of patients to discuss this matter and their tendency to pass this decision on to their family or treating healthcare workers. It also remains possible that physicians hesitate to discuss this issue with patients, feeling that it is not the right time to discuss it or that it may cause distress for the patient. However, several studies show that the latter is not the case.^{33,65,66} If there is no clear reason to avoid the issue, a physician should always explicitly give a competent patient the opportunity to express his or her treatment preferences in case of severe illness in the future. Recently geriatricians seem to involve the patient more often in the discussion, which might be explained by a generational effect or differences in training programs. Of course, it could also be a sign of the increasing autonomy of patients and their families.

When a patient does not want to talk about do-not-resuscitate and other end-of-life decision-making or lacks decision-making capacity, the decision should be made on behalf of the patient. It is then good practice to involve the patient's family in the decision-making process. However clinicians should avoid deferring the final decision to family members, but should provide clear information and a balanced discussion of the patient's current illness, comorbidity and previously expressed preferences.

General practitioners are not often consulted in decision-making (Chapter 4), although they can also provide useful information. They usually have a longstanding relationship with their patients and a good knowledge of their situation and social context.⁶⁷ They might be aware of previously expressed wishes and should preferably be consulted by specialists when the patient is admitted to hospital.

Nurses are most frequently consulted in decision-making (Chapter 4 and 5), probably because they care for the patient on a daily basis and often have a confidential and close relationship with them and their next of kin.⁶⁸ They are mostly well informed about the patient's overall physical and psychosocial situation and preferences regarding the end of life.⁶⁹ Therefore, nurses are often the right people to initiate discussion about do-not-resuscitation and to fulfil a liaison role between physicians and patients.^{50,70,71} They are able to convey a patient's preferences to the physician, and may also have a great influence on acceptance by the patient (or surrogate decision-maker) of the medical recommendation for attribution of do-not-resuscitate status.⁷² Nurses' involvement in do-not-resuscitate decision-making on acute geriatric wards is higher than in other European countries,^{12,59,69,73} and higher than their involvement in non-treatment decision-making in general in Flanders.⁶⁸ It is possible that head nurses, who were asked to report for their nursing team, gave a slight overestimation of this involvement, but some reasons are plausible to explain the higher rate of involvement in do-not-resuscitate decision-making on geriatric wards. One explanation might be the specific character of do-not-resuscitate decisions versus all non-treatment decisions. Not starting cardiopulmonary resuscitation in case of an arrest has an immediate effect on the time of death, which is not true for other non-treatment decisions (e.g. withholding antibiotics), and might impel physicians to seek nurses' opinions. Another explanation might be found in the specificity of the geriatric ward setting. Death is rather common on these wards, which might lead to more open discussion about the end of life and do not resuscitation than on other wards. In addition, geriatricians may be more inclined to forgo futile treatments for frail older people and may be more familiar with multidisciplinary teamwork in general, and with communicating with nurses in particular. However, the high rate of nurses' involvement in do-not-resuscitate decision-making on geriatric wards gives them more responsibility, but it can also cause stressful situations for them.

All discussions and decisions should be clearly documented on patient-specific donot-resuscitation forms. This is an effective way of sharing this information with all healthcare workers involved in the patient's care, and can be useful during future hospitalisations.

Consistency of end-of-life care with the resuscitation status of the patient

The finding that nurses almost always forgo cardiopulmonary resuscitation in cases of an actual cardiopulmonary arrest in patients with do-not-resuscitate status (Chapter 5) is supported in international literature⁷⁴⁻⁷⁶ and was expected since the hierarchical position of physicians and nurses. In addition, we also found that they do not start cardiopulmonary resuscitation in case of an actual cardiopulmonary arrest for a substantial number of patients without such status (Chapter 5). The fact that nurses sometimes seem to decide on the spot (without prior discussion with the

physician) that cardiopulmonary resuscitation would be futile for patients without donot-resuscitate status might be explained by the possibility that it had not yet been considered by the physician but that nurses thought it was appropriate, or that nurses were not properly acquainted with the do-not-resuscitate status of the patient (e.g. this status was not written in the patient's file or there is a lack of communication between team members). Timely, well-discussed and communicated decisionmaking with the nursing team should prevent conflict situations and inadequately considered actions in acute moments of medical emergency with great emotional stress.

4.2 Advance care planning in nursing homes

Prevalence and characteristics of documented advance care plans

Despite the growing interest in advance care planning, chapter 7 shows that at the end of 2006 in Flanders, documented advance care plans were found in only half of the deceased nursing home residents, predominantly physician's orders (51%) and less often advance directives (5%). This is rather low since advance care planning can be of great benefit for qualitative end-of-life care, particularly for nursing home residents who often become incompetent and impaired near the end of life and whose death can generally be expected.^{77,78}

Documentation of advance directives by nursing home residents in Flanders lags far behind compared to other countries like the US, where (in contrast to the Belgian Patients' Rights Act²²) the Patient Self Determination Act obliges health care institutions, including nursing homes, to give patients at time of admission information about advance directives and to encourage them in writing advance directives.²⁵ On the one hand, this gap might be explained by the fact that medical care for nursing home residents in Flanders is provided by their general practitioner, with whom they often have a longstanding confidential relationship; it is possible that, due to this organisational aspect, nursing home residents in Flanders more often neglect to complete advance directives because they have more faith in their physician to make decisions in their best interest and concordant with their preferences should they lose mental capacity in the future. Because of their longstanding confidential relationship, general practitioners should be able to base this kind of decisions on their knowledge of the resident's previously expressed views and preferences, but studies have shown that treating physicians (including general practitioners) are not always familiar with a patient's preferences.⁷⁹ Moreover, where still competent patients (in this case nursing home residents) have expressed their views and preferences to their general practitioner, these should then be documented in advance directives.

This kind of anticipatory, explicit decision would particularly be useful to refer to in the event of future critical situations where treatment or other end-of-life decisions might be made and would avoid stressful decision-making for all involved and especially those who would otherwise be unfamiliar with the patients' preferences. On the other hand, the low completion rate of advance directives among nursing home residents might also be explained by them being unfamiliar with the possibility of completing an advance directive or because competent patients prefer shared decision-making as long as they are competent and feel that it is too early to write an advance directive, and consequently often wait until it is too late.

Residents with dementia had advance directives less often (Chapter 7), meaning that those residents missed out on formalising their end-of-life care preferences and making sure that their end-of-life care is concordant with their values and wishes. In the future, it is possible that the prevalence of advance directives of deceased nursing home residents with dementia will level with residents without dementia, because those of today missed out on all recent evolutions in advance end-of-life care planning (they probably were already incompetent for quite some time). Moreover, since the younger, often highly educated people of today will be the older people of tomorrow, and research has shown that more highly educated people more often have advance directives,⁸⁰ it is plausible to expect a generally higher rate of advance directives in the future, produced early in the life course and thus before onset of dementia.

Most advance care plans (advance directives and physician's orders) concern anticipatory decisions about non-hospitalisation and/or to withhold or withdraw treatments (e.g. resuscitation, administration of antibiotics). This should not come as a surprise because previous research has shown that of all end-of-life decisions preceding deaths in nursing homes, non-treatment decisions are the most frequent.^{2,3,29} Euthanasia, which is performed in 0.6% of all deaths in nursing homes,³ is rarely documented in advance care plans (0.7%), despite the recent legalisation of euthanasia. However, based on this study no conclusions can be made about levels of concordance between advance care plans and actual end-oflife decisions made at the very end of life.

Prevalence of authorisation of a legal representative

Authorization of a legal representative was documented by less than one out of ten nursing home residents (Chapter 7). This is quite low, but there are plausible reasons to explain this. First, authorisation of a legal representative has been included in legislation only since 2002 (Patients' Rights Act²²) and might still be quite unknown. Second, it might have been impossible at time of admission, due to the clinical condition of the resident, to authorise a legal representative. Finally, appointing a representative without written formalisation by the resident might be more popular,

although this has in fact no legal basis. Unfortunately, we have no figures available on this.

Because it is not possible to describe every situation in advance directives, authorisation of a legal representative has the benefit that a person who is familiar with the resident's preferences regarding the end of life could be involved in end-of-life discussions about very specific problems that were difficult to foresee in advance directives. Although it is discussed in the literature whether relatives have correct knowledge about the true wishes of a dying person, it has been proved that having authorised a representative can avoid treatments at the end of life that are very burdensome for the patient.^{1,81}

Palliative care delivery increases advance care planning

Although in-depth investigation of palliative care delivery in nursing homes as such did not belong to our research questions, our study provided some insights. In one third of all deceased nursing home residents or in one fifth of nursing home residents whose death was expected, no palliative care initiatives were taken (Chapter 7). Although Belgian research shows that people who died non-suddenly in a nursing home were twice as likely to have received specialised palliative care than those dying at home, it can be assumed that palliative care delivery in the nursing homes is not yet optimal for these residents. Traditionally, palliative care has focused on patients with cancer, but recently the World Health Organization stated that it is needed for a much wider range of patients with terminal illnesses and should be integrated more broadly across healthcare settings.⁸² Many older people do not die from cancer and clearly have special needs at the end of life because their problems are different from and often more complex than those of younger cancer patients. Nevertheless, they also need timely palliative care, a type of care that should be based on patient and family needs,²⁷ rather than on prognosis which is often difficult to predict among nursing home residents.⁸³ In the palliative phase of life palliative carers still need to discuss end-of-life care preferences (unknown preferences and/or re-evaluation of known preferences) with the nursing home resident if this is possible, or with the resident's family and regular healthcare professionals as these might be informed about the resident's previously stated wishes. This kind of 'late advance care planning' can be of great importance in future situations of deterioration of the resident's clinical situation. According to our findings in chapter 7, delivery of palliative care seems to be a very important factor in documentation of advance care plans (physician's orders and advance directives occurred more often in these cases) and authorisation of a representative. This finding could more or less be expected since discussion of goals of care is inherent in palliation.^{27,84,85}

Timing of advance care planning

For nursing home residents in Flanders, no direct information is available about the timing of existing advance care plans, of both advance directives and physician's orders (before nursing home admission, at time of admission or shortly afterwards, or when death becomes more and more imminent). The fact that physician's orders occurred more often for residents with dementia and whose death was expected, and the fact that residents with dementia less often had advance directives (Chapter 7) seems to confirm other studies stating that formal discussion about preferred end-of-life care often does not occur before the onset of serious illness near the end of life (as was found for do-not-resuscitate decision-making on acute geriatric wards – Chapter 4). This includes cases where it might have become impossible to communicate with the resident.^{78,86}

As many older people will be admitted to nursing homes as they near death, there is an important role for these institutions in enhancing advance care planning. The general practitioner is probably the most important actor in this process. They should, together with nursing home staff (mainly nurses), stimulate nursing home residents on admission or shortly afterwards to discuss this matter and to complete advance directives. And although dementia is one of the most frequent reasons for nursing home admission in Flanders,⁸⁷ some kind of communication with many of them might be supposed at time of admission or shortly afterwards, before progress of the disease. Moreover, since more than half of the deceased nursing home residents (with or without dementia) stayed in the nursing home for more than three years before death (Chapter 7), during this time nursing home staff were in a position to stimulate anticipatory communication concerning the resident's end-of-life care preferences.

Discussion about advance care planning

Documented physician's orders are supposed to have been discussed with the nursing home resident or the resident's representative. Our study did not provide any information about this but it can be doubted that physician's orders were thoroughly discussed with nursing home residents who died with dementia. They were probably documented after the resident became incompetent and are consequently more likely to have been discussed with the resident's legal representative or, if not authorised, other next of kin than with the already incompetent resident him/herself. However, it also remains a possibility that physician's orders are based solely on the best interests of the patient, whether or not they are made after discussion with other professional health care workers.

Consistency of end-of-life care with advance care planning

Currently, controversy exists about the outcome of advance care planning, more specifically about the usefulness of advance directives. In other words, is the care received at the end of life consistent with previously documented end-of-life care preferences of the patient and does their existence result in more qualitative end-oflife care? An argument in favour of advance directives is that they reflect a patient's wishes and consequently enhance a more qualitative end of life.^{1,88,89} It is also shown that physicians endorse the use of advance directives as a standard in end-of-life decision-making.⁹⁰ Others who are against the use of advance directives will claim that people are not able to make solid choices about possible end-of-life issues in the future⁹¹⁻⁹³ or that an authorised representative is able to take decisions according to another person's preferences,⁹⁴ and several studies have questioned the role of written advance directives in medical decision-making for seriously ill persons.⁹⁵⁻¹⁰¹ These studies observing limitations of advance directives has been criticised because of selection bias (overuse of hospital-based sampling procedures) and the suggestion that the true effect of written advance directives may only be found outside the acute care setting (persons who had completed a written advance directive were more likely to die at home than in an acute care hospital).¹⁰²

Our study did not aim to measure the impact of advance care planning on actual practices at the end of life, but provides proof that nursing home residents with physician's orders – which usually include an anticipatory decision not to hospitalise the resident – more often died in the nursing home and had been transferred less to hospital during the last three months of life (Chapter 7). This might be indicative for receiving care concordant with previous decisions, however we do not know the extent to which these physician's orders actually correspond with the resident's true end-of-life care preferences and were not solely based on the physician's sense of the situation. And despite this indication, the profile of nursing home residents' being older and more dependent, seems to be negatively related to receiving end-of-life care concordant with their previously stated wishes. Studies investigating the influence of age on the likelihood of receiving end-of-life care consistent with the patient's treatment preferences found that older people are less likely to receive the desired care than are younger people and that physicians are less likely to base their decisions on older patients' preferences.^{90,103} In another study among residents who died in American long-term care facilities, the proportion of nursing home residents (the most dependent people in the study versus less dependent people in assisted living) was found to be higher in the group of decedents who received care discordant with their wish not to be hospitalised than among those who received care concordant with this wish.¹⁰⁴ This leads to the interpretation that advance directives would be honoured less often in the case of more dependent people. Because lower concordance of actual end-of-life care with desired end-of-life care is related to older age and higher levels of dependency, healthcare workers should be aware for this kind of discrimination and should try to prevent it.

5 In conclusion

End-of-life decision-making in older people is often limited by complicated or suboptimal end-of-life communication, often caused by comorbidity and mental problems caused by dementia. But even when older people still had full mental capacity, they have been found to have little involvement in decision-making at the very end of life. Advance care planning, a process that can start long before dementia or serious illnesses occurs, can enhance concordance of end-of-life care with the values and preferences of older people and can therefore be considered as good quality end-of-life practice.

Currently, institutionalised care settings for older people seem to have implemented advance care planning policies. First, almost all acute geriatric wards have anticipatory do-not-resuscitate policies. Second, almost all nursing homes have policies regarding anticipatory decisions not to hospitalise residents, not to resuscitate them or to withhold or withdraw treatments. Policies regarding anticipatory decisions concerning euthanasia or terminal sedation are less often available in nursing homes. Both care settings used institutional guidelines (to guide healthcare workers in this process) as well as patient-specific planning forms (to document anticipatory decisions and avoid unwanted interventions at the end of life and misunderstandings in an often quite stressful critical situation at the very end of life). However, policy documents remain predominantly institutional instruments and insufficiently focus on enabling end-of-life care communication between patients and their different health care workers.

In actual practice, it seems that still few advance care plans are made concerning end-of-life care for institutionalised older people, in the long-term care setting as well as in the acute care setting, and that where they do exist they are mostly made late in the course of disease; advance directives (formal anticipatory decisions, written by the patient) are especially rare. Physician's orders occur more often, but discussion with the patient cannot always be guaranteed. Where discussion with the patient is not possible, it is good medical practice to involve the patient's legal representative or other next of kin, or at least to decide in the best interest of the patient.

To enhance older people's involvement in decision-making about the end of life, this process should start as early as possible, in institutionalised care settings at the time of admission or shortly afterwards, before deterioration of the patient's situation. Ideally, end-of-life care decision-making should be discussed before admission in a nursing home or before hospitalisation, because it is much easier to do where there is absence of disease. However, since many older people will be admitted to nursing homes without previous advance care planning, there is an important role for these institutions in enhancing advance care planning in general. The general practitioner is probably the most important actor in this process and should start making patients more early aware of the benefits of advance care planning, even before onset of illness or dependency, and at any age.

RECOMMENDATIONS FOR POLICY AND PRACTICE

The findings of this dissertation indicate that medical end-of-life decisions are less common for very old people than for younger people, that older people are too little involved in communication preceding these decisions, and that advance care planning among older people in institutionalised care is not optimal, especially in relation to the documentation of advance directives by these patients.

1 Recommendations for policy

Efforts to enhance the knowledge and communication skills of physicians and other health care workers

Public health authorities have already taken some initiatives to enhance communication about end-of-life care issues, mainly through legislation (Patients' Rights Act,²² Euthanasia Law²³ and Law concerning Palliative Care²⁴ of 2002). The public debate about these laws and information provided to physicians and other healthcare workers have probably already improved knowledge on this topic. However, ongoing efforts should be made to enhance the knowledge and communication skills of healthcare professionals. This can be done through adaptation of the normal curricula of existing medical and para-medical training, but also in additional post-graduate training programs, especially for physicians and other healthcare workers who care for older people, including general practitioners. They should be reminded continuously of the importance of an early exploration of a patient's end-of-life care preferences and specifically of the vulnerable position of older people in (advance) end-of-life decision-making. General practitioners are extremely well placed to stimulate advance care planning since they often have a long-standing confidential relationship with their patients, independent from transitions between different care settings throughout their life course (home, nursing home, hospital). Organising education and training is the responsibility of authorities and healthcare institutions as well as professional organisations.

Efforts to familiarise the general public with end-of-life care issues and to stimulate communication concerning end-of-life care preferences, especially for older people

Since more highly educated people are more likely to be involved in medical decision-making it can be expected that communication with patients will increase in the future because the education level of the population is rising. However, improvement in current communication skills should be a point of action.

The general public should be made more familiar with end-of-life care issues in general and with advance care planning and the writing of advance directives, more specifically, for example, by health information programs. There should be special attention paid to older people in this, but since advance care planning can best be started before the onset of any disease, the whole population should be targeted.

Optimisation of palliative care delivery

Delivery of palliative care was found to be an important factor related to documentation of advance care plans. Although a palliative care culture is more and more embedded in different healthcare settings, we found that palliative care delivery in institutionalised care for older people has not yet reached the optimal level of quality of end-of-life care. This might be subject to improvement, first, by integrating more palliative care training in the basic education programs of professional healthcare workers involved in this care and second, by placing more financial means and manpower at the disposal of these institutions. This way the current workload can be decreased and more time becomes available to deliver all aspects of palliative care, physical, psychological, social as well as spiritual. Third, when palliatives can also intervene more often in institutionalised care settings, with complementary palliative care options or expertise. Currently, this is already possible, but perhaps there might be some reluctance to call for external help.

Development and implementation of national, standardised institutional guidelines regarding advance care planning and patient-specific planning forms

The use of institutional guidelines and patient-specific planning forms seem to be common practice in institutionalised care settings for older people, but they lack standardisation. This might cause confusion for healthcare workers when they care for patients in different institutions, but it also makes it more complex to understand for the general population. Development of clear and standardised national practice guidelines and patient-specific planning forms, inviting physicians and patients to communicate with each other, could be stimulated by public health authorities. These standardised policies will only be effective when they recognise the important role of all professional caregivers and when they are acceptable for all persons involved. Before implementation all parties involved in advance care planning should properly be informed about these documents, but also at the time of admission to institutionalised care. In practice, it might be helpful if medical records in institutionalised care include basic information about advance care planning communication, and if end-of-life care communication was begun at the time of admission or shortly afterwards (as in the US). Starting communication about advance care planning as early as possible after institutionalisation and before the onset of dementia should become the gold standard in institutionalised care for older people. However, where patients explicitly do not want to talk about their end of life, healthcare workers should honour this. In these cases patients can be given the possibility to authorise a legal representative or just to refer less formally to their next of kin, or healthcare workers can turn to the patient's next of kin on their own initiative. As a last resource, the physician should decide in the best interests of the patient.

2 Recommendations for practice

Writing of advance directives and authorisation of a legal representative should be encouraged

Few older people seem to have written an advance directive or to have authorised a legal representative. There is much discussion about the usefulness of advance directives, mainly because it is considered difficult for patients to understand possible future clinical situations and to predict their end-of-life care preferences in these unknown situations. This criticism is an important reason to promote (besides the writing of advance directives) the authorisation of a legal representative by older people. If this representative is familiar with the values and attitudes of the patient regarding end-of-life care issues, he/she can make an assumption of what the patient would have wanted in an actual critical situation when the patient has lost capacity. Support from professional healthcare workers remains always unbearable in this difficult process; together with the patient's representative they can balance all possible choices that can be made.

Advance care planning should start as early as possible

Physicians should discuss medical end-of-life decisions as early as possible with their patients. Planning care in advance provides better opportunities to involve the still competent patient and his or her next of kin, and to collect better information about the patient's wishes and values concerning end-of-life care. In institutionalised

care settings physicians, but also other professional healthcare workers like nurses, should discuss this matter as much as possible at the time of admission because older patients can lose competency when their condition progresses. Preferably, advance care planning should start even earlier, as it is in fact a continuous process of communication that should start before the condition of the patient declines and can begin at any age. Though, when the topic causes too much distress for the patient or when patients are and remain resistant to discuss this matter, this should be respected.

Early anticipatory decision-making has the advantage that enough time can be taken. The patient's end-of-life care preferences can be discussed and re-discussed. Healthcare workers should timely provide patients and/or their next of kin with correct information, e.g. about the success rate of different kinds of treatments like cardiopulmonary resuscitation in different kinds of clinical situations, about possibilities in pain alleviation techniques etc. Since a patient's situation can change over time, they should always be given the opportunity to re-evaluate previous decisions and this should be made clear to them from the start. This way advance care planning becomes a real communication process.

Nurses as intermediates between older people and physicians

Nurses are often very important in end-of-life care for older people, especially in institutionalised care where they work with older patients on a daily basis. They can often communicate during this daily care about all kinds of topics which can be a starting point to discussion of end-of-life care issues. It is not necessary to make real decisions during these discussions, but this kind of conversations can be used to explore the end-of-life care preferences of the patient, to give them some extra information when needed and to signal their needs to physicians who spend less time with the patient. This demands good knowledge and communication skills on the part of nurses and support from their professional organisations, for example by providing legal information in complicated situations.

SUGGESTIONS FOR FURTHER RESEARCH

Studies in this dissertation provide quantitative insights into end-of-life care for older patients in Flanders, Belgium. For the first time information is becoming available on medical end-of-life decision-making among very old people (compared with younger people) and on advance care planning in institutionalised care for older people. Of course, these are only first insights but they can be the starting point for further research.

First, because the studies in this dissertation were performed at different periods of time within a changing legal framework it is necessary to perform a new study which investigates end-of-life care in older people in all the different settings (institutional as well as home) within the current legal framework. Moreover, exactly the same methodology should be used in all settings in order to be able to make reliable comparisons.

Second, an in-depth content analysis of existing policy documents regarding advance care planning and medical end-of-life decision-making should be performed. This information can afterwards be used to develop more standardised guidelines and patient-specific planning forms. Uniformity should be the aim, though it is possible that differences in the profiles of older people in the different care settings will lead to different guidelines and patient-specific planning forms for different settings.

Third, to provide more in-depth and qualitative information it will be necessary to conduct some prospective research, following a cohort of older people. This kind of study should preferably be used to gain more information about decision-making processes concerning the end of life, including advance care planning as well as decision-making at the very end of life. Defining factors that are associated with good communication on end-of-life care issues can be used to facilitate end-of-life care communication, to limit barriers and to optimise this process.

Fourth, there should be investigation into how people can best be stimulated to write advance directives. Intervention studies in one or more institutions can best be used to discover the effect of initiatives. The same methodology can be used to measure the effect of additional training programs for professional healthcare workers; whether this improves the decision-making processes concerning end-of-life care.

Fifth, the impact of policies regarding advance care planning and end-of-life decisionmaking on actual practices should be investigated. According to our study on do-notresuscitate decision-making it can be assumed that availability of policy documents increases do-not-resuscitate orders. However, further research is needed to confirm this and to define minimal criteria required for these policies to have this kind of impact (e.g. format and content of policy documents). Finally, concordance of end-of-life care with advance care planning and the effect of advance care planning on the quality of end-of-life care should be investigated. The hypothesis is that, when end-of-life care is concordant with advance care planning and consequently with the patient's preferences, the quality of care will increase. This, however, needs to be further investigated.

REFERENCES

- 1. Silveira MJ, Kim SY, Langa KM. Advance directives and outcomes ofsurrogate decision making before death. N Eng J Med 2010;362:1211-1218.
- 2. van der Heide A, Deliens L, Faisst K, et al. End-of-life decision-making in six European countries: descriptive study. Lancet 2003;362:345-350.
- 3. Deliens L, Mortier F, Bilsen J, et al. End-of-life decisions in medical practice in Flanders, Belgium: a nationwide survey. Lancet 2000;356:1806-1811.
- 4. van der Maas PJ, van Delden JJ, Pijnenborg L, Looman CW. Euthanasia and other medical decisions concerning the end of life. Lancet North Am Ed 1991;338:669-674.
- 5. van der Maas PJ, van der Wal G, Haverkate I, er al. Euthanasia, physicianassisted suicide, and other medical practices involving the end of life in the Netherlands, 1990-1995. N Eng J Med 1996;335:1699-1705.
- 6. van der Heide A, Onwuteaka-Phillipsen BD, Rurup ML, et al. End-of-life practices in the Netherlands under the Euthanasia Act. N Eng J Med 2007;356:1957-1965.
- 7. Van den Block L. End-of-life care and medical decision making in the last phase of life. Vrije Universiteit Brussel; 2008.
- 8. Chambaere K, Bilsen J, Cohen J, et.al. A post-mortem survey on end-of-life decisions using a representative sample of death certificates in Flanders, Belgium: research protocol. BMC Public Health 2008;8:299.
- 9. Van den Block L, Bilsen J, Deschepper R, Van der Kelen G, Bernheim JL, Deliens L: End-of-life decisions among cancer patients compared with noncancer patients in Flanders, Belgium. J Clin Oncol 2006;24:2842–2848.
- Bilsen J, Norup M, Deliens L, et al: Drugs used to alleviate symptoms with life shortening as a possible side effect: end-of-life care in six European countries. J Pain Symptom Manage 2006;31:111–121.
- 11. Castle N, Owen R, Kenward G, et al. Pre-printed 'do not attemt resuscitation' forms improve documentation? Resuscitation 2003;59:89-95.
- Jacobson JA, Kasworm E. May I take your order? A user-friendly resuscitation status and medical treatment plan form. Qual Manag Health Care 1997;7:13-20.

- 13. Tolle SW, Tilden VP, Nelson CA, et al. A prospective study af the efficacy of the physician order form for life-sustaining treatment. J Am Geriatr Soc 1998;46:1097-1102.
- 14. O'Keeffe ST. Development and implementation of resuscitation guidelines: A personal experience. Age Ageing 2001;30:19-25.
- Diggory P, Cauchi L, Griffith D, et al. The influence of new guidelines on cardiopulmonary resuscitation (CPR) decisions. Five cycles of audit of a clerk proforma which included a resuscitation decision. Resuscitation 2003;56:159-165.
- 16. Combs PL, Stahl LD. Implementing a do-not-resuscitate order in an adult day center. Geriatr Nurs 2002;23:312-315.
- 17. Gastmans C, Lemiengre J, van der Wal G, et al. Prevalence and content of written ethics policies on euthanasia in Catholic healthcare institutions in Belgium (Flanders). Health Policy 2006;76:169-178.
- 18. Lemiengre J, Dierckx de Casterlé B, Verbeke G, et al. Ethics policies on euthanasia in nursing homes: a survey in Flanders, Belgium. Soc Sci Med 2008;66:376-386.
- Lemiengre J, Dierckx de Casterlé B, Denier Y, Schotsmans P, Gastmans C. Content analysis of euthanasia policies of nursing homes in Flanders (Belgium). Med Health Care and Philos 2009;12:313-322.
- 20. Gastmans C, Lemiengre J, Dierckx de Casterlé B. Development nd communication of written ethics policies on euthanasia in Catholic hospitals and nursing homes in Belgium (Flanders). Patient Educ Couns 2006;63:188-195.
- 21. Cohen J, Bilsen J, Hooft P, et al. Dying at home or in an institution using death certificates to explore the factors associated with place of death. Health Policy 2006 Oct;78(2-3):319-329.
- 22. Wet betreffende de rechten van de patient [Patients' Rights Act]. Belgisch Staatsblad van 26 september 2002 [Belgian Law Gazette of September 26, 2002]. [in Dutch]
- 23. Wet betreffende euthanasie [Law concerning euthanasia]. Belgisch Staatsblad van 22 juni 2005 [Belgian Law Gazette of June 22, 2002]. [in Dutch]
- 24. Wet betreffende palliatieve zorg [Law concerning palliative care]. Belgisch Staatsblad van 26 oktober 2002 [Belgian Law Gazette of October 26, 2002]. [in Dutch]
- 25. Bradley EH, Wetle T, Horwitz SM. The patient self-determination act and advance directive completion in nursing homes. Arch Fam Med 1998;7:417-423.
- 26. Somogyi-Zalud E, Zhong Z, Lynn J, Hamel MB. Elderly persons' last six months of life: findings from the Hospitalized Elderly Longitudinal Project. J Am Geriatr Soc 2000;48:S131–S139.

- 27. World Health Organization. Better Palliative Care for Older People. Copenhagen, Denmark: 2004.
- 28. Roger KS. A literature review of palliative care, end of life, and dementia. Palliat Support Care 2006;4:295–303.
- 29. Bilsen J, Cohen J, Chambaere K, et.al. Medical end-of-life practices under the euthanasia law in Belgium. N Eng J Med 2009;361:1119-1121.
- 30. Ghijsebrechts G, Van de Wiele M, De Lepeleire J. Vroegtijdige zorgplanning in rusthuizen: een verkenning [Advance care planning in nursing homes: an exploration]. Tijdschrift voor Geneeskunde 2009;65:180-185. [in Dutch]
- 31. Inghelbrecht E, Bilsen J, Mortier F, Deliens L. Factors related to the involvement of nurses in medical end-of-life decisions in Belgium: a death certificate study. Int J Nurs Stud 2008;45:1022–1031.
- 32. Mello M, Jenkinson C. Comparison of medical and nursing attitudes to resuscitation and patient autonomy between a British and an American teaching hospital. Soc Sci Med 1998;46:415–424.
- 33. Frank C, Heyland DK, Chen B, Farquar D, Myers K, Iwaasa K. Determining resuscitation preferences of elderly inpatients: a review of the literature. Can Med Assoc J 2003;169:795–9.
- 34. Cherniack EP. Increasing use of DNR orders in the elderly worldwide: Whose choice is it? J Med Ethics 2002;28:303-307.
- 35. Dautzenberg PLJ, Hooyer C, Schonwetter RS, et al. Cardiopulmonary resuscitation policy in aged inpatients. Basic considerations when entering decisionmaking in the psychogeriatric field. Geriatrie Forsch 1993;3:175-183.
- 36. Weiss GL, Hite CA. The do-not-resuscitate decision: the context, process, and consequences of DNR orders. Death Stud 2000;24:307–323.
- 37. Vanpee D, Swine C. Scale of levels of care versus DNR orders. J Med Ethics 2004;30:351–352.
- 38. Gulati RS, Bhan GL, Horan MA. Cardiopulmonary resuscitation of old people. Lancet 1983;2:267–269.
- 39. Murphy DJ, Murray AM, Robinson BE, Campion EW. Outcomes of cardiopulmonary resuscitation in the elderly. Ann Intern Med 1989;111:199–205.
- 40. Costello J. Do Not Resuscitate orders and older patients: findings from an ethnographic study of hospital wards for older people. J Adv Nurs 2002;39:491–499.
- 41. Myint PK, Miles S, HHalliday DA, Bowker LK. Experiencces and views of specialist registrars in geriatric medicine on 'do not attempt resuscitation' decisions: a sea of uncertainty? Q J Med 2006;99:691-700.
- 42. Harkness M, Wanklyn P. Cardiopulmonary resuscitation: capacity, discussion and documentation. Q J Med 2006;99:683-390.

- 43. D'Haene I, Vander Stichele RH, Pasman HRW, Van Den Noortgate N, Bilsen J, Mortier F, Deliens L. Policies to improve end-of-life decisions in Flemish hospitals: communication, training of health care providers and use of quality assessments. BMC Palliat Care 2009;8:20.
- 44. Woolf SH, Grol R, Hutchinson A, Eccles M, Grimshaw J. Clinical guidelines: potential benefits, limitations, and harms of clinical guidelines. BMJ 1999;318:527-530.
- 45. Haverkate I, van Delden JJ, Van Nijen AB, van der Wal G. Guidelines for the use of do-not-resuscitate orders in Dutch hospitals. Crit Care Med 2000;28:3039-3043.
- 46. Burns JP, Edwards J, Johnson J, et al. Do-not-resuscitate order after 25 years. Crit Care Med 2003;31:1543–1550.
- 47. Butler JV, Pooviah PK, Cunningham D, et al. Improving decision-making and documentation relating to do not attempt resuscitation orders. Resuscitation 2003;57:139–144.
- 48. O'Toole EE, Youngner SJ, Juknialis BW et al. Evaluation of a treatment limitation policy with a specific treatment-limiting order page. Arch Intern Med 1994;154:425–432.
- 49. Boyd K. Deciding about resuscitation. J Med Ethics 2001;27:291–294.
- 50. Manias E. Australian nurses' experiences and attitudes in the 'do not resuscitate' decision. Res Nurs Health 1998;21:429–441.
- 51. Kapp MB. Nursing home compliance with the patient self-determination act: does Jewish affiliation make a difference? HEC Forum 1993;5:223–36.
- 52. Hayes S, Stewart K. The role of audit in making do not resuscitate decisions. J Eval Clin Pract 1999;5:305–12.
- 53. Haverkate I, van der Wal G. Policies on medical decisions concerning the end of life in Dutch health care institutions. JAMA 1996;275:435–39.
- 54. Bernheim JL, Deschepper R, Distelmans W, Mullie, et al. Development of palliative care and legislation of euthanasia: antagonism or synergy? BMJ 2008;336:864–7.
- 55. Deliens L, van der Wal G. The euthanasia law in Belgium and the Netherlands. Lancet 2003;362:1239–40.
- 56. Van Kan E. ACP in Vlaamse rust- en verzorgingstehuizen. Inhoudsanalyse van richtlijnen en patiëntspecofieke bewonersgeoriënteerd documenten [ACP in nursing homes in Flanders. Content analysis of guidelines and standardized documents for advance directives]. Vrije Universiteit Brussel, Brussel 2010. [in Dutch]
- 57. de Vos R, Koster RW, de Haan RJ. Impact of survival probability, life expectancy, quality of life and patient preferences on do-not-attempt resuscitation orders in a hospital. Resuscitation Committee. Resuscitation 1998;39:15–21.

- 58. Junod Perron N, Morabia A, De Torrente A. Evaluation of do not resuscitate orders (DNR) in a Swiss community hospital. J Med Ethics 2002;28:364–367.
- 59. van Delden JJ, van der Maas PJ, Pijnenborg L, Looman CW. Deciding not to resuscitate in Dutch hospitals. J Med Ethics 1993;19:200–205.
- 60. Wenger NS, Pearson ML, Desmond KA, et al. Epidemiology of do-notresuscitate orders. Disparity by age, diagnosis, gender, race, and functional impairment. Arch Intern Med 1995;155:2056–2062.
- 61. Torian LV, Davidson EJ, Fillit HM, Fulop G, Sell LL. Decisions for and against resuscitation in an acute geriatric medicine unit serving the frail elderly. Arch Intern Med 1992;152:561–565.
- 62. Dautzenberg PL, Duursma SA, Bezemer PD, Van Engen C, Schonwetter RS, Hooyer C. Resuscitation decisions on a Dutch geriatric ward. Q J Med 1993;86:535–542.
- 63. Dautzenberg PL, Bezemer PD, Duursma SA, Schonwetter R, Hooyer C. The frequency of "do-not-resuscitate" order in aged in-patients: effect of patient-and non-patient-related factors. Neth J Med 1994;44:78–83.
- 64. Solloway M, LaFrance S, Bakitas M, Ferken M. A chart review of seven hundred eighty-two deaths in hospitals, nursing homes, and hospice/home care. J Pall Med 2005;8:789-796.
- 65. Hill ME, MacQuillan G, Forsyth M, Heath DA. Cardiopulmonary resuscitation: who makes the decision? Br Med J 1994;308:1677.
- 66. Morgan R, King D, Prajapati C, Rowe J. Views of elderly patients and their relatives on cardiopulmonary resuscitation. Br Med J 1994;308:1677–8.
- 67. Bilsen J, Vander Stichele R, Mortier F, Bernheim J, Deliens L. The incidence and characteristics of end-of-life decisions by GPs in Belgium. Fam Pract 2004;21:282–289.
- 68. Bilsen JJ, Vander Stichele RH, Mortier F, Deliens L. Involvement of nurses in physician-assisted dying. J Adv Nurs 2004;47:583–591.
- 69. Hilden HM, Louhiala P, Honkasalo ML, Palo J. Finnish nurses' views on endof-life discussions and a comparison with physicians' views. Nursing Ethics 2004; 11:165–178.
- 70. Richter J, Eisemann MR. The compliance of doctors and nurses with do-notresuscitate orders in Germany and Sweden. Resuscitation 1999;42:203–209.
- 71. Anderson-Shaw L. The unilateral DNR order one hospital's experience. JONA'S Healthcare Law, Ethics and Regulation 2003;5:42–46.
- 72. Eliasson AH, Howard RS, Torrington KG, Dillard TA, Phillips YY. Do-notresuscitate decisions in the medical ICU: comparing physician and nurse opinions. Chest 1997;111:1106–1111.

- 73. Holzapfel L, Demingeon G, Piralla B, Biot L, Nallet B. A four-step protocol for limitation of treatment in terminal care. An observational study in 475 intensive care unit patients. Intensive Care Medicine 2002;28:1309–1315.
- 74. Goodlin SJ, Zhong Z, Lynn J, Teno JM, Fago JP, Desbiens N, Connors AF Jr, Wenger NS, Phillips RS. Factors associated with use of cardiopulmonary resuscitation in seriously ill hospitalized adults. The Journal of the American Medical Association 1999;282: 2333–2339.
- 75. Hakim RB, Teno JM, Harrell FE Jr, Knaus WA, Wenger N, Phillips RS, Layde P, Califf R, Connors AF Jr, Lynn J. Factors associated with do-not-resuscitate orders: patients' preferences, prognoses, and physicians' judgments. SUPPORT Investigators. Study to understand prognoses and preferences for outcomes and risks of treatment. Annals of Internal Medicine 1996;125:284–293.
- 76. Lee MA, Brummel-Smith K, Meyer J, Drew N, London MR. Physician orders for life-sustaining treatment (POLST): outcomes in a PACE program. Program of all-inclusive care for the elderly. Journal of the American Geriatrics Society 2000;48: 1219–1225.
- 77. Aheam DJ, Jackson TB, McIlmoyle J, Weatherburn AJ. Improving end-of-life care for nursing home residents: an analysis of hospital mortality and readmission rates. Postgrad Med J 2010;86:131-135.
- 78. Daaleman TP, Williams CS, Preisser JS, et al. Advance care planning in nursing homes and assisted living communities. J Am Med Dir Assoc 2009;10:243-251.
- 79. The Support Investigators. A controlled trial to improve care for seriously ill hospitalized patients. The study to understand prognoses and preferences for outcomes and risks of treatments (SUPPORT). JAMA 1995;274:1591-1598.
- 80. van Wijnen MPS, Rurup ML, Pasman HRW, Kaspers PJ, Onwuteaka-Philipsen BD.Design of the Advance Directives Cohort: a study of end-of-life decision-making focusing on Advance Directives. BMC Public Health 2010;10:166.
- 81. Kuo S, Rhodes RL, Mitchell SL, et al. Natural history of feeding-tube use in nursing home residents with advanced dementia. J Am Med Dir Assoc 2009;10:264-270.
- 82. World Health Organization. Palliative Care: The Solid Facts. Copenhagen, Denmark: 2004.
- 83. Brandt H. Palliative care in Dutch nursing homes. Vrije Universiteit Amsterdam, Amsterdam, 2006.
- 84. Boockvar KS, Meier DE. Palliative care for frail older adults: "there are things I can't do anymore that I wish I could . . . ". JAMA 2006;296:2245-2253.
- 85. Blackford J, Strickland E, Morris B. Advance care planning in residential aged care facilities. Contemp Nurse 2007;27:141-151.

- 86. Crane MK, Wittink M, Doukas DJ. Respecting end-of-life treatment preferences. Am Fam Physician 2005;72:1263-1268.
- 87. Devroey D, Van Casteren V, and De Lepeleire J. Placements in Psychiatric Institutions, Nursing Homes, and Homes for the Elderly by Belgian General Practitioners. Aging Ment.Health 2002;6:286-292.
- 88. Rosnick CB, Reynolds SL: Thinking Ahead: Factors Associated with Executing Advance Directives. J Aging Health 2003;15:409-429.
- 89. Tilden VP, Tolle SW, Nelson CA, Fields J: Family decision-making to withdraw life-sustaining treatments from hospitalized patients. Nurs Res 2001;50:105-115.
- 90. Torke AM, Moloney R, Siegler M, Abalos A, Alexander GC.Physicians' Views on the Importance of Patient Preferences in Surrogate Decision-Making. J Am Geriatr Soc 2010;58:533–538.
- 91. Perkin HS. Controlling death: the false promise of advance directives. Ann Intern Med 2007;147:51–7.
- 92. Fried TR, O'Leary J, Van Ness P, Fraenkel L: Inconsistency Over Time in the Preferences of Older Persons with Advanced Ilness for Life-Sustaining Treatment. J Am Geriatr Soc 2007;55:1007-1014.
- 93. Teno JM, Lynn J: Putting advance-care planning into action. J Clin Ethics 1996;7:205-213.
- 94. Barrio-Cantalejo IM, Molina-Ruiz A, Simón-Lorda P, Cámara-Medina C, Toral López I, del Mar Rodríguez del Aguila M, Bailón-Gómez RM: Advance Directives and Proxies' Predictions About Patients' Treatment. Nurs Ethics 2009;16:93-109.
- 95. Schneiderman LJ, Kronick R, Kaplan RM et al. Effects of offering advance directives on medical treatments and costs. Ann Intern Med 1992;117:599–606.
- 96. Teno JM, Lynn J, Phillips RS et al. Do formal advance directives affect resuscitation decisions and the use of resources for seriously ill patients? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments. J Clin Ethics 1994;5:23–30.
- 97. Teno JM, Stevens M, Spernak S et al. Role of written advance directives in decision making: Insights from qualitative and quantitative data. J Gen Intern Med 1998;13:439–446.
- 98. Teno JM, Lynn J, Connors AF Jr et al. The illusion of end-of-life resource savings with advance directives. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J AmGeriatr Soc 1997;45:513–518.
- 99. Teno JM, Lynn J, Wenger N et al. Advance directives for seriously ill hospitalized patients: Effectiveness with the patient self-determination act and

the SUPPORT intervention. SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997;45:500–507.

- 100. Teno JM, Licks S, Lynn J et al. Do advance directives provide instructions that direct care? SUPPORT Investigators. Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment. J Am Geriatr Soc 1997;45:508–512.
- Ditto PH, Danks JH, Smucker WD et al. Advance directives as acts of communication: A randomized controlled trial. Arch Intern Med 2001;161:421– 430.
- Degenholtz HB, Rhee Y, Arnold RM. Brief communication: The relationship between having a living will and dying in place. Ann Intern Med 2004;141:113– 117.
- Parr JD, Zhang B, Nilsson ME, et.al. The Influence of Age on the Likelihood of Receiving End-of-Life Care Consistent with Patient Treatment Preferences. J Pall Med 2010;13:719-726.
- 104. Biola H, Sloane PD, Williams CS, Daaleman TP, Zimmerman S. Preferences versus practice: life-sustaining treatments in last months of life in long-term care. J Am Med Dir Assoc 2010;11:42-51.

SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN

Achtergrond

Gezien de vergrijzing van de bevolking zijn er recent een aantal wijzigingen opgetreden aan het levenseinde; meer en meer mensen, vooral ouderen, sterven na een langdurige periode van chronische ziekte en comorbiditeit. Het aandeel nietplotse sterfgevallen is dan ook aanzienlijk binnen de oudere bevolking waardoor het verlenen van één of andere vorm van levenseindezorg voor hen vaak tot de mogelijkheden behoort. Gedurende de laatste jaren is het besef echter gegroeid dat voor veel van deze mensen het verlengen van het leven door therapeutische hardnekkigheid niet steeds het meest nastrevenswaardige is; palliatieve zorg en het optimaliseren van de levenskwaliteit kunnen belangrijker zijn dan kwantiteit in deze laatste levensfase.

Toch is er nog steeds weinig informatie beschikbaar over de zorg aan het levenseinde van ouderen en de daaraan voorafgaande beslissingsprocessen (zowel voorafgaande, anticiperende zorgplanning omtrent het levenseinde, als medische besluitvorming kort voor het overlijden van de patiënt). Nochtans dient hieraan extra aandacht te worden besteed bij deze leeftijdsgroep, omdat besluitvorming aan het levenseinde ouderen vaak bemoeilijkt van wordt ten gevolge van wilsonbekwaamheid door dementie of andere aandoeningen, een lagere algemene conditie dan jongere patiënten, en comorbiditeit.

Het onderzoek voorgesteld binnen deze doctoraatsthesis hoopt een bijdrage te leveren aan het verkrijgen van meer informatie omtrent het levenseinde van ouderen. In eerste instantie wordt ingegaan op medische besluitvorming en terminale sedatie kort voor het overlijden van ouderen in het algemeen. Vervolgens ligt de focus op voorafgaande zorgplanning omtrent het levenseinde van ouderen binnen de geïnstitutionaliseerde zorgsetting: in acute diensten voor geriatrie worden beleid en praktijk met betrekking tot voorafgaande niet-reanimatie beslissingen toegelicht, en in de chronische zorgsetting van de rust- en verzorgingstehuizen worden beleid en tot voorafgaande praktijk met betrekking zorgplanning omtrent diverse levenseindebeslissingen beschouwd.

Onderzoeksvragen

- I. Medische besluitvorming en terminale sedatie kort voor het levenseinde
 - 1. Voor hoeveel niet-plots overleden 80-plussers wordt kort voor het overlijden een medische levenseindebeslissing genomen of gekozen voor terminale sedatie, welke zijn de karakteristieken van deze beslissingen en het

voorafgaande beslissingsproces, en bestaat er een verschil met jongere patiënten?

- II. Voorafgaande besluitvorming met betrekking tot niet-reanimatie binnen acute diensten voor geriatrie
 - 2. Hoeveel acute diensten voor geriatrie hebben een beleid met betrekking tot niet-reanimatie beslissingen, wanneer werd dit geïmplementeerd, welke zijn de karakteristieken van de ontwikkeling en implementatie, en wat is de algemene inhoud?
 - 3. Wat is de prevalentie van patiënten met een niet-reanimatie beslissing op acute diensten voor geriatrie en welke zijn de karakteristieken van het voorafgaande beslissingsproces?
 - 4. Worden verpleegkundigen betrokken bij het nemen van niet-reanimatie beslissingen en hoe vaak handelen zij volgens de voorafgaande (niet-)reanimatie status van de patiënt?
- III. Voorafgaande zorgplanning omtrent diverse levenseindebeslissingen in rust- en verzorgingstehuizen
 - 5. Hoeveel runt- en verzorgingstehuizen hebben een beleid met betrekking tot voorafgaande zorgplanning omtrent diverse levenseindebeslissingen, wanneer werd dit geïmplementeerd, en wat is de algemene inhoud?
 - 6. Voor hoeveel bewoners van rust- en verzorgingstehuizen waren op het moment van overlijden voorafgaande levenseindebeslissingen gedocumenteerd en hoeveel hadden een vertegenwoordiger benoemd, en bestaat er een verband met demografische, klinische en/of zorgkarakteristieken aan het levenseinde van deze bewoners?

Methode

Er warden 3 verschillende studies uitgevoerd om deze onderzoeksvragen te beantwoorden.

Sterfgevallenonderzoek

Om de eerste onderzoeksvraag te beantwoorden werd gebruik gemaakt van een sterfgevallenonderzoek in Vlaanderen, uitgevoerd in 2001, waarvoor een toevallige steekproef (N=5,005) werd getrokken van alle officiële overlijdensstatistieken in Vlaanderen van patiënten die één jaar of ouder waren bij overlijden. De artsen die de betreffende overlijdensattesten invulden, werden gevraagd een vragenlijst in te vullen over het voorkomen van medische levenseindebeslissingen kort voor het overlijden
van de patiënt, de karakteristieken van het voorafgaande beslissingsproces en over het voorkomen van terminale sedatie. Secundaire analyses werden uitgevoerd om niet-plots overleden 80-plussers te vergelijken met niet-plots overleden jongere patiënten.

DNR-studie

Voor het beantwoorden van de onderzoeksvragen 2 tot 4 over voorafgaande besluitvorming met betrekking tot niet-reanimatie (**D**o-**N**ot-**R**esuscitation), werden in 2002 drie verschillende vragenlijsten verstuurd naar alle 94 ziekenhuiscampussen met een acute dienst voor geriatrie in Vlaanderen.

Door middel van de eerste vragenlijst werd het Diensthoofd Geriatrie (steeds een geriater) bevraagd over het bestaan van een niet-reanimatie beleid op de acute dienst voor geriatrie en over de karakteristieken van ontwikkeling en implementatie van een dergelijk beleid. Zij werden tevens gevraagd bestaande beleidsdocumenten bij te sluiten bij het terugsturen van de ingevulde vragenlijst.

De tweede vragenlijst werd, via het Diensthoofd Geriatrie, gericht aan die geriater van de dienst die het meest klinisch werk verricht. Er werd gepeild naar de aanwezigheid van een niet-reanimatie beleid op de dienst, de punt-prevalentie van patiënten met een niet-reanimatie beslissing en de karakteristieken van het beslissingsproces dat vooraf ging aan de laatst genomen niet-reanimatie beslissing, bvb tijdstip, redenen, betrokken actoren.

Hoofdverpleegkundigen van de acute dienst voor geriatrie werden met de derde vragenlijst bevraagd over de betrokkenheid van verpleegkundigen in het beslissingsproces dat vooraf ging aan de laatst genomen niet-reanimatie beslissing op hun dienst (niet noodzakelijk hetzelfde geval als in de tweede vragenlijst). Daarenboven werden zij, op een geaggregeerd niveau, gevraagd in welke mate verpleegkundigen in geval van een reële hartstilstand handelen in overeenstemming met de niet-/reanimatie status van patiënten.

ACP-studie

De twee laatste onderzoeksvragen over voorafgaande zorgplanning omtrent diverse levenseindebeslissingen (**A**dvance **C**are **P**lanning) werden beantwoord door een studie waarbij alle 594 rust- en verzorgingstehuizen in Vlaanderen werden betrokken, uitgevoerd in 2006.

Een eerste vragenlijst werd gezonden naar de Dagelijks verantwoordelijke van elke instelling. Zij werden bevraagd over een aantal karakteristieken van de instelling met betrekking tot zorg aan het levenseinde van hun bewoners en over het instellingsbeleid ten aanzien van voorafgaande zorgplanning omtrent diverse levenseindebeslissingen.

De Dagelijks verantwoordelijke van elke instelling ontving daarnaast een aantal identieke exemplaren van een tweede vragenlijst. Ze werden gevraagd het aantal overleden bewoners gedurende september-oktober 2006 te rapporteren en voor elk van hen een exemplaar van de tweede vragenlijst door te geven aan die verpleegkundige die het meest betrokken was bij de zorg van een overleden bewoner. Verpleegkundigen werden vervolgens bevraagd over de karakteristieken van de overleden bewoner, het voorkomen van ziekenhuistransfers en het verstrekken van palliatieve zorg aan het levenseinde, de aanwezigheid van schriftelijk, voorafgaande zorgplannen op het moment van overlijden (zijnde neergeschreven wilsbeschikking van de patiënt en/of voorafgaande instructies van de arts) en of de bewoner een vertegenwoordiger had benoemd.

Resultaten

De resultaten van alle studies werden verwerkt in de hoofdstukken 2 tot 7 van deze doctoraatsthesis.

I. Medische besluitvorming en terminale sedatie kort voor het levenseinde

1. Voor hoeveel niet-plots overleden 80-plussers wordt kort voor het overlijden een medische levenseindebeslissing genomen of gekozen voor terminale sedatie, welke zijn de karakteristieken van deze beslissingen en het voorafgaande beslissingsproces, en bestaat er een verschil met jongere patiënten? (Hoofdstuk 2)

Het nemen van medische levenseindebeslissingen kort voor het overlijden komt voor bij meer dan de helft van de niet-plots overleden 80-plussers, maar is significant verschillend ten opzichte van jongere patiënten; voor 53.6% van de 80-plussers werd minimum één levenseindebeslissing genomen (versus 63.3% bij jongere patiënten). Een beslissing om letale middelen toe te dienen met het expliciete doel het leven van de patiënt te verkorten werd bij 1.1% van de 80-plussers genomen (zes keer minder vaak dan bij jongere patiënten). Bij 80-plussers werden geen gevallen gerapporteerd waarbij euthanasie werd uitgevoerd (versus 16 gevallen of 0.9% bij jongere patiënten). Het intensiveren van pijn- en symptoombestrijding met een mogelijk levensverkortend effect kwam voor bij 27.3% van de 80-plussers (de helft zo vaak in vergelijking met jongere patiënten), en het niet opstarten of stopzetten van potentieel levensverlengende behandelingen bij 25.2% (niet significant minder vaak dan bij jongere patiënten). Terminale sedatie wordt toegepast bij 6.9% van de 80-plussers, wat slechts half zo vaak is dan bij jongere patiënten.

Een belangrijke bevinding van deze studie is dat de communicatie bij de diverse vormen van levenseindebeslissingen bij 80-plussers niet optimaal verloopt. Meer dan vier vijfden van de 80-plussers met een levenseindebeslissing werden door de arts beschouwd als wilsonbekwaam. Zij worden, net zoals de wilsonbekwame jongere patiënten, weinig betrokken in de besluitvorming (ongeveer 15%). Bij wilsbekwame patiënten werd vastgesteld dat 80-plussers minder vaak betrokken werden in de besluitvorming dan jongere patiënten (56.1% versus 71.9%).

Verpleegkundigen worden bij 69.3% van de levenseindebeslissingen voor 80plussers betrokken (versus 44.3%), vaker dan een andere arts.

II. Voorafgaande besluitvorming met betrekking tot niet-reanimatie binnen acute diensten voor geriatrie

2. Hoeveel acute diensten voor geriatrie hebben een beleid met betrekking tot nietreanimatie beslissingen, wanneer werd dit geïmplementeerd, welke zijn de karakteristieken van de ontwikkeling en implementatie, en wat is de algemene inhoud? (Hoofdstuk 3)

In 2002 bleken 86.1% van de acute diensten voor geriatrie in Vlaanderen te beschikken over een niet-reanimatie beleid, meestal bestaande uit zowel institutionele richtlijnen als patiëntspecifieke instructieformulieren. Implementatie van een dergelijk beleid op acute diensten voor geriatrie startte in 1985 en maakte een grote sprong in 2001. Geriatrische diensten in private ziekenhuizen implementeerden hun beleid meestal op een later tijdstip, maar beschikken vaker over patiëntspecifieke instructieformulieren dan in de openbare ziekenhuizen.

Het niet-reanimatie beleid werd meestal ontwikkeld vanuit de instelling, met weinig of geen inspraak van patiënten of patiëntenorganisaties. De ontvangen beleidsdocumenten zijn niet gestandaardiseerd en variëren sterk qua vorm en inhoud. Op de patiëntspecifieke instructieformulieren is geen ruimte voorzien om de betrokkenheid van de patiënt in het beslissingsproces te documenteren.

3. Wat is de prevalentie van patiënten met een niet-reanimatie beslissing op acute diensten voor geriatrie en welke zijn de karakteristieken van het voorafgaande beslissingsproces? (Hoofdstuk 4)

Eén vijfde van de patiënten opgenomen op acute diensten voor geriatrie hebben een niet-reanimatie status gekregen van de geriater. Geriaters die nog niet zo lang actief zijn in de patiëntenzorg en zij die werken op een dienst met een niet-reanimatie beleid hebben een hoger percentage patiënten met een niet-reanimatie status. Een niet-reanimatie beslissing blijkt pas laat in het ziekteverloop van de patiënt toegekend te worden, hoofdzakelijk omwille van redenen gerelateerd aan de conditie van de patiënt. Leeftijd wordt nooit als alleenstaande reden gerapporteerd voor het toekennen van een niet-reanimatie status. Tachtig procent van de niet-reanimatie beslissingen wordt genomen na overleg met anderen, meestal verpleegkundigen en de naasten van de patiënt. De patiënt zelf en diens huisarts zijn zelden betrokken. Niet-reanimatie beslissingen worden vaker toegekend tijdens de dagelijkse zaalronde van de geriater dan tijdens de wekelijkse multidisciplinaire teamvergadering. In 93.7% van de gevallen wordt de beslissing door de geriater gedocumenteerd in het patiëntendossier.

4. Worden verpleegkundigen betrokken bij het nemen van niet-reanimatie beslissingen en hoe vaak handelen zij volgens de voorafgaande (niet-)reanimatie status van de patiënt? (Hoofdstuk 4 en 5)

Verpleegkundigen zijn vaak, maar niet altijd betrokken in het beslissingsproces voorafgaand aan het toekennen van een niet-reanimatie status aan patiënten opgenomen op acute diensten voor geriatrie; ze werden voor drie kwart van de beslissingen voorafgaand geconsulteerd. Wanneer er een niet-reanimatie beslissing werd genomen, wordt dit wel steeds gecommuniceerd naar het verpleegkundig team, meestal in geschreven vorm.

Wanneer patiënten met een niet-reanimatie status een reële hartstilstand hebben, wordt bijna nooit CPR gestart. Wanneer patiënten met een reële hartstilstand voorafgaand geen niet-reanimatie status hebben gekregen, zullen verpleegkundigen toch bij een aantal patiënten geen CPR opstarten.

III. Voorafgaande zorgplanning omtrent diverse levenseindebeslissingen in rust- en verzorgingstehuizen

5. Hoeveel runt- en verzorgingstehuizen hebben een beleid met betrekking tot voorafgaande zorgplanning omtrent diverse levenseindebeslissingen, wanneer werd dit geïmplementeerd, en wat is de algemene inhoud? (Hoofdstuk 6)

In 2006 bleken 95.1% van de rust- en verzorgingstehuizen in Vlaanderen te beschikken over een beleid over voorafgaande zorgplanning omtrent diverse levenseindebeslissingen. Implementatie van een dergelijk beleid startte geleidelijk aan sinds 1989, maar nam sterk toe vanaf 2000. Meestal omvat dit beleid patiëntspecifieke documenten, maar deze gaan in vele gevallen samen met institutionele richtlijnen. Beide types van beleidsdocumenten behandelen vaak meerdere vormen van levenseindebeslissingen. Voorafgaande beslissingen om bewoners niet meer te hospitaliseren zijn het meest frequent, nauw gevolgd door voorafgaande beslissingen om de bewoner niet meer te reanimeren in geval van een reële hartstilstand en het niet opstarten of stopzetten van andere behandelingen zoals het kunstmatig toedienen van vocht en/of voeding en het toedienen van antibiotica. Bijna de helft van de rust- en verzorgingstehuizen vermelden het intensiveren van pijn- en symptoombestrijding met een mogelijk levensverkortend effect in het beleidsdocumenten. Voorafgaande beslissingen omtrent terminale sedatie en euthanasie worden minder vaak vermeld en in sommige rust- en verzorgingstehuizen wordt euthanasie uitdrukkelijk verboden, hoewel dit een gelegaliseerde handeling is sinds 2002. Minder dan één derde van de rust- en verzorgingstehuizen heeft het benoemen van een vertegenwoordiger door de bewoner opgenomen in zijn beleidsdocumenten.

6. Voor hoeveel bewoners van rust- en verzorgingstehuizen waren op het moment van overlijden voorafgaande levenseindebeslissingen gedocumenteerd en hoeveel hadden een vertegenwoordiger benoemd, en bestaat er een verband met demografische, klinische en/of zorgkarakteristieken aan het levenseinde van deze bewoners? (Hoofdstuk 7)

Op het moment van overlijden zijn meer dan 80% van de bewoners van rust- en verzorgingstehuizen 80 jaar of ouder, en één derde is zelfs 90 jaar of ouder. Bij een meerderheid werd dementie gediagnosticeerd (65.2%) en 76.4% is sterk afhankelijk van derden. Het overlijden van vier vijfden van de bewoners was niet geheel onverwacht. Tijdens de laatste drie levensmaanden werden 43.1% van de overleden bewoners ten minste één maal getransfereerd naar het ziekenhuis, en één vijfde stierf in het ziekenhuis. Twee derden werd palliatieve zorg verleend aan het levenseinde.

Bij de helft van de overleden bewoners werd een voorafgaand zorgplan gedocumenteerd (51.8%), meestal voorafgaande instructies van de arts (50.6%) en minder vaak voorafgaande wilsbeschikkingen gedocumenteerd door de bewoner (5.0%). Voorafgaande zorgplannen betreffen meestal beslissingen de bewoner niet meer te hospitaliseren en/of beslissingen om potentieel levensverlengende behandelingen niet op te starten of stop te zetten. Euthanasie en terminale sedatie komen zelden voor in voorafgaande zorgplannen. Palliatieve zorgverlening bleek positief gerelateerd te zijn aan het hebben van voorafgaande zorgplannen (voorafgaande instructies van de arts en wilsbeschikkingen gedocumenteerd door de bewoner). Overlijden in het rust- en verzorgingstehuis, verwachte overlijdens en een diagnose van dementie zijn gerelateerd aan het hebben van voorafgaande instructies van de arts. Bewoners met dementie hebben minder vaak voorafgaande wilsbeschikkingen gedocumenteerd.

Minder dan één op tien bewoners heeft op het moment van overlijden een vertegenwoordiger benoemd. Dit gebeurde vaker door bewoners met kanker dan door anderen.

Discussie/Aanbevelingen

Hoofdstuk 8 van deze doctoraatsthesis behandelt eerst de sterktes en zwaktes van de diversie studies die werden uitgevoerd voor het beantwoorden van de onderzoeksvragen. Nadien worden de resultaten van de studies bediscussieerd en aanbevelingen geformuleerd naar beleid, praktijk en verder onderzoek. Hieronder volgen enkele belangrijke discussiepunten en aanbevelingen.

Medische levenseindebeslissingen en terminale sedatie kort voor het overlijden van ouderen

Medische levenseindebeslissingen die kort voor het overlijden worden genomen en een mogelijk of zeker levensverkortend effect hebben, zijn een gebruikelijke medische praktijk geworden bij niet-plots overleden 80-plussers. Toch blijken artsen op dit vlak meer terughoudend te zijn wanneer de patiënt een hogere leeftijd heeft, vooral voor wat betreft het gebruik van letale middelen. Het feit dat euthanasie helemaal niet werd gerapporteerd voor de oudste leeftijdsgroep zou ofwel kunnen betekenen dat ouderen minder snel geneigd zijn tot het uiten van een euthanasievraag ten opzichte van jongere patiënten, ofwel zou dit het gevolg kunnen zijn van het door professionele zorgverleners niet opnemen of begrijpen van een door de oudere gestelde euthanasievraag. Communicatie aan het levenseinde van door ouderen is immers vaak zeer complex geworden toenemende wilsonbekwaamheid door dementie of andere aandoeningen. Dergelijke communicatieproblemen kunnen bijvoorbeeld ook een oorzaak zijn van het minder frequent voorkomen van intensiveren van pijn- en symptoombestrijding met een mogelijk levensverkortend effect en het toepassen van terminale sedatie bij ouderen; pijn en andere symptomen blijken bij ouderen eerder onderschat te worden door een verstoorde communicatie en een gebrek aan diagnostische instrumenten in dergelijke gevallen.

Participatie van ouderen in medische besluitvorming aan het levenseinde

De betrokkenheid van ouderen bij het nemen van medische levenseindebeslissingen kort voor het overlijden blijkt niet optimaal te zijn. Wanneer het gaat over wilsonbekwame patiënten betreft het een gelijkaardig niveau als bij jongere patiënten, maar wanneer het gaat over wilsbekwame patiënten scoren ouderen opmerkelijk lager. Artsen zijn in deze gevallen vaak ook niet op de hoogte van de wensen en voorkeuren van de patiënt met betrekking tot diens levenseindezorg. Het in de medische praktijk integreren van voorafgaande zorgplanning omtrent het levenseinde zou de participatie van patiënten in besluitvorming omtrent het levenseinde kunnen bevorderen. Het is een proces dat reeds kan starten lang voor er sprake is van dementie of andere ernstige aandoeningen en ertoe kan leiden dat de zorg aan het levenseinde van een patiënt zo veel als mogelijk in overeenstemming is met diens waarden en voorkeuren waardoor het kan beschouwd worden als goede medische praktijkvoering.

Gezien de nog resterende levensverwachting afneemt met de leeftijd en de kans op gecompliceerde communicatie aan het levenseinde dan toeneemt, stijgt het nut van voorafgaande zorgplanning omtrent levenseindebeslissingen met de leeftijd. Voor ouderen binnen de geïnstitutionaliseerde zorg kan voorafgaande zorgplanning zelfs als nog belangrijker worden beschouwd, gezien velen van hen binnen deze zorgsetting komen te overlijden nadat ze wilsonbekwaam zijn geworden.

Instellingsbeleid met betrekking tot voorafgaande zorgplanning in de geïnstitutionaliseerde zorg voor ouderen

Het nut van voorafgaande zorgplanning omtrent diverse levenseindebeslissingen lijkt momenteel erkend te worden binnen de geïnstitutionaliseerde zorg voor ouderen. Bijna alle acute diensten voor geriatrie hebben een beleid geïmplementeerd met betrekking tot voorafgaande niet-reanimatie beslissingen. Daarnaast blijken bijna alle rust- en verzorgingstehuizen een beleid te hebben geïmplementeerd met betrekking tot voorafgaande beslissingen betreffende het niet hospitaliseren van bewoners, het niet reanimeren en het niet opstarten of stopzetten van potentieel levensverlengende behandelingen. Voorafgaande beslissingen omtrent euthanasie en terminale sedatie komen opmerkelijk minder vaak voor in het instellingsbeleid.

Instellingen in Vlaanderen begonnen vanaf de tweede helft van de jaren 80 geleidelijk aan met de ontwikkeling en implementatie van hun beleid (eerder laat in vergelijking met andere landen zoals de VS) en dit nam sterk toe vanaf 2000 à 2001. Deze toename is waarschijnlijk mede te verklaren door het publieke debat over de legalisatie van euthanasie dat toen gaande was, alsook over twee andere wetten die, net als de wet betreffende euthanasie, in 2002 van kracht gingen, namelijk de wet op de patiëntenrechten en de wet betreffende palliatieve zorg. Geen van deze wetten gaf instellingen aan hoe zij deze dienden om te zetten in de praktijk, maar het is plausibel dat ze toch een belangrijke invloed hebben gehad op het beleid dat instellingen individueel gingen ontwikkelen.

Zowel de acute diensten voor geriatrie als de rust- en verzorgingstehuizen ontwikkelden institutionele richtlijnen (als leidraad voor de professionele zorgverleners) als patiëntspecifieke documenten (om voorafgaande beslissingen voor een specifieke patiënt te documenteren en ongewilde interventies aan het levenseinde en misverstanden te vermijden), maar de individuele ontwikkeling ervan heeft geleid tot een grote diversiteit qua inhoud en vorm van deze beleidsdocumenten. Toch blijken al deze documenten niet enkel te zijn ontwikkeld vanuit een professionele nood om besluitvorming aan het levenseinde te stroomlijnen, maar ze dienen mede als een soort van defensieve strategie vanuit de instelling binnen een toenemend wettelijk kader. Hierdoor ligt de focus in deze documenten nog te weinig op het bevorderen van communicatie omtrent levenseindezorg tussen de patiënt, diens naasten en de diverse professionele zorgverleners.

Voorafgaande zorgplanning in de praktijk binnen de geïnstitutionaliseerde zorg voor ouderen

In de praktijk blijkt dat schriftelijke, voorafgaande zorgplannen nog niet zo vaak voorkomen in de geïnstitutionaliseerde zorg voor ouderen, zowel in de rust- en verzorgingstehuizen als in acute diensten voor geriatrie, en dat wanneer ze toch bestaan, ze meestal pas laat in het ziekteverloop van de patiënt werden gedocumenteerd. Vooral voorafgaande wilsbeschikkingen gedocumenteerd door de patiënt en het door de patiënt officieel benoemen van een vertegenwoordiger worden weinig teruggevonden. Schriftelijke, voorafgaande instructies van de arts komen vaker voor, maar het blijft onzeker of deze daadwerkelijk werden overlegd met de patiënt zelf, die in het algemeen nog te weinig betrokken blijkt te zijn bij de besluitvorming omtrent het levenseinde. Wanneer overleg met de patiënt niet meer mogelijk is, dienen dergelijke voorafgaande instructies van de arts wel overlegd te zijn met diens vertegenwoordiger of naasten, zodat zij meer inzicht kunnen bieden in de wensen en voorkeuren van de patiënt. Wanneer ook dit onmogelijk zou zijn, dient, volgens de wet betreffende de patiëntenrechten, de arts te beslissen in het belang van de patiënt. Multidisciplinair overleg kan hierbij een ondersteuning bieden, maar ook in andere gevallen is overleg met de huisarts van de patiënt en verpleegkundigen niet onbelangrijk. De huisarts heeft vaak een lange vertrouwensrelatie opgebouwd met de patiënt en kan op deze manier op de hoogte zijn van diens wensen en voorkeuren met betrekking tot levenseindebeslissingen, zonder dat deze daadwerkelijk werden gedocumenteerd. Verpleegkundigen die instaan voor de dagelijkse zorg voor geïnstitutionaliseerde patiënten vervullen ook een belangrijke rol. Ook zij kunnen op deze manier een goede relatie hebben opgebouwd met de patiënt en kunnen een brugfunctie vervullen tussen patiënt en arts.

Momenteel bestaat er discussie over de outcome van voorafgaande zorgplanning, meer specifiek over het nut van voorafgaande wilsbeschikkingen gedocumenteerd door de patiënt. Men stelt in vraag of de zorg verleend aan het levenseinde daadwerkelijk overeenstemt met de voorafgaand gedocumenteerde wensen van de patiënt en of dit dan ook bijdraagt aan een betere kwaliteit van leven en zorg aan het levenseinde. Voorstanders argumenteren dat voorafgaande wilsbeschikkingen net de voorkeuren van de patiënt weergeven en op die manier betere garanties kunnen bieden voor een hogere kwaliteit aan het levenseinde. Ook artsen zijn in het algemeen voorstanders, gezien wilsbeschikkingen van de patiënt een voor hen tastbaar bewijs zijn van de voorkeuren van de patiënt omtrent diens levenseindezorg en een houvast vormen bij het nemen van beslissingen in vaak kritische situaties. Tegenstanders daarentegen beweren dat het voor mensen onmogelijk is voorafgaand te oordelen over mogelijke, toekomstige situaties en dat ze moeilijk kunnen inschatten wat hun voorkeur in een dergelijke situatie zou zijn. Vertegenwoordigers zouden volgens hen in een reële situatie ook moeilijk de voorkeuren van de patiënt kunnen inschatten. De voorliggende doctoraatsthesis had echter niet tot doel een uitspraak te doen over de impact van voorafgaande zorgplanning op de daadwerkelijk verleende zorg aan het levenseinde en de kwaliteit van leven en zorg aan het levenseinde, maar toont wel aan dat bewoners van rusten verzorgingstehuizen met voorafgaande instructies van de arts om niet meer te worden gehospitaliseerd, daadwerkelijk minder transfers naar het ziekenhuis ondergaan gedurende de laatste drie levensmaanden en ook vaker in het rust- en verzorgingstehuis sterven. Dit kan een indicatie zijn voor het verkrijgen van zorg aan het levenseinde, consistent met de wensen van de patiënt, hoewel niet met zekerheid kan gesteld worden dat een dergelijke voorafgaande instructie van de arts volledig overeenstemt met de voorkeur van de patiënt.

Aanbevelingen voor beleid, praktijk en verder onderzoek

Diverse aanbevelingen werden voorgesteld, waaronder:

- Voortdurend dienen initiatieven te worden genomen om de kennis en communicatievaardigheden van artsen en andere professionele zorgverstrekkers omtrent levenseindezorg te verbeteren. Dit dient zowel te gebeuren tijdens de basisopleiding van zorgverleners, als tijdens aanvullende trainingen, en behoort tot de verantwoordelijkheden van zowel de overheid, gezondheidszorginstellingen als beroepsverenigingen. Zorgverleners in contact met oudere patiënten dienen attent te worden gemaakt voor het belang van een vroegtijdige verkenning van de voorkeuren van hun patiënten met betrekking tot levenseindezorg en de vaak kwetsbare positie van ouderen in het beslissingsproces voorafgaand aan levenseindebeslissingen. Huisartsen hebben een belangrijke rol bij het stimuleren van voorafgaande zorgplanning gezien zij vaak een langdurige vertrouwensrelatie hebben opgebouwd met de patiënt, onafhankelijk van de setting waarin deze verblijft (thuis, rusthuis, ziekenhuis).

- De bevolking dient algemeen meer vertrouwd te worden gemaakt met diverse onderwerpen betreffende het levenseinde, en meer specifiek met betrekking tot voorafgaande zorgplanning en het schrijven van voorafgaande wilsbeschikkingen, bijvoorbeeld door middel van gezondheidsvoorlichting programma's.

- Palliatieve zorgverlening binnen de geïnstitutionaliseerde zorg voor ouderen dient te worden geoptimaliseerd. Dit kan enerzijds door middel van een betere integratie van palliatieve zorg in de opleiding van zorgverleners en anderzijds door het ter beschikking stellen van meer financiële middelen. Complementair aan de eigen mogelijkheden van de instelling, kunnen ook externe, gespecialiseerde palliatieve zorg initiatieven worden ingeschakeld.

- De ontwikkeling van duidelijke, gestandaardiseerde beleidsdocumenten kunnen voorafgaande zorgplanning omtrent het levenseinde en de communicatie daarover bevorderen. Diverse disciplines van zorgverleners en patiënten(organisaties) dienen bij de ontwikkeling ervan betrokken te worden en dienen ook voldoende geïnformeerd te worden bij implementatie.

- Naast inspanningen tot het bevorderen van voorafgaande wilsbeschikkingen van patiënten, dient ook het benoemen van een vertegenwoordiger aangemoedigd te worden. In moeilijk vooraf in te schatten situaties kan deze persoon soms meer inzicht geven over wat de voorkeur van de patiënt zou zijn geweest.

- Om de betrokkenheid van patiënten in medische besluitvorming omtrent het levenseinde te verhogen, dienen artsen, maar ook andere professionele zorgverleners zoals verpleegkundigen, zo vroeg als mogelijk te overleggen met patiënten over diens voorkeuren met betrekking tot levenseindezorg. Zeker binnen de geïnstitutionaliseerde zorg voor ouderen zou dit bij opname of kort daarna aan bod kunnen komen. Bij voorkeur zou het zelfs een continu proces moeten zijn, dat reeds lang voor institutionalisering of fysieke/mentale achteruitgang van de patiënt van start kan gaan, maar waarbij op elk moment kan worden teruggekomen op genomen beslissingen. Echter, wanneer het te belastend zou zijn voor de patiënt of wanneer deze dit onderwerp liever negeert, dient dit gerespecteerd te worden. Desgevallend kunnen wel de vertegenwoordiger van de patiënt of naasten geraadpleegd worden. In laatste instantie beslist de arts in het belang van de patiënt. In alle gevallen is multidisciplinair overleg aangewezen.

- Verpleegkundigen dienen in de dagelijkse zorg voor ouderen steeds opmerkzaam te zijn voor minder formele uitingen van patiënten over hun voorkeuren met betrekking tot het levenseinde. Gezien de vertrouwensrelatie die zij vaak hebben opgebouwd met oudere patiënten binnen de geïnstitutionaliseerde zorg, kunnen zij hierbij een brugfunctie vervullen tussen patiënt en arts.

- Verder onderzoek, gelijktijdig uitgevoerd in diverse zorgsettings voor ouderen, is nodig opdat betrouwbare vergelijkingen kunnen worden gemaakt met betrekking tot diverse aspecten van zorg aan het levenseinde. Prospectief en meer kwalitatief gericht onderzoek kan resulteren in een verdere uitdieping van de bevindingen van deze doctoraatsthesis, vooral met betrekking tot het verloop van de eigenlijke beslissingsprocessen en factoren die een goede communicatie kunnen bevorderen. Daarnaast dient ook verder onderzocht te worden welke de invloed is van beleid omtrent voorafgaande zorgplanning op de eigenlijke praktijkvoering, en of deze laatste in overeenstemming is met de wensen van de patiënt en leidt tot een betere kwaliteit van leven en zorg aan het levenseinde.

CURRICULUM VITAE

Cindy De Gendt was born on October 8, 1977 in Beveren-Waas, Belgium. She studied Accountancy-Informatics in high school (1995), Social Work at the Sociale Hogeschool KVMW Gent (1998) and finished her Master in Social Health Sciences at the Vrije Universiteit Brussel in 2002. In 2003, Cindy started working as a junior researcher at the UGent-VUB End-of-Life Care Research Group (Vrije Universiteit Brussel), where she conducted her PhD research. This was funded by different research grants from the Research Council of the Vrije Universiteit Brussel and with financial support from the Geriatric Departments of the Vrije Universiteit Brussel and the Universiteit Gent. Since August 2008 Cindy is working at the Belgian Cancer Registry as a senior researcher.