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# **CARE IN THE LAST MONTHS OF LIFE**

End-of-Life Care registration in the Netherlands

by a Network of General Practitioners

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The EMGO<sup>+</sup> Institute collaborates nationally and internationally with several other partners, is a founding partner of the Netherlands School of Primary Care Research (CaRe), and is acknowledged by the Royal Netherlands Academy of Arts and Sciences (KNAW) as one of the first academic research institutes in the Netherlands to measure the societal impact of research.

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**VRIJE UNIVERSITEIT**

**CARE IN THE LAST MONTHS OF LIFE**

End-of-Life Care registration in the Netherlands

by a Network of General Practitioners

**ACADEMISCH PROEFSCHRIFT**

ter verkrijging van de graad Doctor aan  
de Vrije Universiteit Amsterdam,  
op gezag van de rector magnificus  
prof.dr. L.M. Bouter,  
in het openbaar te verdedigen  
ten overstaan van de promotiecommissie  
van de faculteit der Geneeskunde  
op woensdag 20 april 2011 om 11.45 uur  
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De Boelelaan 1105

door

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geboren te Londen, Engeland

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dr. M.A. Echteld

*- How people die always remains  
in the memory of those who live on -  
by Dame Cicely Saunders*

### **How the Leaves Came Down**

by *Susan Coolidge*

"I'll tell you how the leaves came down"  
The great tree to his children said,  
"You're getting sleepy, Yellow and Brown,  
Yes, very sleepy, little Red.  
It is quite time to go to bed."

"Ah!" begged each silly, pouting leaf,  
"Let us a little longer stay;  
Dear Father Tree, behold our grief;  
'Tis such a very pleasant day  
We do not want to go away."

So, for just one more merry day  
To the great tree the leaflets clung,  
Frolicked and danced, and had their way,  
Upon the autumn breezes swung,  
Whispering all their sports among,--

"Perhaps the great tree will forget,  
And let us stay until the spring,  
If we all beg, and coax, and fret."  
But the great tree did no such thing;  
He smiled to hear their whispering.

"Come, children, come to bed," he cried;  
And ere the leaves could urge their prayer,  
He shook his head, afar and wide,  
Fluttering and rustling everywhere,  
And down came more leaflets swimming through the air.

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## Chapters 2–7 are based on the following manuscripts:

- Chapter 2 Abarshi E, Echteld M, Van den Block L, Donker G, Deliens L, Onwuteaka-Philipsen B. **Recognising patients who will die in the near future.** BJGP [in press].
- Chapter 3 Abarshi E, Echteld M, Donker G, Van den Block L, Onwuteaka-Philipsen B, Deliens L. **Discussing end-of-life issues in the last months of life: a nationwide study among General Practitioners.** J Palliat Med 2011 Jan 21 [Epub ahead of print].
- Chapter 4 Abarshi E, Onwuteaka-Philipsen B, Donker G, Echteld M, Van den Block L, Deliens L. **General practitioner awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands.** J Pain Symptom Manage 2009 Oct;38(4):568–77.
- Chapter 5 Abarshi E, Echteld M, Van den Block L, Donker G, Deliens L, Onwuteaka-Philipsen B. **Transitions between care settings at the end of life in the Netherlands: results from a nationwide study.** Palliat Med 2010 Mar;24(2):166–74.
- Chapter 6 Abarshi E, Echteld M, Van den Block L, Donker G, Bossuyt N, Meeussen K, Bilsen J, Onwuteaka-Philipsen B, Deliens L. **Use of palliative care services and GP visits at the end of life in the Netherlands and Belgium.** J Pain Symptom Manage Sept 14, 2010.
- Chapter 7 Abarshi E, Echteld M, Van den Block L, Donker G, Deliens L, Onwuteaka-Philipsen B. **The oldest old and end-of-life GP care in the Dutch community: A nationwide study.** Age Ageing doi: 10.1093/ageing/afq097 Sept 4, 2010.

# Chapter 1

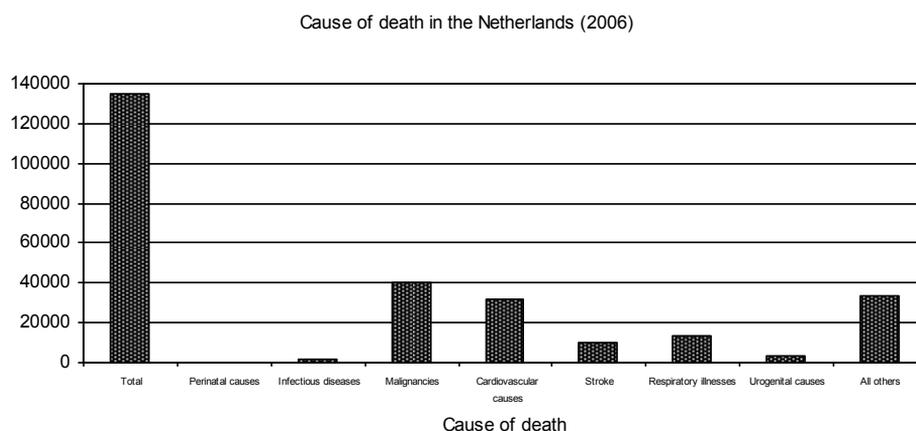
## Introduction

## 1.1 PATIENT CARE IN THE LAST MONTHS OF LIFE

Recent medical advances have altered the age and pattern of dying in many parts of the world (1), such that several people suffer as a result of the consequences of chronic progressive illnesses in many parts of the world. These deaths occur often later than before, making palliative care an increasingly important public health issue today (1–3). Towards the end of life, affected patients, together with their loved ones are usually confronted with challenges which accompany non-sudden dying, such as acceptance, dignity, peacefulness... that is, besides the actual physical complaints (1). In many of these instances, the general practitioners (GPs) manage the patients through the last months of life, ensuring continuity of care within and between settings and/or disciplines in the last months of life (5–13), except where such care is handed-over completely to other carers or specialists (14). Regardless of age, disease, care setting, or treatment focus, the overall aim of palliative care is to improve the quality of life for these patients with life threatening illnesses, and their families, by supporting all three dimensions of life (physical, psychological, spiritual), and help the patients live the very best life possible until death (4). However, the number and diversity of patients that can benefit potentially from planned palliative care (15;16) remains unknown. To the best of our knowledge, there has been no nationwide research conducted in a general sense, to estimate the extent to which this pattern might be a problem (17). In the Netherlands, previous nationwide studies on end-of-life care had been largely limited, in terms of age (18;19), symptoms (20;21), diagnoses (22;23), care settings or place of death (24;25), and the benefits of engaging in a general population-based end-of-life care study have not been fully explored before now (17). That is, a nationwide study which examines societal patterns or the summation of specified conditions on a population- rather than an individual-level, i.e. the forest rather than the trees (26). And despite the fact that prospective studies effectively cover the period of illness just before death, they are done less frequently due to ethical reasons, high patient drop-out rates due to illness, and unexpected or sudden deaths (17). In this study therefore, we requested GPs from an existing surveillance network, the Sentinel Network of GPs in the Netherlands, to register salient aspects of care which recently deceased patients had received in the last three months of their lives. This is the first time this method of data collection is used in this context in the Netherlands, following its successful application in Belgium by Van den Block et al. (5). In the following chapters, we shall be considering end-of-life experiences in a selection of patients whose deaths were non-sudden and expected, as shaped by differences in characteristics (27), wishes /preferences (1), and socio-demographic factors (28), and care provided.

## 1.2 BACKGROUND OF STUDY

Approximately two out of three deaths are non-sudden and expected, occurring as a result of chronic progressive debilitating illnesses (29;30). In 2006, cancers and cardiorespiratory diseases together accounted for more than half of the Dutch national mortality (Fig 1). Because these morbidities predispose to frequent use of health and social services, they influence transitions between a patient's home and less regular settings in the last months of life (11;31). Towards the end of a terminal illness, the place, type and timing of care are important parameters of quality of the dying process (32–35). According to research, the home is the setting most people prefer to die in (27), but this is not always practical or feasible (10;11;27). The word 'home' here refers to a familiar, regular and non-specialized setting (36). In the Netherlands, everyone at home in principle has (or is registered with) one personal GP, who treats most complaints either in the practice or at the patient's home, but refers a number of cases to other health professionals or secondary carers (36).

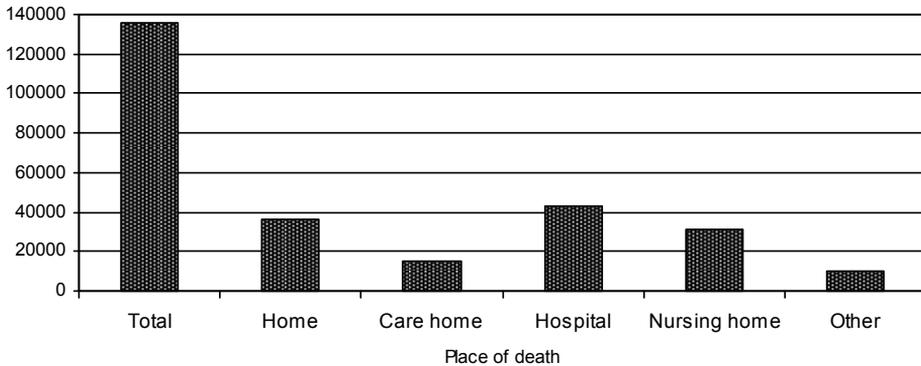


**Figure1:** Cause of death in the Netherlands from 2006 national mortality rates  
(Source: Centraal bureau voor de Statistiek)

### Dutch end-of-life care settings and GP care

The Dutch healthcare system is organised with the GP as a strict gate-keeper, at its centre (36). This GP manages patient care at home and in care homes, the place of death for about one in every three deaths (Fig 2). Although GPs have access to patient records, they have little or no control over the management of care when these patients are institutionalised. In the course of this study, we shall be exploring patient care in the last three months of life, based on GP involvement per time, at home or care home, in hospitals, specialised nursing homes, and hospices (21).

Place of death in the Netherlands (2006)



**Figure 2:** Place of death in the Netherlands from 2006 national mortality rates  
(Source: Centraal bureau voor de Statistiek)

### Residential (care) home versus Dutch nursing home

In the Netherlands, a residential but care home situation is created for older people who can no longer live at home due to common age-related reasons. Such persons usually are re-housed alone or alongside their spouses, personal belongings, including furniture (if so desired), into these long-term 'care' homes, which provide basic hands-on care and the same GP is retained (18;24). On the other hand, Dutch nursing homes accommodate persons with more psycho-geriatric needs (14;22), and are managed by physicians who specialise in elderly care (14). Thus, while GPs continue to manage patient care in the residential care homes, they hand-over such care completely once a patient is transferred to a nursing home. The Netherlands is the only country in Europe that offers this unique nursing home specialization (14;36).

### The Sentinel Network of General Practitioners

The Sentinel Network is an epidemiological surveillance system, consisting of 65–70 GPs (varying somewhat over the four-year registration period) from 45 practices (38) distributed over the country. The GPs are representative by age, gender, geographic distribution and population density, of all practising GPs in the Netherlands (Fig. 3). The Network covers approximately one percent of the Dutch population (37), and is coordinated by NIVEL (Netherlands Institute for Health Services Research). This Network has been involved in several national and international projects since 1977, including the European Influenza Surveillance Scheme currently run by the European Centre for Disease Control (38). Beginning in January 2005, the sentinel GPs participated in the SENTI-MELC study (monitoring end-of-life care via a sentinel network of GPs) in the Netherlands. The findings which are reported in this dissertation specifically cover the period between 2005–2008.



**Figure 3:** Distribution of the sentinel GP practices in the Netherlands  
Source: Continuous morbidity registration at Dutch sentinel stations, 2007 (38)

### **Representativeness of data**

We examined the representativeness of the data generated by the Network of GPs; comparing gender and age per setting with corresponding national data for the year 2006 (39). We chose to compare our data with national mortality rates because the latter are more complete datasets (unlike attempting to select non-sudden deaths, for instance). There were no significant differences between our sample and the deaths at home, care home and hospital in the Netherlands. Expectedly though, the nursing home deaths were not comparable with the national figures, because of the presence of nursing home physicians. We used this as a basis for excluding nursing home deaths from the study, except when otherwise mentioned. Some more details on data representativeness can be found in Chapter 4.

Also, we considered performing multi-level analyses, particularly at the level of “GP practice” (some were solo /duo/ group). However, this was not possible because the observations per ‘level’ were few (38 practices supplied <20 registration forms), there were large differences in the number of observations per level, and multiple GPs filled registration forms for unknown or unnumbered practices. Hence we will not comment on differences in patient care per GP practice in this dissertation.

## Annual end-of-life care registration

The SENTI-MELC study was designed primarily to monitor end-of-life patient care on a population-level, through sentinel GPs. As mentioned earlier, this method was first used for end-of-life research in Belgium (40;41), and the research protocol has been published (5). As was done in Belgium, we tested most questions, requested that the sentinel GPs registered patient, illness and care-related characteristics, using a one-sided (2005/6) and later a two-sided A4 registration form (2007, 2008). At the onset of each registration exercise, participating GPs were given detailed instructions including guidelines, definitions, and explanatory examples. Overall, the exercise was straightforward and cost-efficient. The GPs were reliable as informants based on the premise that they had cared for many of the patients in question, in and out of the illness that eventually led to death. The ideal of course, would have been to collect some of the information from the patients themselves.

## Nationwide registration of end-of-life care

In compiling topics to include in the registration forms, we considered some known characteristics of good or “quality” care for patients whose deaths are non-sudden or are somewhat expected. This was because palliative care, unlike other clinical fields, yet lacks well-defined indicators for monitoring quality on a population-level (33). Then we generated a list of important themes applicable in these instances (32–35), and framed questions based on them (read individual chapters for details).

**Table 1:** Main themes that were explored in the SENTI-MELC registration forms

	<b>Main themes</b>	<b>Year of registration</b>
1	Communication about diagnoses, prognoses, and care-plans	2005–2006, 2008
2	Continuity of care between care settings	2005–2006
3	Place of care, place of death, care alignment with patient wishes	2005–2006
4	Frequency of GP contact (home visits) at the end of life	2007
5	Use of palliative care services	2005–2006, 2007, 2008

## The Dutch SENTI-MELC registration form

We explored the themes above in different batches over the four-year registration period, so that the GPs were not overloaded with research work - there were 14 other registrations running alongside this one in the Network at the time (38). In advance, NIVEL pegged the length of registration forms to a maximum of one A4 size. We asked GPs to register patient characteristics, such as, age at death, gender, socio-economic measures (education or income level, post-code); cause of death as registered in the death certificate; places of care, in the order of use in the last three months of life; main dimensions of care received in the last months of life

(physical, psychosocial, spiritual); the main treatment goal in the last months of life (curative, life prolonging, palliative or comfort); the frequency of GP contact or total number of home visits in the last months of life; how often palliative care services were used in the last months of life; the preferred place of death, and few other specified wishes; GP awareness of patient's preferred place of death and source of awareness (patient, relative, care provider); the actual place of death (home, care home, nursing home, hospice or palliative care unit). In general, we used internationally-accepted nomenclature and disease classifications (ICD-10), and questions from well-known, validated instruments (42–44), e.g. the Memorial Symptom Assessment Scale (MSAS), and Eastern Cooperative Oncology Group performance status (ECOG).

### **Concepts used in the SENTI-MELC registration form**

We explored care in different time intervals (last 2–3 months, last 2–4 weeks, last seven days) in the last three months of life, for patients who had died non-suddenly and expectedly from chronic progressive or life-limiting illnesses, i.e. cancer, organ failure. *Palliative care* referred to patient-centred attention to physical, psychosocial and spiritual challenges, and was geared towards optimizing the quality of life for patients and their families (1;4). We asked the GPs for the *main aim of care* and the *treatment goal*, assuming they had managed each patient using a formal or informal care plan (1). The term *specialised palliative care services* was used at the onset of the study, to refer to the level of palliative care provided by a multidisciplinary team of palliative care professionals (45). In the Netherlands, this would include five broad categories of well-known palliative care services that were readily accessible to patients: (i.) a GP with palliative care training operating in a team, (ii.) a palliative care consultant (trained nurse or physician) operating in a team, (iii.) hospital-based palliative care units, (iv.) specialist nursing-home-based palliative care units, or (v.) a hospice day care facility. However, in the course of the registration we dropped the tag *specialised* because its application and interpretation in the international community was oftentimes varied (45). The other concepts used are described in more detail in the chapters that follow.

### **The Netherlands versus the rest**

International comparisons in research are interesting, and such comparisons could be powerful tools for developing national targets and policies, providing valuable lessons and helping countries learn from each other. Given the distinctive features of the Dutch healthcare system i.e. the strict gate-keeping GP function and presence of nursing home physicians, we sought to compare some end-of-life care findings with those of another country. Comparison with Belgium was possible because a

similar study was on-going at the time place (5). In addition to proximity, the geographical composition, culture, and income levels of the Belgian people are all quite comparable with those of the Dutch. Therefore in 2007, a similar registration was undertaken in the two countries, using the same questionnaire and methodology to simultaneously explore salient aspects of patient care in the last months of life. Detailed findings on these are reported in Chapter 6.

### 1.3 RESEARCH QUESTIONS, RATIONALE & SAMPLE SELECTION

The central aim of this dissertation is to describe care in the last months of life, of patients who had died non-suddenly and expectedly, following chronic progressive illnesses, from a general (practice) patient population in the Netherlands.

#### 1. Research Question One

**Rationale:** Recognising patients who will die in the near future is important for planning and providing adequate end-of-life care. GPs can play a key role in this.

**Question:** At what time before death did the GPs recognise that patients were likely to die in the near future? Which patient, illness and care characteristics were related to recognising death in the near future, and how did recognising death in the near future relate with care in the very last week of life?

**Sample studied:** To answer this question, we selected from patients whose deaths had been non-sudden and expected, those who had spent most of their last year at home/care home, using the 2008 data set, because their care had been largely under the purview of a GP.

#### 2. Research Question Two

**Rationale:** Communication is a necessary tool for ensuring provision of patient-centred care for people with life threatening illnesses and their families.

**Question:** What was the incidence and timing of discussing important end-of-life issues, in three different time intervals before death (before the last month, in the last 2–4 weeks, in the last week), and which factors were associated with discussing these issues?

**Sample studied:** We selected from the 2008 data set, those patients who had spent the most part of their last year of life at home/care home, and had died non-suddenly and expectedly (same as above).

#### 3. Research Question Three

**Rationale:** To improve end-of-life care and the quality of dying, GP awareness of where patients prefer to die is important.

**Question:** How many GPs were aware of their patients' preferred place of death, what patient and care-related characteristics were associated with the GP-awareness, and what was the congruence between the preferred and actual place of death?

**Sample studied:** We combined 2005 and 2006 data sets, selected patients who had died non-suddenly and expectedly, and who had been managed by GPs in the last months.

4. Research Question Four

**Rationale:** Multiple transitions between care settings in the last months of life could jeopardise continuity of care, suggesting a low quality of end-of-life care.

**Question:** How often did care setting transitions occur in the last months of life, what was the timing of the transitions between the settings and to the place of death, and what factors were associated with the transitions?

**Sample studied:** We combined all non-sudden deaths registered in 2005–2006 so as to capture all possible transitions and care trajectories within this period.

5. Research Question Five

**Rationale:** At the end of life, personalised and specialised care is required, and the way GP visits and use of palliative care services are organised in different countries could influence the frequency of care provision. Nationwide data on such prevalence, and country comparisons are scarce.

**Question:** What was the frequency of GP home visits and use of palliative care services by patients who died at home and in care homes in the Netherlands and Belgium, and what was the relationship between these and certain patient, disease, and care characteristics?

**Sample studied:** We combined the 2007 data sets for the two countries, and selected home and care home deaths only, because these were the most comparable patient groups.

6. Research Question Six

**Rationale:** Provision of adequate care for the oldest old is increasingly crucial, given current ageing trends.

**Question:** What differences exist in care of the oldest ( $\geq 85y$ ) vs. younger (65–84y) old at the end of life within the Dutch community? Could age be an independent correlate of receiving (specialised) palliative care services, having palliative-centred treatment, and dying in a preferred place?

**Sample studied:** We combined all four data sets (2005–2008), before selecting the required age groups, so as to increase the power of this study and allow for robust analyses.

The six main questions were explored via a four-year registration of end-of-life care through a network of Sentinel GPs. Within one week of dying, the GPs registered salient details about care in the last three months (see section on registration form). We asked the GPs to identify which deaths had been ‘sudden and unexpected’ themselves, and we excluded them, since in principle, they could not have benefited from planned end-of-life care by a GP. Also, deaths of patients  $\leq 1$ y were excluded so as to rule out congenital-related deaths. The specific method and analyses applied to each question are provided in greater detail in the chapters which follow.

In all six cases, an ethical review was not required by the Dutch law because our data were collected after the patients had died. However, we maintained patient and GP anonymity throughout the registration processes.

## 1.4 DISSERTATION OUTLINE

After this introductory chapter, the six main research questions would be answered in Chapters 2–7. These chapters are based on articles that have been accepted for publication in international peer-reviewed journals specialising in palliative care, general practice, or both. The methods overlap in the chapters intentionally, such that each chapter can be read independently. Chapter 8 concludes the dissertation with a discussion of some key findings, and implications for research and the future.

An overview of Chapters 2–8:

**Chapter 2** describes the period before death during which GPs identify patients who are likely to die in the near future, which patient, illness and care-related characteristics influence the identification of death in the near future, and which factors may indicate quality of end-of-life care i.e. use of palliative care services, timing of chemotherapy use, place of death, and GP-patient communication.

**Chapter 3** examines the incidence and timing of discussing ten important end-of-life issues with respect to three time intervals before death (before the last month, in the last 2–4 weeks, in the last week), and identifies factors associated with discussing these issues with patients.

**Chapter 4** explores GP awareness of patients’ preferred POD, associated patient and care-related characteristics, and the congruence between preferred and actual POD.

**Chapter 5** describes the nature and prevalence of care setting transitions in the last three months of life, and identifies potential characteristics associated with them.

**Chapter 6** describes the frequency of GP home visits and use of palliative care services by patients who die at home and in care homes in the Netherlands and Belgium, and explores the relationship with certain patient, disease, and care characteristics.

**Chapter 7** explores differences in end-of-life care for the oldest ( $\geq 85$ y) and younger (65–84y) old in the Dutch community; testing the hypothesis that age could be an independent correlate of receiving specialised palliative care services (SPCS), having palliative-centred treatment, and dying in a preferred place.

**Chapter 8** summarizes major findings from the four-year permanent registration of deaths via the Sentinel Network general practitioners, raises methodological issues arising from the studies, and examines the implications for current practice and further end-of-life research.

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## Chapter 2

# Recognising patients who will die in the near future: A nationwide study via the Dutch Sentinel Network of GPs

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## Abstract

*Background:* Recognising patients who will die in the near future is important for adequate planning and provision of end-of-life care. GPs can play a key role in this.

*Aim:* To examine GP recognition of death in the near future (DNF) in patients whose deaths were non-sudden; exploring characteristics associated with recognising death in the near future, and following recognising death in the near future within the last week of life.

*Design of study:* One-year follow-back study via a surveillance GP network.

*Setting:* General practice

*Method:* Registration of demographic and care-related characteristics.

*Results:* Of 252 non-sudden deaths, 70% were at home /care home and 30% in hospital. GP-recognition of DNF was absent (30%), occurred prior to the last month (15%), within the last month (19%) and in the last week (34%). Logistic regression analyses showed cancer and low functional status were positively-associated with recognising DNF; cancer and discussing palliative care options were positively-associated with recognising DNF before the last week of life. Recognising DNF before patients' last week of life was associated with: fewer hospital deaths, more GP-patient contacts in the last week, more deaths in a preferred place, and more frequent GP-patient discussions about specific topics in the last seven days of life.

*Conclusion:* Recognising DNF precedes several aspects of end-of-life care. The proportion in whom DNF is never recognised is large, suggesting GPs could be assisted in this process through training / implementation of care protocols which promote timely recognition of the dying phase.

*How this fits in:* GPs can play an important role in the timely recognition of patients who will die soon, but nationwide research exploring how often they do so is scarce. Our results show that cancer is yet the main reason for recognising death in the near future, and recognising death in the near future precedes several aspects of end-of-life care. The relatively large number of patients in whom death in the near future is never recognised suggests that GPs can be assisted in this process by training or by implementing care protocols which promote timely recognition of the dying phase.

## Introduction

Due to ageing and multiple progressive illnesses, patients facing the end of life at home are growing in number (1). Regardless of disease, timely identification of these patients is vital in planning and the provision of appropriate end-of-life care (1;2). The complexity of using the dying phase in non-acute situations is such that oftentimes it is unclear when the end of life starts. Depending on the trajectory of non-sudden dying, there could be a short period of evident decline (cancer), a period of long-term limitations with intermittent crises (organ failure), or a period of steady decline (frailty). By and large, patient needs differ depending on which of these trajectories they encounter (3).

GPs can play an important role in identifying when patients will die. They are involved in home visits, treatment provision, treatment choices, and end-of-life decisions concerning place and type of care. Realising that a patient will die in the near future has important repercussions for the care given, such as the control of aggressive diagnostic interventions, acceleration of comfort care, and alignment of care with patient wishes (6). Given the increasing incidence of cancer, congestive heart failure, dementia, and other life-limiting conditions in general practice (7–9), GP-care at the end-of-life (10;11) is pivotal, particularly for patients who choose to die at home (9–11), and many do (12). Timely awareness of death in the near future (DNF) has been associated with less hospitalisations, more palliative care referrals, and better bereavement adjustment (13;14). However, not much is known about GPs recognising the final phase in patients who die at home (15), especially among those with non-malignant diseases (5). The ability to identify patients in the final phase of life, according to Andersen's behavioural model on access to medical care, is a behavioural trait or practice (10;16), that could be learned. Also, previous literature suggests certain characteristics may influence recognition of patients' DNF (17;18). However, related studies have been limited to specific settings (17;19;20), diagnoses (4;17;21), age-groups (18;21), and functional states (18;22). To the best of our knowledge, this is the first nationwide study that examines the timing of and the factors associated with recognising DNF from a general patient-population.

In this paper, we explore the timing and extent of recognising DNF and its correlates, in those who died non-suddenly or unexpectedly, using a nationwide representative surveillance network of GPs. The following 3 research questions are addressed: (1). how long before death do GPs recognise patients' DNF? (2). Which patient, illness and care-related characteristics are related to such recognition? (3). how does the recognition of DNF before the last week of life relate with care in the last week of life?

## **Method**

### **Selection and procedure**

Between 1 January and 31 December 2008, data of patients were collected in a sentinel network of general practitioners (GPs), an epidemiological surveillance system which is representative by age, gender, geographic distribution and population density of all GPs practising in the Netherlands (23;24). The network covers close to 1% of the entire registered patient population. On average, it comprises of 65–70 GPs who work singly or in groups, within 45 practices nationwide. The current study is part a series of studies beginning in 2005 as a nationwide mortality follow-back study (25;26). In 2008, we sent a structured registration form to all sentinel GPs, requesting them to provide information on all deceased patients of 1 year or older on the care they received in the last three months of life. Of the 405 registered deaths, we excluded 129 “sudden and totally unexpected” patients, six who had spent most of their last year outside home/care home, one with >70% values missing, and 17 who died in a Dutch nursing home. In the Netherlands, GPs manage primary care for those at home and in residential care facilities, but hand over care once the patient is moved to a Dutch nursing home.

### **Data collection**

The data collection process was performed by NIVEL (the Netherlands Institute of Health Services Research), using a standardised protocol (24). Completed forms were sent by each sentinel GP to NIVEL, where the forms were scrutinised closely for errors and missing data. When possible, missing data were retrieved by telephone contact. Next, the forms were sent to the researchers for data entry and analyses. Because the registration forms were not uniquely identifiable, the researchers had access to neither the patients’ nor the GPs’ identities. More details on this methodology were published elsewhere (26).

### **Research instrument**

The 21 question registration form consisted of multiple-choice and open-response questions designed to assess demographics, cause of death, and the following patient and end-of-life care characteristics: involvement of a multidisciplinary palliative care team; number of hospital and/or ICU admissions in the last 3 months of life; GP home visits and personal contact (excluding telephone calls) made in the last 3 months, last 2–4 weeks, and within the last week of life; GP home visits to family members and relatives after the bereavement; presence of dementia and/or coma in the last week of life; symptom frequency and distress in the last week of life

using the Memorial Symptom Assessment Scale (31); functional state in the last week of life using the Eastern Cooperative Oncology Group performance status (30); the GP's awareness about patient's preferred place of death and/or other specific wishes; GP-patient communication about diagnosis, prognosis, incurability of illness, and treatment options; and the timing of GP recognising DNF. The forms were tested rigorously for comprehensibility, and pilot tested among GPs so as to ensure that the participating GPs understood the items as intended (1). The main question, "how long before this patient's death did you recognise that the patient would die in the near future?", was assessed never recognised, versus recognised in the last week, the last 2–4 weeks, the last 2–3 months, and before the last 3 months.

### **Statistical analysis**

All analyses were done using SPSS 15.0 (SPSS Inc. Chicago, USA). Descriptive statistics on relevant variables were derived. In order to analyse which patient and care characteristics are related to recognition of DNF we performed univariate and multivariate logistic regression analyses. This was done looking at ever versus never having recognised DNF (Table 1), and for recognising DNF before the patient's last week of life versus in the last week of life or never (Table 2). For this last analysis we chose care characteristics that occurred before the last week of life as independent variables: admitted in hospital in the last month of life, palliative care initialisation before the last week of life and the GP discussing several end-of-life issues before the last week of life.

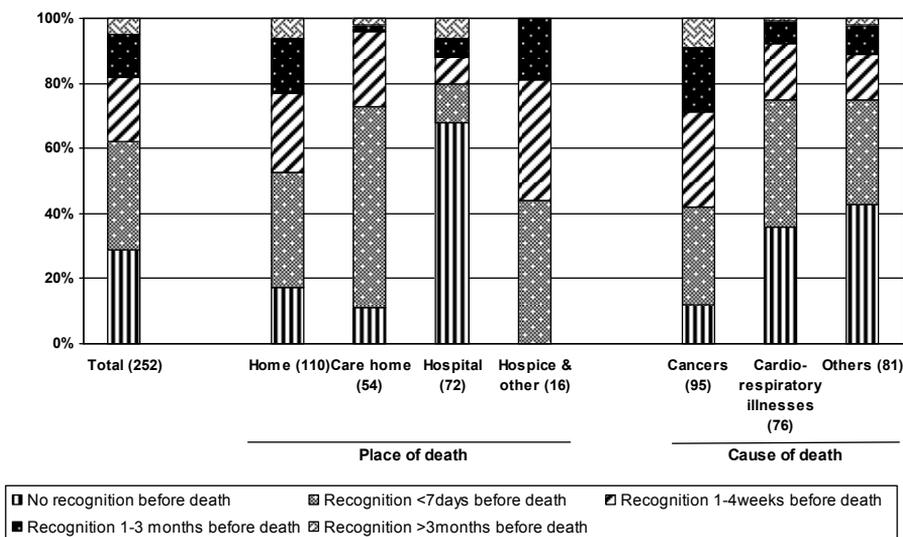
To analyse which care characteristics taking place after recognising DNF were related to this recognition, we performed logistic regression analyses with recognising DNF as the independent variable (Table 3; never vs ever recognised). Dependent variables were care characteristics that concerned the last week of life. Patients for whom DNF was recognised in their last week of life were omitted from this analysis to ensure that in this analysis the recognition took place before the care characteristic. In these analyses we controlled for the two patient characteristics that found to be related to recognising DNF: cancer and the patient's functional state (Table 1).

## **Results**

### **Incidence and timing of recognising patients with likely DNF**

We studied 252 patients who had died non-suddenly in 2008. Excluding the 16 patients who had died elsewhere, 70% of the registered deaths took place at home or in a care home, while 30% occurred in a hospital or acute setting. DNF was never

recognised by a GP in 30% cases, in less than a fifth of home and care home deaths, and in about two-thirds of hospital deaths. Death was recognised before the last month, within the last month and in the last week of life, in 15% 19% and 34% respectively. Before or within the last month, DNF was recognised more among patients who died at home (23%), compared to those who died in both care homes and hospitals (6%). In the last four weeks, DNF was recognised more among patients at home (24%) and care home (23%), than among patients in hospital (8%). Across all the care settings, DNF was recognised most frequently in the last week of life. Altogether, DNF was never recognised thrice as often among patients with cardio-respiratory (36%) and other (43%) illnesses, than cancer (12%) (Figure 1).



**Figure 1:** Recognition of death in the near future in patients who died non-suddenly, per place and cause of death N=252<sup>1</sup>

<sup>1</sup> Includes 5 missing values; percentages of missing observations variables ranged between 0.4 and 5.6%

### Characteristics associated with recognising DNF

Of the variables explored, age, gender, education, ethnicity, level of consciousness and mental state, did not appear to be associated with recognising DNF. On univariate analyses, recognising DNF was positively associated with diagnosis cancer, lack of appetite, lack of energy, and limited functional status. Multivariately, recognising DNF was positively associated with diagnosis cancer and low functional status (Table 1).

### **Characteristics associated with recognising DNF before the last week of life**

Age, diagnosis cancer , and discussing 'diagnosis', 'prognosis', 'incurability', and 'palliative care options' with the patient before the last weeks of life were associated positively with recognising DNF before the very last week of life - univariately. Multivariately, cancer death and discussing palliative care options maintained a positive relationship with recognising DNF before the last week of life (Table 2), Similar results were obtained when the analyses were repeated for the period up to one month before death (not shown).

### **Care characteristics that are related to recognition of DNF**

On correcting for cancer and functional status, recognising DNF up to at least one week before patient's death was related to fewer hospital deaths, more GP-patient contacts in the last week of life, more deaths in a preferred place, more frequent GP-patient discussions about "possible complications", 'physical complaints', 'psychological problems', and 'palliative care options' in the last seven days of life (Table 3).

**Table 1:** Characteristics associated with recognising / not recognising death in the near future in patients who died non-suddenly at home/care home N=252<sup>1</sup>

Patient and care characteristics		Total %	Did not	Recognised	Logistic regression <sup>2</sup> (odds [95% CI])	
			recognise DNF (N=72) Column %	DNF (n=175) Column %	Univariate analyses	Multivariate analyses <sup>3</sup>
Age	1–64	20	18	21	1	
	65–85	41	42	40	0.84 (0.4–1.8)	<sup>4</sup>
	≥85	39	39	39	0.86 (0.4–1.9)	<sup>4</sup>
Gender	Male	45	53	42	1	
	Female	55	47	58	1.53 (0.9–2.6)	<sup>4</sup>
Education	Elementary	48	59	44	1	
	Secondary	39	31	41	1.77 (0.9–2.6)	<sup>4</sup>
	Tertiary	13	9	14	2.02 (0.8–5.4)	<sup>4</sup>
Dutch nationality	1 parent	94	96	93	1	
	<1 parent	6	4	7	1.58 (0.4–5.8)	<sup>4</sup>
Cause of death	Cancer	38	15	47	1	1
	Not cancer	62	85	53	<b>0.20 (0.1–0.4)</b>	<b>0.18 (0.1–0.4)</b>
Dementia diagnosed by a physician	No	88	88	88	1	
	Yes	12	12	12	0.95 (0.4–2.3)	<sup>4</sup>
<b>Related symptoms &amp; functional state before death</b>						
Comatose	No	48	59	48	1	
	Yes	52	41	52	0.64 (0.3–1.2)	<sup>4</sup>
Lack of appetite	No	22	46	17	1	
	Yes	78	54	83	<b>4.10 (1.9–8.8)</b>	<sup>4</sup>
Lack of energy	No	8	18	6	1	
	Yes	92	82	94	<b>3.68 (1.3–10.6)</b>	<sup>4</sup>
Pain	No	52	58	50	1	
	Yes	48	42	50	1.39 (0.7–2.8)	<sup>4</sup>
Difficulty breathing	No	59	66	57	1	
	Yes	41	34	43	1.45 (0.7–3.0)	<sup>4</sup>
Anxiety	No	60	58	60	1	
	Yes	40	42	40	0.94 (0.4–2.0)	<sup>4</sup>
Low functional status capable of only limited self-care (ECOG score ≥ 4) <sup>5</sup>	No	85	32	8	1	1
	Yes	15	68	92	<b>5.39 (2.5–11.5)</b>	<b>5.21 (2.3–11.7)</b>

DNF=Death in the near future

<sup>1</sup> Includes 5 missing values; percentages of missing observations variables ranged between 0.4 and 5.6%

<sup>2</sup> Dependent variable: patients in whom GPs ever recognised death in the near future N=175, Reference group: patients who died without their GPs recognising death in the near future N=72

<sup>3</sup> Stepwise backwards logistic regression. Variables removed after 3 steps of the backward analyses. Significant values in **bold print**

<sup>4</sup> Not entered /retained following multiple backwards logistic regression analyses <sup>5</sup> ECOG scale {Oken, 1982}

**Table 2:** Characteristics associated with recognising / not recognising death in the near future before last week of life in patients who died non-suddenly at home/care home N=252<sup>1</sup>

Patient and care characteristics	Total %	Did not recognise DNF before the last week or after (N=154)		Recognised DNF before patient's last week (n=93)	Logistic regression <sup>2</sup> (odds [95% CI])	
		Column %	Column %	Column %	Univariate analyses	Multivariate analyses <sup>3</sup>
Age	1–64	20	18	24	1	
	65–85	41	37	47	0.93 (0.5–1.8)	<sup>4</sup>
	≥85	39	45	29	<b>0.46 (0.2–0.9)</b>	<sup>4</sup>
Gender	Male	45	44	47	1	
	Female	55	56	53	0.88 (0.5–1.5)	<sup>4</sup>
Education	Elementary	48	53	42	1	
	Secondary	39	36	43	1.50 (0.8–2.7)	<sup>4</sup>
	Tertiary	13	11	16	1.80 (0.8–4.1)	<sup>4</sup>
Dutch nationality	1 parent	94	96	90	1	
	<1 parent	6	4	10	2.58 (0.9–7.5)	<sup>4</sup>
Primary cause of death	Cancer	38	25	59	1	1
	Not cancer	62	75	41	<b>0.23 (0.1–0.4)</b>	<b>0.29 (0.2–0.5)</b>
Dementia diagnosed by a physician	No	88	85	93	1	
	Yes	12	15	7	0.38 (0.2–1.0)	
Admitted in hospital and/or ICU in the last 30 days of life	No	55	55	55	1	
	Yes	45	45	45	0.99 (0.6–1.7)	<sup>4</sup>
Palliative care initialisation (before the last week of life)	No	75	65	85	1	
	Yes	25	35	15	0.32 (0.1–1.0)	<sup>4</sup>
<b>GP-patient communication prior to the last week of life</b>						
GP discussed the diagnosis	No	48	55	38	1	
	Yes	52	45	62	<b>1.93 (1.1–3.3)</b>	<sup>4</sup>
GP discussed the prognosis	No	44	53	30	1	
	Yes	56	47	70	<b>2.68 (1.5–4.7)</b>	<sup>4</sup>
GP discussed the incurability	No	48	60	28	1	
	Yes	52	40	72	<b>3.80 (2.1–6.7)</b>	<sup>4</sup>
GP discussed palliative care options	No	55	67	35	1	1
	Yes	45	33	65	<b>3.73 (2.1–6.5)</b>	<b>2.37 (1.3–4.4)</b>

DNF=Death in the near future

<sup>1</sup> Includes 5 missing values; percentages of missing observations variables ranged between 0.4 and 5.6%.

<sup>2</sup> Dependent variable: patients in whom GPs recognised death in the near future before versus not before the last week of life N=93: 154

<sup>3</sup> Stepwise backwards logistic regression. Variables removed after 3 steps of the backward analyses.

Significant values in **bold** print

<sup>4</sup> Not entered /retained following multiple backwards logistic regression analyses

**Table 3:** Relationship between recognising death in the near future before the last week of life and care characteristics in the last week of life (N=165)<sup>1</sup>.

		Never recognised DNF before patient died (n=72) Row %	Recognised DNF before patient's last week (n=93) Row %	OR (95% CI) <sup>2</sup>
Place of death: hospital	No	24	76	<b>0.15 (0.06–0.4)</b>
	Yes	77	23	
	Total	44	56	
Initiation of palliative care services (PCS) in the last week	No	37	63	6.7 (0.6–73.1)
	Yes	9	91	
	Total	15	85	
Number of GP-patient contact in the last week of life (2 or median)	No	65	35	<b>11.5 (4.2–31.0)</b>
	Yes	9	91	
	Total	42	58	
Dying in a preferred place	No	54	46	<b>4.38 (1.4–14)</b>
	Yes	21	79	
	Total	28	72	
<b>GP-patient communication on specific end-of-life issues in the last week of life</b>				
Possible complications	No	49	51	<b>3.08 (1.1–8.5)</b>
	Yes	22	78	
	Total	43	57	
Physical complaints	No	57	41	<b>4.39 (1.9–10.3)</b>
	Yes	23	77	
	Total	43	57	
Psychological problems	No	50	50	<b>2.55 (1.0–6.4)</b>
	Yes	24	76	
	Total	42	57	
Social problems	No	50	50	2.07 (0.8–5.5)
	Yes	25	75	
	Total	43	57	
Spiritual /existential issues	No	46	54	4.5 (0.5–41.3)
	Yes	9	91	
	Total	43	57	
Palliative care options	No	53	47	<b>4.92 (1.6–14.7)</b>
	Yes	12	88	
	Total	42	58	
Treatment burdens	No	47	53	1.81 (0.6–5.1)
	Yes	23	77	
	Total	43	57	

DNF=Death in the near future

<sup>1</sup> Excluding 82 in whom DNF was recognised within the last week of life and 5 missing values. Percentages of missing observations variables ranged between 0.4 and 5.6%.

<sup>2</sup> Corrected for cancer diagnosis and ambulant functional state. Significant levels in bold print

## Discussion

### Summary of main findings

The GPs never recognised DNF in about a third of the non-sudden deaths, and a third of the patients who died at home (fig 1). Patients who died in hospital (versus elsewhere) had the largest proportion of non-recognition. “Last week” recognition of DNF was commonest in care home deaths. Recognition of DNF was strongly associated with dying from cancer (versus other diagnoses), and having limited functional state. Recognising DNF before the last week of life was associated with cancer, younger age (<85y), and GP discussing diagnosis, prognosis, incurability and palliative care options with patient. Care characteristics in the last week of life related to recognising DNF before the patient’s last week were: fewer hospital deaths, more GP-patient contacts, more deaths in a preferred place, more frequent GP-patient discussions about ‘possible complications’, ‘physical complaints’, ‘psychological problems’, and ‘palliative care options’ (Table 3).

### Strengths and limitations of the study

To the best of our knowledge, this is the first nationwide population-based study that examined GP-recognition of DNF in patients whose deaths were non-sudden. To produce reliable results, we enlisted nationally-representative GPs from an existing surveillance network with a data collection and quality assurance protocol to minimise incomplete data and GP recall bias. We selected a general patient population, all of whom in principle could benefit from planned terminal care. The independent variables were selected in such a way that they preceded the dependent variables, in terms of timing. A retrospective collection was advantageous because all the deaths were captured upfront, unlike in prospective studies where patients are sought based on diagnosis (cancer) or certain characteristics (pain, breathlessness), and drop-out rates are often high (15). Although the “expected” and “non-sudden” categorisations may have been better understood in retrospect, this limitation is a reality of clinical practice. However it is possible that some GPs provided socially-desirable responses, given the self-reporting nature of the study. Altogether, the exclusion of Dutch nursing home residents from this study calls for some caution in interpretation and generalisation of our results.

### Comparison with existing literature

Murray et al. demonstrated palliative care needs accompanying the three main illness trajectories (3;4). Patients at home are increasingly dying from a combination of these illness trajectories. McKinley et al. highlighted the need for GPs to be able

to identify the terminal phase of diseases during their care of patients with non-malignant diseases, i.e. organ failure (acute deterioration and recovery) and frailty (prolonged decline), based on the notion that such patients received less care, perhaps due to non-recognition of their terminal status (5). Our results like McKinley's, show that DNF was (five times) less recognised in patients with non-cancer versus cancer. However our data associates recognising DNF with less hospital deaths – it is possible the GPs did not recognise DNF in many of the hospitalised patients because they ceased to be involved in their care following admission. In Belgium, Van den Block et al. reported the institutionalised nature of dying, even among GP-managed patients with “palliative care” treatment goals (27).

DNF was recognised relatively earlier (before the last month) in patients at home than those in a care homes, and last week recognition was more common in care home than home residents. Regardless of disease, non-recognition of DNF was more common in patients who died in a non-preferred place, experienced less GP contact, and were less informed about their illness and other related end-of-life issues, than similar patients in whom DNF was recognised at least one week prior to death. It could be argued that an earlier recognition would even be more desirable in conditions like heart failure and COPD which have no curative treatment, and dementia that lacks an accurate scale for such recognition.

Our results show recognition of DNF in the last seven days to be associated with having cancer, having a low functional status (ECOG  $\geq 4$ ), older age (>85y), and the presence of communication about end-of-life issues in /by the last 2–4 weeks of life. From research, we know that patients with chronic cardiorespiratory illnesses have unmet communication needs (28), and it is possible that if their GPs were able to recognise DNF, they may be able to better manage communication and care.

### **Implications for future research or clinical practice**

Recognising DNF is vital for planning end-of-life care, decision-making, and allocation of resources. Our results show that this, and it may actually pre-empt the initiation of end-of-life discussions. Across settings, DNF was completely missed in almost 20% of all home deaths, and 80% of all hospital deaths (Figure 1). While we acknowledge that the dying phase will not always be discernable, these results point to the fact that GPs may utilise salient triggers in the process of recognition, i.e. by assessing palliative care needs more systematically (30). Systematic assessment of needs can be aided by interventions such as the Gold Standards Framework (GSF), which is a generic improvement tool, initially used for cancer patients, but currently developed for any patient, with a life limiting illness, living in any setting. Unlike the Liverpool Care Pathway for the Dying (LCP) which addresses only the last days of

life, the GSF extends to a considerably longer period before death (31), and is used increasingly alongside the LCP (32).

## Ethical review

An ethical review was not required by the Dutch law since data were collected after the death of patients. However the study complied with the protocol and anonymity procedures of the Netherlands Institute of Health Services Research, and more details on this are published elsewhere.

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## Chapter 3

# Discussing end-of-life issues in the last months of life: a nationwide study among General Practitioners

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## Abstract

*Background:* Communication is a necessary tool for ensuring the provision of quality patient-centred care for patients who have life threatening illnesses, and discussing all relevant end-of-life issues should not be limited to cancer patients.

*Objective:* To examine the incidence and timing of GPs discussing end-of-life issues with patients whose deaths were expected, and to identify the factors associated with them discussing these issues.

*Methods:* Between January and December 2008, GPs participating in a nationally representative sentinel surveillance network of GPs, were asked to register, using standardised forms, the extent of discussing 10 end-of-life issues with patients.

*Results:* We examined 252 patients who died non-suddenly, 38% of whom died of cancer, and 86% of whose treatment goal was essentially palliative care. Findings show that GPs often waited until death was very close, before they discussed end-of-life issues with the patients, and they discussed spiritual and social issues less frequently than physical symptoms, diagnoses and psychological problems. In 74% of cases, the GPs were informed of their patients' preferred place of death; and 8 out of 10 patients with known preferences for place of death, died there. Being diagnosed with cancer was associated with a higher frequency of discussing all 10 end-of-life issues than being diagnosed with other (noncancer) conditions, but this is a state of mind we did not explore in this study.

*Conclusion:* Promotion of timely discussion of all relevant end-of-life issues, in patients with cancer and noncancer diagnoses, is advisable based on systematic needs assessment.

## Introduction

At the end of life, communication is a key tool for identifying, assessing and relieving illness burdens (1;2), and for providing patient-centred care (3). At such times, preferences for information and communication differ, depending on individual patient characteristics (4;5) and the symptoms they experience (6;7). Failure to discuss end-of-life issues can affect the quality of palliative care for patients and their families (6;8). Understandably, some issues are more pressing at certain periods in the course of illness (1;2), and may prompt more frequent discussions (2;4). However content, extent and changes in patient needs are best assessed and addressed through adequate communication of relevant topics. Studies show that many patients with life-threatening illnesses may have unmet information needs (1;2;7;9).

In the Netherlands, the gate-keeping function of general practice is highly developed, such that virtually all patients are registered with a general practitioner (GP), whose referral is required for accessing specialised medical services (10;11). GPs provide basic end-of-life care for patients living at home and in residential care homes (11), and could play a key role in communicating end-of-life issues with the terminally ill (12). First, they have a contextual knowledge of the patients and the family dynamics, given that their work is community-based. Secondly, they manage the pain and other burdens that accompany end-stage disease (13;14), can provide at-home care for patients and their carers (15;16), and maintain continuity of care between disciplines (13;17;18) and settings (18–22).

Cartwright et al. surveyed GPs and specialists in Australia and six European countries, on the extent to which they discussed end-of-life issues with terminally ill patients (4). Their results show that in the Netherlands, GPs “in principle, always” discuss aspects of the disease with patients in >90% of cases, whereas they “in principle, always” discuss social and spiritual problems in 60% and 26% of cases, respectively. However these were assessments of how GPs discussed these topics in general, because they were not focused on specific patients. Asking about how one would act in an instance is especially vulnerable to receiving socially desirable responses. Also, previous studies had been limited to physician intentions (6;23;24) and diagnoses (2;6;9;25). This is the first nationwide study that asks GPs about the end-of-life issues they had discussed with actual patients. Using a surveillance network of GPs (26–28), we examined the incidence and timing of discussing end-of-life issues with respect to three intervals before death (before the last month, in the last 2–4 weeks, in the last week) with patients whose deaths were expected, and identified factors associated with discussing 10 issues: primary diagnosis, incurability of illness, life expectancy or prognosis, possible medical complications, physi-

cal symptoms, psychological problems, social problems, spiritual or existential problems, palliative care options and treatment burdens.

## **Methods**

### **Selection and procedure**

Between January and December 2008, patients' deaths were registered via a sentinel network of GPs, nationally representative of practising GPs (26). The network comprised 65–70 GPs from 45 practices, and covered close to 1% of the registered patient population (27;28). The GPs received a structured registration form one week after a patient ( $\geq 1$ year) died, with a request to fill and return it. If necessary, they also received reminders (26;27). Based on the question, "Was death sudden and unexpected?", all sudden deaths (i.e., with a "yes" response) were excluded on the premise that such did not received palliative care from their GP. Patients were classified based on their place of death: in the nursing home, in their homes, in a care home, or in a hospital (a care home death was death that occurred in a care home setting). All patients who died in the nursing home were excluded from this study because medical care in Dutch nursing homes was provided by specialists, and not by the GP; however the GP managed the care of patients at home and in care homes until death (the selection process is presented in Figure 1). Lastly, "dying in a preferred place" was derived in three steps – we asked the GPs if they were aware of their patients' preferred place of death; requested for the place of death as reported in patient's death registration, and checked for congruence between both sets of variables. Expectedly, "dying in a preferred place" could not be derived for those patients whose GPs were unaware of their preferred place of death.

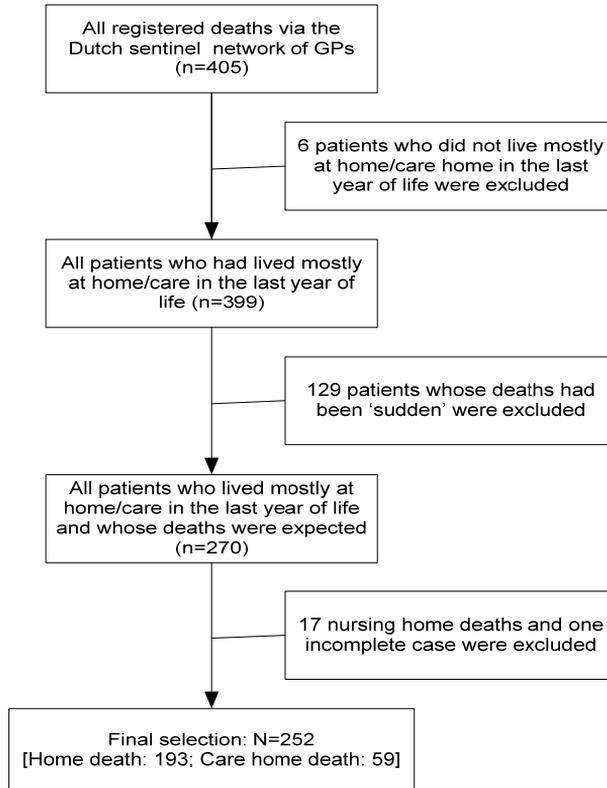


Fig. 1: Flow chart illustrating selection process

**Figure 1:** Flow chart illustrating the selection process

The data collection process was supervised by NIVEL (the Netherlands Institute of Health Services Research), using a standardised protocol (29). Participating GPs returned their forms to NIVEL, where they were scrutinised for errors and missing data, and missing data were retrieved by telephone contact. Next, the forms were duplicated and sent to the researchers for data entry and analyses.

An ethical review was not required by the Dutch law since data were collected after the death of patients. More details on the methodology of this study have been published elsewhere (27).

### Research instrument

The research instrument, a 21-item registration form, consisting of multiple-choice and open-response questions, was designed to explore socio-demographic characteristics, causes of death (as recorded in the death certificate) and end-of-life care

characteristics. We used it to survey place of care/ death; involvement of a multidisciplinary palliative care team; hospital / ICU admissions in the last 3 months of life; GP home visits or personal contacts (excluding telephone calls) made in the last 3 months, last 2–4 weeks, and within the last week of life; treatment goal in the last week of life (curative, life-prolonging or palliative); dementia / coma; functional state in the last week of life using ECOG performance scale (30); symptom frequency and distress in the last week of life using MSAS Scale (31); and patient's preferred place of death. Every year, new questions were tested among some sentinel GPs using interviews, to ensure comprehensibility and acceptability. When the GPs did not understand the concepts in the registration form as intended, revisions were made. In addition, operational definitions were provided so that respondents understood exactly how to approach the different items in the forms.

The GPs were asked to specify whether they had discussed - primary diagnosis, incurability of illness, life expectancy or prognosis, possible medical complications, physical symptoms, psychological problems, social problems, spiritual or existential problems, palliative care options and treatment burdens with the terminally ill patient in question. These issues had been derived from a cross-national survey of physicians by Cartwright et al (4). Each issue was explored in three stipulated time intervals using a multiple-choice answer format. Options available included 'never discussed', 'discussed before last month of life', 'discussed 2–4 weeks' (i.e., before the last week of life, but within the last month of life), "discussed in the last week", and "question not applicable". It was possible to select more than one answer per issue.

### **Statistical analysis**

Statistical computations were done using SPSS 15.0 (SPSS Inc. Chicago, IL). From the three answer categories provided, we calculated the interval in which each end-of-life issue was discussed for the very first time, and the frequency of discussing this in the three stipulated time intervals (table 2). We used Pearson's  $\chi^2$  test to analyse whether several patient and care characteristics were associated with the different end-of-life issues ever being discussed. We chose patient and care characteristics that were found relevant from literature (2;32–35); age, gender, education, cancer diagnosis, presence of dementia, and treatment focus (table 3).

Separately, we analysed the dimensionality of the issues, using principal component analyses (4), and this indicated a uni-dimensional scale with components that explained 52% and 64% of the variance, and a Cronbach alpha of 0.90 and 0.94, respectively. Removal of any one of the ten issues did not alter the alpha values.

Next we constructed two scales ('ever discussed end-of-life issue', and 'discussed end-of-life issue in last week of life') as dependent variables, and computed the

total mean for all the ten end-of-life issues. In order to explore which patient and care-related characteristics are independently associated with the single (mean) communication scale per the two above-mentioned time intervals, we performed univariate and multiple regression analyses using the backward elimination method (table 4).

## **Results**

### **Characteristics of study population**

Patient and care characteristics are shown in table 1. We registered a total of 252 non-sudden deaths, representative of all deaths outside those in the nursing homes and hospitals. Mean age was 77y (SD 15.8), 55% was female, and 48% had little or no elementary education. GPs were informed of patients' preferred place of death in 74% of cases. Cancer was the cause of death in 38%, dementia was diagnosed by GP/ physician in 12%, and about 9 in 10 patients had a 'palliative care' treatment goal, in the last week of life.

### **Incidence and timing of discussing end-of-life issues**

Table 2 shows that all but spiritual/existential problems were discussed by more than half of the GPs. Physical symptoms were discussed most frequently (73%) in the three stipulated time intervals. Four main patterns of discussing end-of-life issues were observed before the last month to the last week of life; physical symptoms, life expectancy and palliative care options were discussed more frequently in the last 2–4 weeks, and slightly less frequently in the last week of life; psychological problems, medical complications and social problems were discussed at about the same frequency before the last month and in the last 2–4 weeks, but less frequently in the last week of life; primary diagnosis and incurability were discussed progressively less frequently towards death; while treatment burdens and spiritual/ existential problems were discussed most in the last 2–4 weeks, and least in the last week of life. The differences in discussing each issue were few and far between per time interval, and only for three cases did a GP discuss all ten end-of-life issues before death.

**Table 1:** Patients' demographic, clinical and care characteristics (N=252)<sup>1</sup>.

Characteristics	%
Age range	
<64y	20
65–84y	41
≥85y	39
Gender	
Male	45
Female	55
Education level	
Primary or less	48
Secondary or equivalent	39
Tertiary or equivalent	13
Cause of death	
Cancer	38
Cardiovascular disease	21
Others [including COPD, renal failure, liver disease]	41
Dementia diagnosed	12
Number of hospital admissions in the last 30 days of life	
None	55
One	39
Two or more	13
Number of ICU admissions in the last 30 days of life	
None	90
One	9
Two or more	1
Patient received palliative care initiatives in the last 3 months	34
Patient was visited /contact by GP (excluding phone calls) in the last 3 months	94
Patient's GP was informed of his/her preferred place of death	74
Patient died in his/her preferred place of death (i.e. of those with known preferences)	86
Patient's treatment goal in last week of life was mainly	
Palliative care	86
Cure or life-prolonging	14

<sup>1</sup>Percentages of missing observations variables ranged between 0.4 and 5.6%

**Table 2:** Percentages of patients whose GPs discussed end-of-life issues ‘ever’ and in three time periods before death (N=252)<sup>1</sup>.

End-of-life issues discussed with patients	Discussed ‘ever’ before death (%)	Answer categories for the timing of GPs discussing the end-of-life issues with patients					
		Before the last month of life (%)		Within the last 2–4 weeks of life (%)		In the last week of life (%)	
		Total <sup>2</sup>	Very first time	Total <sup>2</sup>	Very first time	Total <sup>2</sup>	Very first time
Physical symptoms	73	45	45	50	17	47	11
Life expectancy (prognosis)	69	33	33	38	22	37	14
Psychological problems	67	39	39	39	16	35	11
Primary diagnosis	62	40	40	34	11	33	11
Incurability of illness	61	39	39	35	13	30	9
Palliative care options	59	29	29	33	16	32	14
Possible medical complications	55	28	28	28	16	25	9
Treatment burdens	55	27	27	29	15	24	12
Social problems	51	29	29	29	15	22	7
Spiritual /existential problems	27	13	13	16	9	11	4

<sup>1</sup> Percentages of missing observations variables ranged between 0.4 and 5.6%

<sup>2</sup> More than one answer possible per the 3 time intervals before death

**Table 3:** GPs discussed end-of-life issues ‘ever’ before death by patient and care characteristics (N=252)<sup>1</sup>.

End-of-life issues the GPs ever discussed with their patients before death	Patient and care characteristics																	
	Age		Gender		Only elementary Education			Diagnosis: Cancer		Had dementia		Treatment goal <sup>2</sup>						
	<65y	≥65y	M	F	Yes	No	*	Yes	No	Yes	No	Yes	No	Care	Cure			
	<i>p</i>		<i>p</i>		<i>P</i>			<i>p</i>		<i>p</i>		<i>p</i>						
	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %	Column %			
Physical symptoms (n=238)	77	72	76	71	66	82	*	91	62	*	33	79	*	78	50	*		
Life expectancy (n=238)	78	68	72	68	62	79	*	93	55	*	39	74	*	74	47	*		
Psychological problems (n=236)	72	66	73	62	58	77	*	83	57	*	31	72	*	71	53			
Primary diagnosis (n=229)	69	61	70	56	48	77	*	83	50	*	37	62	*	67	47			
Incurability of illness (n=235)	77	57	*	70	54	*	46	76	*	94	40	*	29	65	*	67	29	*
Palliative care options (n=238)	74	55	*	63	56		49	69	*	89	40	*	14	65	*	61	38	*
Possible medical complications (n=236)	66	52		62	49		47	63	*	78	41	*	18	60	*	58	41	
Treatment burdens (n=237)	64	54		61	51		45	65	*	77	42	*	30	60	*	67	23	*
Social problems (n=232)	57	49		54	48		44	57		65	42	*	26	55	*	54	39	
Spiritual problems (n=232)	33	25		28	26		20	33	*	43	17	*	7	30	*	30	16	

<sup>1</sup> Percentages of missing observations variables ranged between 0.4 and 5.6%

<sup>2</sup>Treatment goal: Cure = treatment was focussed on cure or life prolongation; Care = treatment was focussed on palliation or comfort care

Pearson’s test for association ( $\chi^2$ ); \* signifies  $p < 0.05$

**Table 4:** Determinants of GPs discussing all end-of-life issues ‘ever’ before death and one week before death (N=252)<sup>1</sup>.

Associated factors	Standardised regression coefficients			
	Ever before death		One week before death	
	Univariate	Multivariate	Univariate	Multivariate
<i>Factors measured with regards to the period ‘one-three months’ before death</i>				
Age	-0.18*		-0.10	
Gender (male=1; female=0)	-0.13		-0.14*	
Education level	0.24*		0.25*	0.16
Cause of death cancer (cancer=1; not cancer=0)	0.46*	0.32*	0.33*	0.20*
Cause of death cardiovascular disease	-0.17*		-0.05	
Diagnosis: dementia	-0.32*	-0.25*	-0.22*	-0.22*
Number of hospital admissions	-0.004	0.12	-0.04	
Number of ICU admissions	-0.25*	-0.15*	-0.18*	
Palliative care was used	0.20*		0.15*	
GP-patient contact 3 months before death	0.37*	0.16*	0.34*	
GP informed about patient’s preferred place of death	0.45*	0.25*	0.31*	0.18
<i>Factors (symptom distress)<sup>2</sup> measured with regards to the period ‘one week’ before death</i>				
Treatment goal: cure or life prolongation			-0.19*	
Treatment goal: palliative care			0.22*	
Functional status			0.01	
Lack of appetite			0.19*	
Lack of energy			0.20*	
Pain			0.22*	
Drowsy			0.06	
Constipated			0.20*	

<sup>1</sup> Percentages of missing observations variables ranged between 0.4 and 5.6%; \* $p < 0.05$ ; significance levels for the t statistics.

<sup>2</sup> Symptom derived from the Memorial Symptom Assessment Scale, MSAS (31).

### Patient characteristics of ever discussing end-of-life issues

Table 3 relates the rate of ever discussing end-of-life issues to specific patient and care characteristics (age, gender, education, cancer diagnosis, presence of dementia and treatment focus). Differences exist in discussing incurability of illness and palliative care options - both were discussed more frequently with patients under 65 years (77% and 74%) than with those over 65 years (57% and 55%). Primary diagnosis and incurability were discussed more frequently with men (both 70%) than

women (56% and 54%). GPs discussed more frequently all end-of-life issues (except social problems) significantly with more educated patients. Also, all end-of-life issues were discussed significantly more frequently with cancer than non-cancer patients, but significantly less frequently with dementia patients than patients without dementia, with a difference of up to 50% for discussing palliative care options (14%:65%). In addition, some issues were discussed significantly more frequently when treatment goal was palliative care: physical symptoms (78% and 50%), life expectancy (74% and 47%), incurability of illness (67% and 29%), palliative care options (61% and 38%), and treatment burdens (67% and 23%).

### **Factors associated with discussing the end-of-life issues: ever and in the last week of life**

Table 4 shows results from linear regression analyses relating patient and care characteristics to the aggregate mean score for ever discussing and discussing all end-of-life issues in the last week of life. On univariate analyses, ever discussing end-of-life issues was positively associated with cancer, GP being informed of a patient's preferred place of death, GP-patient contact in the last 3 months of life, having higher education, and using palliative care initiatives. Ever discussing end-of-life issues was inversely associated with dementia, more ICU admissions, and older age. The multivariate analyses show ever discussing end-of-life issues to be significantly associated with cancer, GP informed of a preferred place of death, not having dementia, GP-patient contact in the last 3 months of life, and fewer ICU admissions. Treatment goals and symptom distress were not assessed prior to the last month of life given the wide spectrum of diagnoses examined. In the last week of life, the aggregate mean score for ever discussing the end-of-life issues was associated with GP-patient contact in the last 3 months of life, cancer, GP informed of a preferred place of death, higher education, and the use of palliative care initiatives, having a palliative care treatment goal, pain, lack of energy, constipation and lack of appetite. Ever discussing end-of-life issues was inversely associated with dementia, treatment goal being cure or life prolongation, having more ICU admissions and being male. On multivariate analyses, ever discussing end-of-life issues was significantly associated with cancer and the absence of dementia.

## **Discussion**

Altogether we examined 252 patients whose deaths were non-sudden and foreseen by GPs of the Dutch sentinel national network. In each of three time intervals, physical and psychological problems were discussed most frequently, while social and spiritual issues were discussed least frequently. GPs, in more than one third of

cases, discussed physical symptoms, diagnosis, psychological problems, incurability of illness and prognosis, for the very first time before the last month of life, whereas in about 10% of cases, they discussed incurability of illness, possible medical complications, social and spiritual problems, for the very first time in the last week of life. All ten end-of-life issues were discussed only with three patients. There were relatively more discussions with more educated patients, cancer patients, patients without dementia, and those for whom the treatment goal was palliative care. Cancer was most frequently associated with discussing all end-of-life issues in before the last month, in the last 2–4 weeks, and in the last week of life. Cancer, not having dementia, GP's knowledge of preferred place of death, GP-patient contact and not being admitted to the ICU were the only independent associated factors for ever discussing the end-of-life issues.

To the best of our knowledge, this is the first nationwide study which seeks to explore the incidence of actual GP-patient communication at the end of life. From a general patient-population, we made a selection of all patients who we felt could have benefited from planned terminal care. Via an existing surveillance network, we enlisted trained GP, representative of all GPs nationally, so as to produce results that could reflect the actual state of affairs in The Netherlands. However, one limitation was the fact that we could not combine the GP characteristics with the patient cases. Also, given the retrospective nature of the study, there might have been some recall bias. We limited the chances of this by sending the registration form one week after a patient's death. Another drawback was that the GPs self-reported on the care they had provided, and even though we asked about actual behaviour, it is possible that they provided 'ideal responses' in some instances, or simply conceptualised some themes i.e. "treatment burdens" in ways different from what we expected. We did not explore whether some of the undiscussed issues had in fact been adequately communicated to the patients by other care providers, because that was outside our research question, and we did not examine plausible demographic or clinical predictors among patients who appear to have had the issues brought up 'for the very first time' in less than one month prior to death, because of the lack of power.

Our findings show that GPs often wait until very close to death before discussing end-of-life issues, that cancer patients receive a greater focus than patients with dementia or other chronic conditions, GPs generally avoid social and spiritual issues compared to physical symptoms (36;37). The former is in consonance with results from Cartwright et al., who showed Dutch GPs as discussing end-of-life issues more often, compared to GPs from Australia and six other western European countries (4). This could be related to the open debate on end-of-life issues in the Netherlands, and the congruence in results may suggest that intentions and actual behav-

your match, in this instance. The relative lack of GPs discussing spiritual issues is not surprising, but contrasts substantially with the importance patients place on their GPs broaching spiritual issues (38). Cancer was the main diagnosis that strongly correlated with discussing all the end-of-life issues, although cardiovascular disease was still a major cause of death in this population. Given the predictability of its trajectory (39), we know that cancer opens up people for discussing end-of-life issues. However, patients with cardiovascular and other chronic illnesses have palliative care needs which may not always be obvious (9;39), and also have much need for adequate and timely information (9;40;41). Finally, about a quarter of the patients studied had GPs who were not aware of their preferred place of death, compared with 46% of patients in a similar selection from a previous dataset (27). This rise in GP awareness may have been as a result of the regular feedback participating GPs received, following analysis of the SENTI-MELC study datasets (26,27,42,43). In both instances, a patient was 4 times more likely to die in a preferred place when the GPs had been informed of his/her preference.

In conclusion, cancer remains the main reason for discussing end-of-life issues in the Netherlands. It has been widely stated in literature that palliative care provision, which includes discussing end-of-life issues, should not be limited to cancer patients (8;9;12). This message should be extended to physicians in palliative care training. Because there is substantial disease-specific variation in the end of life trajectory, promotion of timely discussion of all important end-of-life issues, including spiritual and social issues, is advisable. A useful tool that GPs can utilize to determine when such discussion is appropriate for a specific patient is the question: “would I be surprised if this patient would not live any more than a year or half a year from now”, which is used in the UK in the Gold Standards Framework (44).

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## Chapter 4

# GP awareness of preferred place of death and correlates of dying in a preferred place: a nationwide mortality follow-back study in the Netherlands

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## Abstract

To improve the quality of end-of-life care, general practitioner (GP) awareness of where their patients prefer to die is important. To examine GP awareness of patients' preferred place of death (POD), associated patient- and care-related characteristics, and the congruence between preferred and actual POD in The Netherlands, a mortality follow-back study was conducted between January 2005 and December 2006. Standardized registration forms were used to collect data on all non-sudden deaths (n=637) by means of the Dutch Sentinel Network, a nationally representative network of general practices. Forty-six percent of patients had GPs who were not aware of their preferred POD. Of those whose GPs were aware, 88% had preferred to die in a private or care home, 10% in a hospice or palliative care unit and 2% in a hospital. GPs were informed by the patients themselves in 84% of cases. Having financial status "above average", a life-prolongation or palliative care goal, and using specialist palliative care services were associated with higher GP-awareness odds. Four-fifth of patients with known preferred POD died there. There is a potential for improving GP awareness of patients' preferred POD. Such awareness is enhanced when palliation is an active part of end-of-life care. The hospital is the POD least preferred by dying patients.

## Introduction

Approximately two-thirds of all deaths are non-sudden and protracted (1). For these people, death can be anticipated, making the provision of end-of-life care a relevant consideration. GPs play a vital role in ensuring that patients are carried along as they manage their care, since many patients are under their care in the final phase of their lives (2;3). Awareness of preferences is key in order to be able to tailor care to the patients' wishes, minimize decision-making burdens on relatives and carers (2), and effectively plan and execute end-of-life care programs. One important subject that GPs need to be aware of, is where their patients would prefer to receive terminal care and die, across the multiple settings in which death would normally occur (4–7).

Care settings at the time of death affect the philosophy of care, the types and intensity of services that can be delivered, who controls these services, expectations, skill and availability, and ultimately exert an influence on the quality of a person's death (5;8;9). While it is known that most patients prefer to die at home (10–13), studies clearly suggest that significant proportions would rather die in care homes (12;14;15), in hospices (16;17), and in hospitals (18–21). Unfortunately, most of these studies were undertaken within specific patient populations (e.g. cancer patients) or specialized settings (e.g. old peoples' homes); hence it is often difficult to generalize the results. Arguably, there is a distinction between preferences of patients and the choices actually available to them (22;23). While dying in a preferred place may not be feasible in every case (17;24;25), an awareness by the GP, of what is preferred is fundamental (7) to providing relevant care. It is likely that certain patient or care-related characteristics are related, directly or indirectly, to GP awareness of patients' preference (6;22;23), and to a patient's ability to die in a preferred place (9;25–28).

A basic prerequisite for GP awareness of patients' care preferences is communication (26;26;29–32). Literature on GP-patient communication at the end of life shows that discussing 'death and dying' could prove challenging for some GPs, especially those who have had close and /or prolonged relationships with their patients (7;30). However, purposeful exploration of patient preferences, particularly when done in a sensible and caring manner is key to improving the overall care process (2;3). Moreover some patients would become incompetent as their illnesses progress, making GP awareness of their end-of-life care preferences, whether verbal or in writing, again useful (3).

This study sought to examine GP awareness of the preferred place of their patients' death, and whether this awareness was related to patient and care characteristics.

Furthermore, it assessed the extent to which those patients whose GPs knew their preferred places of death actually died there.

## **Methods**

### **Study design and population**

Patients were recruited by means of the Dutch Sentinel Network of general practitioners (GPs), an existing nationwide health surveillance instrument (33–36). This network consists of 45 general practices (65–70 GPs) and covers approximately 1% of the entire 16 million registered patient population in the Netherlands (35;36). It is evenly distributed in terms of number of patients per GP; both in population and degree of urbanisation (35;36).

The data collection process was managed by the Netherlands Institute of Health Services Research (NIVEL). Within one week of reporting a patient's death, the participating Sentinel GPs were asked to fill in a short registration form on the care the deceased received in the last three months of life (36). All sudden or totally unexpected deaths were excluded. Also deaths were excluded where a patient was less than one year old in order to exclude deaths that might have resulted from congenital causes. On completion, the registration forms were returned to NIVEL where they were closely scrutinised for errors, duplicated and then sent to the researchers for analyses. Approval from the Dutch Ethical Review Board was not required since our data were collected from deceased patients. Patient and physician anonymity was preserved throughout the registration process, and NIVEL maintained its standardised protocol for monitoring the scale and continuity of case reporting per practice (35;36).

Before commencing this research, the authors, after a review of literature, had developed a registration form along themes relevant to end-of-life care. The contents were reviewed for validity by multidisciplinary team members, and pretested by some GPs for readability and comprehensibility. This method of monitoring end-of-life care via a Sentinel Network of GPs (SENTI-MELC) was developed and successfully applied in Belgium, and the protocol of the study design has been published (33).

### *Research instrument*

The research instrument, a 15-item registration form included multiple-choice and open-response questions for exploring from a non-sudden death population, characteristics of patients and the care they received in specified time frames (second to

third month / second to fourth week / last week) within the last 3 months of life. Patient characteristics included basic socio-demographic information, cause of death, and preferred place of death (POD); care characteristics included locations of care in the last 3 months of life, GP awareness of POD, involvement of specialist (multidisciplinary) palliative care services, the main goal of patient's treatment (curative/life prolonging /palliative), the main focus of care (physical / psychosocial /spiritual), the place of care (3 months to weeks before death), and the actual POD.

To eliminate those patients who in principle were not eligible to have received end-of-life care, a routing question was asked; "was the patient's death sudden and totally unexpected". With regards to the GP's awareness of the patient's preferred POD, they were asked "were you aware (verbally or in writing) of where this patient preferred to die"; "who informed you" (patient/ family member/ specify, if other); and "where did this patient wish to die?" (at home or with family/ in a care home/ in a hospital/ in a hospice or palliative care unit).

### **Statistical analysis**

Using SPSS 14.0, the non-sudden deaths were selected (n=637), and logistic regression analyses were used to identify the variables that were associated with a GP being aware of where his patient preferred to die. Associated patient and care characteristics (variables) were analysed using univariate logistic regression. Next, all variables having significant relationships were included in a stepwise backward logistic regression in order to make a predictive model. Variables were removed if  $p > 0.05$ .

### **Place of death in the Dutch context**

Places for receiving terminal care and dying in the Netherlands include patients' own homes or with family members; care homes otherwise known as "verzorgingshuizen"; hospices or palliative care units; hospitals; and nursing homes, otherwise known as "verpleeghuizen". These places offer a variety of care packages. The care homes provide basic formal assistance to patients, and are considered "home" by many, because patients reside there in the last phase of their lives. Care home patients remain under the care of their GPs (4). Hospices and palliative care units exist independently, but could also operate from private homes, hospitals, care and nursing homes (37). They provide more specialised end-of-life care options, for which reasons some units have GPs attached to them. However, patients usually continually maintain contact with their GPs (37). Therefore GPs are the physicians with the best overview of care received and place of care in the last phase of life. The nursing homes provide care predominantly for the elderly, and are unique in the sense that

they have their own (nursing home) physicians (4;38). Care trajectories that involve long-term stay in nursing homes are essentially outside the purview of the GPs.

### Representativeness of data

To investigate the representativeness of the data for all deaths in the Netherlands, we compared gender and age of our sample per setting with figures for all deaths per setting in the Netherlands. The data on all deaths were derived from the Dutch national bureau for statistics (Statistics Netherlands) for the year 2006. Table 1 shows no statistically significant differences for gender and age between our sample (both expected and unexpected), and all deaths for home deaths, care home deaths and hospital deaths; i.e. the percentages of the national death rates fall within the 95% confidence interval of this cohort. The hospital deaths were somewhat under-represented (40% versus 45% of all deaths excluding nursing home deaths), and for patients  $\geq 80$  years somewhat overrepresented (47% versus 41%); perhaps due to underreporting of some hospital deaths. However the national value falls well within the 95% confidence interval in our study data. The nursing home deaths were obviously infrequently reported, and given the Dutch situation, are clearly not comparable with all nursing home deaths in the Netherlands. These differences were to be expected, because nursing home physicians take over care from GPs once transferred; and subsequent monitoring of such patients by their GPs is non-existent or irregular (38). For this reason we decided to exclude all nursing home deaths from our study and to weigh our data for POD. The resulting data are representative for all deaths, i.e. excluding nursing home deaths, in the Netherlands.

**Table 1:** Demographics of deceased people of 1 year and older per setting\* for all deaths (sudden and non-sudden) in the SENTI-MELC study and for all deaths in the Netherlands. Comparability of the Dutch SENTI-MELC study (2005/6) with national death statistics (2006)<sup>†</sup>

	Home		Care home		Hospital		Nursing home	
	S-MELC n=321 % (95% CI)	All deaths n=36,467 %	S-MELC n=137 % (95% CI)	All deaths n=15,065 %	S-MELC n=300 % (95% CI)	All deaths n=42,076 %	S-MELC n=55 % (95% CI)	All deaths n=31,122 %
<b>Sex</b>								
Men	60 (54–66)	58	27 (19–35)	28	56 (50–62)	53	48 (33–63)	37
Women	40 (34–46)	43	73 (65–81)	72	44 (38–50)	47	52 (37–67)	63
<b>Age</b>								
1–49 years	7 (5–11)	8	0	0	3 (2–6)	6	2 (0–10)	1
50–79 years	56 (51–62)	61	10 (5–16)	12	50 (44–55)	54	45 (32–60)	28
80 years and older	37 (31–42)	31	90 (85–95)	88	47 (41–53)	41	53 (39–67)	71

\* the rest group 'other setting was left out': 23.1% of all deaths and 5.7% of deaths in the MELC study.

† derived from Statistics Netherlands (2006) Central Death Registry

## Results

Of the 637 non-sudden deaths (aged  $\geq 1$  year) that the Sentinel GPs registered, 52% were men. Majority of the deaths were of patients over 80 years (53%), followed by patients 41–80 years (44%); most commonly resulted from malignancies (43%) and cardiovascular diseases (29%). Excluding nursing homes, 34% of all the deaths occurred at home (private or with family), 16% in a care home, 40% in a hospital, and 9% in a hospice or palliative care unit.

Table 2 shows the incidence of GP awareness of patients' preferred POD within the last 3 months of life. Slightly more patients had GPs who were aware of their preferred POD than unaware. Of GPs who were aware of their patients' preferred POD, 84% were informed by the patients themselves, 44% (also) by family members of the patients. Most of the patients preferred to die at home, although some preferred to die in a care home, a hospice or palliative care unit, and in a hospital.

Table 3 shows patient and care characteristics of the patients, and their association with the GPs' awareness of patients' preferred POD. Of the patient characteristics assessed, only the patients' financial status remained associated with GP-awareness in the multiple regression analysis, patients with a financial status above average (as estimated by the GP) having about 7 times higher chance of the GP-awareness of their preferred POD, than those financially below average. Having cancer, as opposed to other diagnoses, was positively associated univariately (odds ratio [OR]: 3.2), but did not remain so in the multivariate analysis.

Although all investigated care characteristics were univariately associated with GP-awareness, five variables remained significant in the multivariate analysis. Those positively associated with GP awareness were being cared for at home; receiving care directed at palliation or life prolongation (rather than cure) in the last two to three months of life, using specialized palliative care services, receiving care that was focused on spiritual or psychosocial needs (rather than physical) in the last week of life, and dying elsewhere than in a hospital (especially strong for dying at home; OR: 24).

Table 4 shows the relationship between preferred and actual place of death in percentages, for those patients whose GPs were aware of their preferred place of death. The proportion of patients whose preferences were met was calculated, per the actual place of death. Overall, 84% of the patients died in the place they had preferred. When the patient's preference was for a hospital death, this preference was met in all cases. The lowest proportion of patients whose preferences were met died at home or in a hospice.

**Table 2:** GP awareness of their patient's preferred place of death (N=637<sup>1</sup>)

	%
	(N=637)
Not aware of patient's preferred place of death	46
Aware of patient's preferred place of death	54
<hr/>	
The general practitioner was informed by:	(n=374) <sup>2</sup>
Patient himself / herself	84
A family member or a significant relative	44
Specialist, carer or some other person	3
Preferred place of death for these patients:	(n=374) <sup>2</sup>
At home (private or with family)	69
In a care home	19
In a hospice or palliative care unit	10
In a hospital	2

<sup>1</sup>Weighted percentages, excluding nursing home deaths

<sup>2</sup>More than one answer possible

## Discussion

This study provides information on GP awareness of their patients' preferred POD, dying in a preferred place, and factors that are related to them. It is the first study reporting on end-of-life care from a general end-of-life patient population in the Netherlands. Its methodology is akin to one previously used in Belgium (33), and the nationwide collection of reliable data was made possible by the participation of committed Sentinel GPs (33–36).

Forty-six percent of patients had GPs who were not aware of their preferred POD. Of those whose GPs were aware, 88% had preferred to die in a private or care home, 10% in a hospice or palliative care unit and 2% in a hospital. The GPs had been informed by the patients themselves in 84% of cases. Having financial status 'above average', a life-prolongation or palliative care goal, and using specialist palliative care services were associated with higher GP-awareness odds. Four-fifth of patients with known preferred POD died there.

Our data were sourced via the Sentinel Network of GPs in the Netherlands. This network is well-suited for reporting in retrospect, prospectively-collected data through a continuous morbidity registration (CMR) process, and its outcome is typically used for monitoring and harmonising health information (33–36). The general practice milieu additionally suits our study because in the Netherlands, registration with a GP is compulsory for access to health care (35;36). The Dutch primary care system is equally accessible to all socio-demographic subgroups (36). Also, involving GPs ensured that the quality of registration was high and virtually all the sentinel

deaths were captured; since GPs are routinely informed about the death of their patients, and sentinel GPs are specially trained for this form of data collection (33–35). With the exclusion of all nursing home deaths, our sample was representative nationally. The lack of representativeness for nursing home patients is a limitation that was expected because nursing home physicians take over care from GPs once patients are admitted in nursing homes for long-term care (4;38). Another limitation was the use of information derived from GPs alone, rather than alongside information from the patients themselves - research demonstrates that ‘proxies’ are not very accurate in representing patient needs (39).

This study portrays a patient’s financial (or social) status as being important, in determining GP awareness of preferred POD. While it is known that a higher socioeconomic status generally translates to more education and more access to information, Andersen’s model on the use of health services explains how a person’s financial status could determine his (or her) ability to cope with presenting problems and command resources to deal with same (27;32). Other patient characteristics, such as age and gender were however not associated with GP awareness.

Among the various care characteristics analysed, patients whose care focused on palliation (comfort) or prolongation of life appeared to have discussed their preferred POD with their GPs more often as opposed those with care focussed on cure. This could be related to the fact that a lot of these patients died from cancer-related causes which have a more predictable trajectory towards death (40); and cancer patients are more likely to discuss end-of-life issues with their care-givers, than non-cancer patients (16;17;26). Similarly, caregivers are more likely to refer cancer patients for specialist palliative care services (41;42). With respect to the focus of care, GP awareness of a patient’s preferred POD was realised more often when the care focus was on psychosocial or spiritual (religious and existential) needs. Both forms of care could be used as proxies for good GP-patient communication (43), and for assessing a GP’s orientation towards end-of-life care (44).

Again from this study, it comes as no surprise that patients with more chances of GPs contact, or more communication (i.e. those at home, in care homes, and hospices, rather than hospitals) tended to die more often in a preferred place. Van Royen et al. (2002), using a theoretical framework of items showed that aside creating a closer GP-patient relationship, home visits actually allow for in-depth understanding of patient contextual information (45), and this might explain the higher congruence observed in these patients. Furthermore, GP-awareness was relatively higher (82%) among patients who had experienced no transitions in location of care in the last 3 months of lives, irrespective of the place of care, although only in the univariate analysis. While it is known that some transitions in location or domain of

care are inevitable (46), it could again be suggested that patients who are transferred, are less likely to have GPs who are aware of their preferred place of death. This is because some transfers disrupt the flow of care and attention that patients receive from their GPs (7;46). It is also possible that for some of these patients, the focus of care remained curative for a significant proportion of the illness time, resulting for instance, in recurrent hospital transitions. This may explain why the care setting transitions were not significant in the multivariate analysis, since the aim of treatment was significant in this analysis.

Although previous studies from selected populations have shown that most patients wish to die at home (10–13), our study shows that about 1 in 5 patients prefer to die in a care home and 1 in 10 patients in a hospice or palliative care unit. More so, in the Dutch context, a care home is really ‘home’ for most residents, and more people appear to be choosing care home deaths. Gott et al. (2004) in their study among older people demonstrated that whilst patients generally considered ‘home’ as their ideal place of care during dying, others identified practical problems in achieving this. Hence they prefer to die anywhere (other than home), but simultaneously strive for factors associated with ‘home’ such as the presence of family, familiarity and comfort (18).

Again from our results, GPs were twice as likely to have been informed of a patient’s preferred POD by the patients themselves, than by family members, and far less by other carers or even specialists. Though the exact time these GPs became aware was not examined in this study, one would suggest the need for timely exploration of care preferences directly from the patients themselves. Patients are often more comfortable sharing personal information with their GPs (47;48), and this opportunity is sadly lost if they are no longer able to communicate or represent themselves (3;39). Having said that, GPs should be aware that care preferences could change in the course of an illness, and therefore make allowances for this (22;48).

Given that this study focused on non-sudden deaths only, the proportion of patients whose GPs were aware of their preferred place of death (54%) would appear low. Possibly this was because some GPs did not find it important to ask, judged it too early to ask, or probably the patients were simply too sick to provide such information. Also it makes sense that some GPs would be less aware of their patients preferred POD if such patients had not been directly under their care for prolonged periods in the last months of their lives, e.g. those in hospital or in a hospice. However the positive association between GP-awareness and reception of care focused mainly on palliation and life prolongation, use of specialized palliative care services, and reception of spiritual or psychosocial care in the last week of life, suggests that imminent recognition of palliative needs is important for achieving GP-awareness.

While such an association may best be described as that of the “chicken and the egg”, yet this study suggests that a timely focus on palliative care is needful.

Finally, to provide quality care at the end-of-life, GPs require a sizeable amount of patient-detail, for which open and direct communication about diagnoses, prognoses and related preferences is encouraged (47;48). On-time recognition of impending death allows for better management of dying patients (49). This could prove challenging when planning care for non-cancer patients (such as those with congestive heart failure or chronic obstructive pulmonary disease), whose illness trajectories are relatively more complicated, and oftentimes less predictable (40). GPs should be taught to determine the last phase of all illnesses, and trained to discuss the dying process more openly with patients, including where the patients would prefer to die. Such conversations, with patients, their family members and primary caregivers will allow GPs make sharper assessments of their patients’ situation, and simultaneously prepare patients for all possible eventualities (2;43;48). On the whole, we advocate the employment of a more holistic approach to end-of-life care, and this incorporates palliation while seeking to provide cure.

In conclusion, this study demonstrates that there is a potential for improving GP awareness of patients’ preferred POD in the Netherlands. This can be achieved if palliative care ideals are integrated into general end-of-life care. Also it shows that the hospital remains the POD least preferred by a general practice population of patients facing death.

**Table 3:** Characteristics associated with the GP awareness of their patients' preferred place of death  
N=637<sup>1</sup>

	% of patients for which GP was aware <sup>2</sup>		Logistic regression <sup>3</sup>	
	Row %	Yes	Univariate Odds ratio (95%CI)	Multivariate <sup>4</sup> Odds ratio (95%CI)
Patient characteristics:	No	Yes		
Age				
1–64 years	41	59	1.0	<sup>5</sup>
65–89 years	50	50	0.7 (0.5–1.1)	
90–105 years	38	62	1.2 (0.7–2.1)	
Gender				
Male	43	57	1.0	<sup>5</sup>
Female	46	54	0.9 (0.6–1.3)	
Relational status				
Having a regular partner	43	57	1.2 (0.9–1.6)	<sup>5</sup>
Without regular partner	47	53	1.0	
Financial status				
Below average	54	46	1.0	1.0
Average	47	53	1.3 (0.9–2.0)	<b>2.4 (1.3–4.7)</b>
Above average	29	71	<b>2.9 (1.7–4.7)</b>	<b>5.8 (2.2–15.1)</b>
Primary cause of death				
Cancer	30	70	<b>3.2 (2.3–4.4)</b>	<sup>6</sup>
Not cancer	57	43	1.0	
Care characteristics:				
2–3 months before death				
Location of care				
Home	44	56	1.0	1.0
Other	46	54	0.9 (0.6–1.5)	0.4 (0.2–1.0)
Main goal of treatment				
Curative	71	29	1.0	1.0
Life prolonging	37	63	<b>4.0 (2.4–6.7)</b>	<b>3.5 (1.6–7.9)</b>
Palliative	26	74	<b>6.9 (4.4–10.9)</b>	<b>4.1 (2.0–8.4)</b>
Main focus (domain) of care				
Physical	51	49	1.0	<sup>6</sup>
Psychosocial	33	67	<b>2.1 (1.3–3.3)</b>	
Spiritual	43	57	1.3 (0.9–2.1)	
No. of care setting transitions				
None	18	82	<b>3.3 (2.1–5.3)</b>	<sup>6</sup>
One	68	32	0.3 (0.2–0.5)	
Two or more	42	58	1.0	
Use of specialized PC services				
Present	23	77	1.0	1.0
Absent	54	46	<b>0.3 (0.2–0.4)</b>	<b>0.4 (0.2–0.9)</b>
7 days before death				
Place of care <sup>2</sup>				
Hospital	83	17	1.0	1.0
Home	10	90	<b>40.1 (23.3–69.2)</b>	<b>27.4 (12.6–59.4)</b>
Care home	33	67	<b>9.5 (5.7–16.1)</b>	<b>13.9 (5.6–34.7)</b>
Hospice	31	69	<b>11.1 (5.9–20.9)</b>	<b>7.5 (2.6–21.2)</b>

	% of patients for which GP was aware <sup>2</sup>		Logistic regression <sup>3</sup>	
	Row %		Univariate	Multivariate <sup>4</sup>
			Odds ratio (95%CI)	Odds ratio (95%CI)
Main care domain				
Physical	62	38	1.0	1.0
Psychosocial	36	64	<b>2.9 (1.8–4.7)</b>	1.3 (0.6–3.0)
Spiritual	42	58	<b>2.2 (1.4–3.5)</b>	<b>3.0 (1.3–6.9)</b>

<sup>1</sup> Between 1–9% of these values could not be provided by the GP (i.e. missing observations)

<sup>2</sup> Weighted row percentages

<sup>3</sup> Dependent variable: GP aware of patient's preferred place of death (n=374), reference group: GP unaware (n=316)

<sup>4</sup> Stepwise backwards logistic regression (significant values in bold print)

<sup>5</sup> Not entered in multiple backwards logistic regression

<sup>6</sup> Variable removed within steps 2–7 of the backward regression analysis

**Table 4:** Percentage agreement between Preferred and Actual place of death (POD) for patients whose GPs were aware of their preferred place of death (N=374)

Actual POD <sup>1</sup>					
Preferred POD <sup>1</sup>	% Home (95% CI)	% Care home (95% CI)	% Hospital (95% CI)	% Hospice (95% CI)	Row % Total (N=374)
Home	<b>83</b> (78–88)	3 (1–6)	13 (9–18)	1 (0.1–3)	100 (n=221)
Care home	6 (2–14)	<b>92</b> (84–97)	1 (0.3–6)	0 (-)	100 (n=79)
Hospital	0 (-)	0 (-)	<b>100</b> (91–100)	0 (-)	100 (n=41)
Hospice	6 (1–24)	0 (-)	11 (1–31)	<b>83</b> (62–97)	100 (n=20)

<sup>1</sup> Rounded percentages, weighted values, excluding 13 reported nursing home deaths

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## Chapter 5

# Transitions between Care Settings at end of life in the Netherlands: results from a nationwide study

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## Abstract

Multiple transitions between care settings in the last phase of life could jeopardise continuity of care and overall end-of-life patient care. Using a mortality follow-back study, we examined the nature and prevalence of transitions between Dutch care settings in the last 3 months of life, and identified potential characteristics associated with them. During the 2-year study period, 690 registered patients died 'totally expectedly and non-suddenly'. These made 709 transitions in the last 3 months, which involved a hospital two times out of three, and covered 43 distinct care trajectories. The most frequent trajectory was home-to-hospital (48%). Forty-six percent experienced  $\geq 1$  transition in their last month of life. Male gender, multimorbidities, and absence of GP awareness of a patient's wish for place of death were associated with having a transition in the last 30 days; age of  $\leq 85$  years, having an infection and the absence of a palliative-centred treatment goal were associated with terminal hospitalisation for  $\geq 7$  days. Although the majority of the 'totally expected and non-sudden' deaths occurred at home, transitions to hospitals were relatively frequent. To minimize abrupt or frequent transitions just before death, timely recognition of the palliative phase of dying is important.

## Introduction

Care setting transitions at the end of life can be burdensome for those concerned (1–4). Arguably, such transitions pose a challenge to the continuity of patient care (5). With rising life expectancy in developed countries, significant numbers of deaths will follow ageing and multiple chronic illnesses (1;6). The protracted nature of these non-acute deaths often warrants transitions between settings (2;3;7), since different illness trajectories suggest different care needs (8). The underlying aim of palliative care is to ensure the best possible quality of life for the entire duration of an illness (1;9). To achieve this, patients require optimal comfort and relative stability (1;10), devoid of ill-planned transitions (2;4;7). There is a potential relationship between end-of-life transitions and patient safety, comfort, quality of life and general well being (10;11). Moreover transitions to hospitals and other acute care settings at the end of life tend to provide more aggressive and potentially futile treatments (2;4;11), at the expense of enhancing continuity (12;13).

From a care perspective, some transitions will be inevitable (2;11;14). In the Netherlands, the tradition of openness and candour makes the expression of preferences for place of care commonplace (15). Dutch General Practitioners (GPs) provide continuity between different settings at the end of life (2;12;13), but in common with other physicians may be unable to identify the terminal phase in all dying patients (16). In addition, they oversee terminal care in residential homes and at home (17), the preferred place of death for many (18). However, data monitoring from the general population on the epidemiology of transitions at the end of life, rather than individual evaluation of the care of dying patients, is scarce (2;18). Past studies on end-of-life transitions have focussed on characteristics of dying in certain settings (17;18), on transitions within distinct patient or care groups (3;10;17), or on transitions to specific settings (19;20). The first population-based study on transitions between care settings (SENTI-MELC) was performed in Belgium (7). Using a similar methodology, this study seeks to address the following four research questions:

1. How often are patients transferred between care settings in the final three months of life?
2. Which distinct care setting trajectories can be identified in the final three months of life?
3. Where are the patients cared for in the last 90 days of life?
4. What patient, disease and healthcare characteristics are associated with care setting transitions in the last month (30 days) of life, and with terminal hospitalisation throughout the last week (7 days) of life?

## Methods

### Study design and population

This study, the **Senti-Monitoring End-of-Life Care (SENTI-MELC)** is a mortality follow-back study which seeks to monitor the quality of care provided via GPs to a general population of end-of-life patients in the Netherlands. This method was first used and reported in Belgium (7,19,21). Between 2005 and 2006, appropriate patient data were collected via the nationwide Dutch Sentinel Network of general practitioners (GPs), an existing health surveillance instrument (22;23). This network consists of 45 general practices (65–70 GPs) and covers approximately 1% of the entire 16 million registered patient population in the Netherlands (23). The data collection process was supervised by the Netherlands Institute of Health Services Research (NIVEL). With the exception of nursing home deaths, our sample was representative nationwide; gender and age were comparable per setting to corresponding mortality rates per setting in the Netherlands (24).

### Procedure

Within 1 week of reporting a patient's death, participating Sentinel GPs were asked to fill in a registration form surveying information regarding the care the deceased received in the last 3 months of life. In order to clearly identify those patients who were eligible to receiving palliative care in their last days, GPs were asked if the death in question had been "sudden and totally unexpected". Deaths of patients  $\leq 1$  year old were excluded to exclude deaths from congenital problems. On completion, the registration forms were returned to NIVEL where they were scrutinised for missing data and errors, duplicated and then sent to the researchers for analysis.

### Measurement instrument

Following an exhaustive literature review of themes relevant to end-of-life care, and review by a multidisciplinary team of researchers, questions were developed, reviewed and adapted. The resulting registration form was made of 15 items (one A4 page) which included multiple-choice and open-response questions on the following: patient characteristics; cause of and preferred place of death; care characteristics including locations of care in the last 3 months of life; GP awareness of preferred place of death; involvement of specialist (multidisciplinary) palliative care services; the main goal of patient's treatment (curative/life prolonging /palliative); the main focus of care (physical / psychosocial /spiritual); the place of care (3 months to weeks before death); and the actual place of death. Next the GPs were

asked to provide the settings in which the patients had received care during the last 3 months of life, and the number of days spent per transition.

### **Definitions**

- A transition is a change in the setting or location of patient care
- A trajectory is the pathway of care settings a patient lived in, during the last 3 months of life
- Terminal hospitalisation refers to hospitalisation until death

### **Place of death in the Dutch context**

Settings for receiving end-of-life care and for dying in the Netherlands can be classified into 2 broad categories:

- Regular settings (homes and care homes)
- Specialised settings (nursing homes, palliative care units -including hospices, hospitals)

These settings offer a variety of possibilities or care packages. Care homes are homes for the elderly and provide basic support through informal caregivers. Inhabitants of care homes like those at home remain under the care of their GPs (16). Nursing homes have their own specialist physicians who take over patient care from GPs following transfer of the patient. This implies that care trajectories involving nursing homes are usually outside the purview of GPs (16;25). Palliative care units and hospices provide patients with specialised end-of-life care (26). They operate exclusively, or sometimes as part of hospitals, care and nursing homes.

### **Statistical analyses**

From the 690 non-sudden deaths registered via the Sentinel GP Network, we calculated the frequency of transitions and charted all distinct care trajectories per place of death in the last 3 months of life. We then used regression analyses to examine the characteristics which were associated with having a transition in the last 30 days of life or being hospitalised for all the last 7 days of life. Multivariate analyses followed the univariate binary regression whenever the patient or care characteristics were found to be significantly associated with  $\geq 1$  transition. All variables having significant relationships were included in a stepwise backward logistic regression in order to make a predictive model. Results were tested using the Wald chi-square test at one degree of freedom and were considered significant if the p-value was  $<0.05$ . Similar analyses were repeated to identify characteristics associated with having a terminal hospital admission of at least seven days. SPSS for Windows version 15.0 was used for all our analyses.

## **Ethical consideration**

An approval from the Dutch Ethical Review Board was not required for this study because data were collected post-mortem. However, strict patient and physician anonymity was preserved throughout the registration and data entry process as required.

## **Results**

### **Study Population and frequency of transitions in the last 3 months of life**

Between 1 January 2005 and 31 December 2006, 690 ‘totally expected and non-sudden deaths’ were registered via the Dutch Sentinel network of GPs. Thirty-five percent of the patients were aged 85 years or more, 52% were male, 52% had no regular partner or spouse, 25% had financial resources estimated as ‘below average’ and 42% died of cancer. Most patients (67%) experienced one or more transitions in the last three months, 46% in the last month, and 19% in the last week of life. A total of 709 transitions were made within the last three months, producing 43 distinct care trajectories 67% of which involved a hospital at some point in time.

### **Distinct care setting trajectories in the last 3 months of life**

Forty-three distinct care setting trajectories were identified in all (Figure 1): 19; 8; 5; 1 and 10 for patients who resided at home, in a care home, nursing home, palliative unit or hospice, and hospital three months prior to death respectively. Of those patients at home 3 months prior to death, 36% died there without any transition, 36% were transferred to a hospital and died there, and 9% were transferred from home to hospital and back home again. With regards to care homes, 73% of the patients were not transferred, 17% were transferred once to a hospital where they died, and 5% were transferred via the hospital to a home, care home or nursing home. Overall, trajectories from home to hospital (48%); home to hospital to home (12%); care home to hospital (5%); and home to hospital to nursing home (5%) occurred most frequent. There was no transition from a hospice or palliative care setting to a hospital in the last 3 months of life.

### **The places of care in the last 3 months of life**

Figure 2 shows the number of patients staying in a particular setting on a day by day sequence, per 3 time-intervals within the last 90 days of life. Within the 60–90-day interval prior to death, patient numbers remained fairly same per setting. In the 30–60-day interval prior to death, the proportion of patients on hospital admission

increased gradually, while the proportion at home reduced likewise. In the last 30-day interval, there was a much steeper increase and drop in the proportion of patients at home and in the in hospitals respectively. Proportions of patients in nursing homes and palliative care units (or hospices) also increased somewhat. The proportion of patients in care homes remained relatively stable throughout the three time-intervals within the patients' last 3-month period.

### **Characteristics associated with $\geq 1$ transition in the last 30 days, and terminal hospitalisation throughout the last 7 days of life**

Within the last month of life, female patients, patients aged below 65 and those above 84 years, those with single morbidities, those suffering from acute respiratory disorders and infections such as pneumonia were less likely to be transferred in the last month of life. Also, the patients whose GPs were aware of their 'place of death' wish and whose care in the last phase of life was primarily 'palliative' were less likely to be transferred (table 1). With respect to the terminal hospitalisation in the last seven days of life, patients older than 84, those without infections, those whose GPs were aware of their 'place of death' wish, and those with a 'palliative' care goal were least likely to be moved than all others (table 2).

## **Discussion**

We examined the pattern of end-of-life transitions between different care settings over a 2-year period in the Netherlands. From 690 patients whose deaths were "totally expected and non-sudden", we identified 43 distinct care trajectories and 709 transitions (67% of which involved a hospital) in the last three months of life. The most frequent trajectory was home-hospital (48%). Forty-six percent of the cohort experienced  $\geq 1$  transition in their last month of life. Being male, having multiple morbidities and an absent GP-awareness of a patient's preferred place of death were associated with having a transition in the last 30 days of life; whereas being aged  $\leq 85$  years, having an infection and no palliative-centred treatment goal were associated with terminal hospitalisation for  $\geq 7$  days.

This is the first nationwide study that attempts to monitor and estimate the number of transitions between care settings at the end of life in the Netherlands. Rather than evaluate individual patient care, we examined a general patient population of all those who could potentially benefit from planned terminal care, or at least palliative care – which comprised more than just cancer patients (1;3;12). The ultimate goal is to use the information generated for organizing health care, particularly for

older people. Adequate knowledge of transition trends could dictate areas where potential challenges lie, in terms of planning.

The quality of this study was enhanced by the participation of trained sentinel GPs (21;23), who play a gate-keeper function to the health care system in the Netherlands (23). Their function as patient-proxies, however, may have constituted a limitation, perhaps resulting in self-reporting and information biases (14;21). Also, it is possible that some GPs missed out on some transitions in the course of the registration. Nevertheless, the chance of GPs missing a transition would be higher for patients in nursing homes than for those residing at home or in care homes.

In comparison with the Belgian SENTI-MELC study on transitions (7), patient characteristics were quite similar; patients >85 years (35%: 32%), male gender (52%: 49%) and deaths from cancer (42%: 41%) respectively. At least one transition was experienced by 78% of patients residing at home and 92% of patients residing in care homes, in contrast to 73% and 36%, respectively, in Belgium. The most frequent trajectory in the Netherlands (as in Belgium) was from home-to-hospital (36% versus 40%). The Belgian cohort experienced no transition at all in more instances than the Dutch (38% versus 33%), although the Belgian cohort had many more hospitalized versus home patients at death (40% to 26%) than the Dutch (34% to 37%). However, the variation in transition trends observed cannot be interpreted in isolation, despite some inherent similarities in both health care systems (7;17;27).

The majority of the transitions we reported took patients away from, rather than to, their homes or usual place of residence. This is ironical because the 'home' is often considered to be the most preferred place of death (2;17;18), and dying in one's preferred place could be related to the quality of dying and terminal care (2;11;28). Comparatively, transitions from care homes were fewer than those from homes, even though care in both settings is routinely managed by the same GPs. This is perhaps because care homes residents are predominantly elderly, who often demand less aggressive treatment (29). It is understandable also that based on age, death would be more expected and discussed in care homes (14;18;30). From our results, those who were not transferred in their last month of life were more frequently women, were >85 years of age, and had no regular partners. These characteristics generally match those of care home inhabitants, and are in consonance with findings from a Canadian study (10).

Overall, a small percentage of transitions involved a palliative care setting or hospice. The pattern observed may be unique to the Dutch system of care which has specialist physician-run nursing homes (25). However, late decisions for referral to hospices could debar terminally ill patients from the various kinds of specialized

palliative care initiatives that such units provide. Unlike findings from Belgium and Japan, our study shows that no patient was transferred away from a hospice or palliative care setting to a hospital (7;30). This may have been due to the fact that these settings are better equipped to handle medical emergencies (17).

We recognise that all transitions to hospitals are not in themselves bad or unnecessary. Gott et al. (29) demonstrated that many older people prefer to be cared for away from home at the end of life. Also, it is clear that some of the medical conditions which led to death in the patients who were hospitalised might have required the kind of care hospitals are best equipped to provide (exploration of this was outside the scope of our study), i.e. an acute episode of infection could warrant hospitalisation. These points notwithstanding, definite attempts should be made to factor transitions into individual patient management, with increased GP awareness of patient and family preferences, and timely communication of the care goals, including those outside the realm of immediate care. Our findings - the GP being aware of a patient's preferred place of death and the main treatment goal being palliative care - point in this direction.

In conclusion, our data show that most 'non-sudden and totally expected' deaths in the Netherlands take place at home, and that transitions to hospitals are relatively frequent. Two-thirds of patients who died non-suddenly experienced transitions between care settings in the last three months of life, while 20% were transferred between care settings in the last week of life. The frequency of transitions on a population level increased markedly in the last month of life, possibly due to changes in the clinical situation of the patients as death approached. In Belgium unlike the Netherlands, the percentage number of patients in hospital exceeds those at home in the last 10 days of life, probably as a result of country-specific reasons. In order to minimise transition-related burdens to patients and carers, even in the most justifiable of cases, anticipation and timely recognition of the palliative phase is advised. Furthermore, integration of palliative care into general end-of-life care may accrue long-term cost benefits (31).

**Table 1:** Total number of care setting transitions made during the last 3 months of life (n=690<sup>†</sup>)

Number of transitions <sup>†</sup>	Last 3 months of life		Last month of life		Last seven days of life	
	N	Column % (95% CI) *	N	Column % (95% CI) *	N	Column % (95% CI) *
None	224	32.8 (29.3–36.3)	371	54.0 (50.3–57.7)	551	80.2 (77.2–83.2)
One	258	38.4 (34.8–42.0)	254	37.0 (33.4–40.6)	132	19.2 (16.3–22.2)
Two	143	20.7 (17.7–23.7)	57	8.3 (6.3–10.6)	4	0.6 (0.2–1.5)
Three	55	8.1 (6.2–10.4)	5	0.7 (0.2–1.7)	0	-

**Table 2:** Characteristics associated with ‘one or more transition’ in the last 30 days of life (N=690\*) and with staying in a hospital for ALL the last seven days of life (N=690)

Patient characteristics:	Patients had a transition between care settings in last 30 days of life			Patients who spent their last 7 days on a hospital admission		
	No n=371	Yes N=316	Odds ratio	No n=540	Yes n=147	Odds ratio
Age						
1–64 years	59	41	1.5 (0.8–2.7)	76	24	<b>3.2 (1.6–6.5)</b>
65–84 years	48	52	<b>1.7 (1.1–2.7)</b>	75	25	<b>2.1 (1.2–3.6)</b>
85–104 years	62	38	1.0	85	15	1.0
Gender						
Male	50	50	<b>1.9 (1.2–2.9)</b>	77	23	<sup>3</sup>
Female	60	40	1.0	82	18	
Had a regular partner						
Yes	52	48	<sup>3</sup>	77	23	<sup>3</sup>
No	56	44		81	19	
Financial resource						
Below average	52	48	<sup>3</sup>	82	18	<sup>3</sup>
Average	54	46		77	23	
- Above average	59	41		81	19	
Disease entities registered by GP:						
Cancer						
No	52	48	<sup>3</sup>	76	24	<sup>3</sup>
- Yes	57	43		82	18	
Heart disease						
No	57	43	<sup>3</sup>	80	20	<sup>3</sup>
- Yes	50	50		77	23	
Respiratory disorders						
No	56	44	<sup>4</sup>	79	21	<sup>3</sup>
- Yes	37	63		72	28	
Infection (pneumonia, sepsis)						
No	57	43	<sup>4</sup>	81	19	1.0
- Yes	45	55		68	32	<b>2.1 (1.3–3.6)</b>
Multiple morbidities						
No	61	39	1.0	82	18	<sup>4</sup>
- Yes	42	58	<b>1.7 (1.1–2.6)</b>	71	29	
Care characteristics:						
GP awareness of ‘place of death’ wish						
No	33	67	<b>4.1 (2.7–6.3)</b>	62	38	<b>6.6 (4.0–11.1)</b>
Yes	72	28	1.0	93	7	1.0
Main ‘care goal’ 30 days before death						
Curative	32	68	<b>2.8 (1.5–5.0)</b>	63	37	<b>2.1 (1.1–3.8)</b>
Life prolonging	34	66	<b>2.8 (1.6–4.9)</b>	66	34	<b>2.0 (1.2–3.6)</b>
Palliative	66	34	1.0	86	14	1.0

	Patients had a transition between care settings in last 30 days of life			Patients who spent their last 7 days on a hospital admission		
		Row %			Row %	
Main 'care content' 30 days before death						
Physical	48	52	<sup>4</sup>	78	22	<sup>3</sup>
Psychosocial	61	39		84	16	
Spiritual	53	47		76	24	
Specialized palliative care consult						
Absent	50	50	<sup>3</sup>	79	21	<sup>3</sup>
- Present	59	41		81	19	

\* 3 missing values

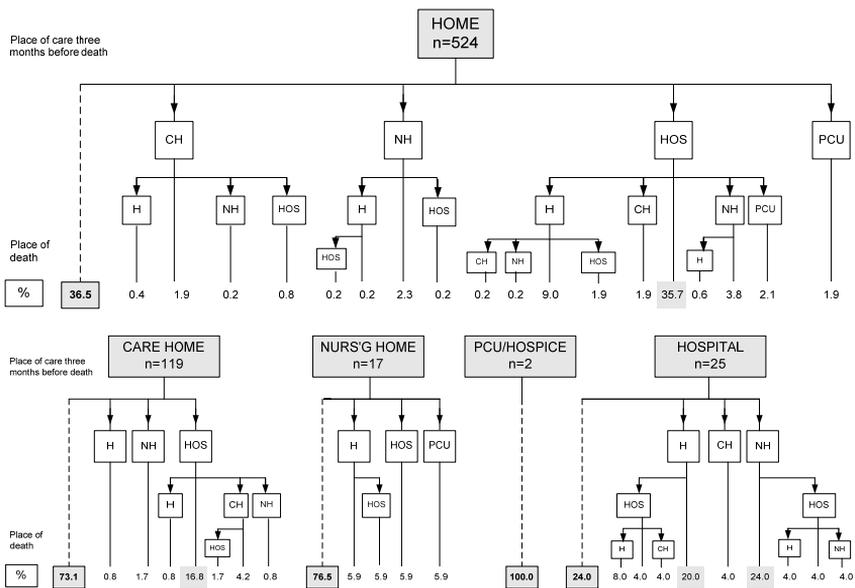
<sup>1</sup> Dependent variable<sup>1</sup>: People not transferred at all in the last month (30days) prior to death (n=371), reference group: people who had one or more transitions in the last month of their lives (n=316)

<sup>1</sup> Dependent variable<sup>2</sup>: People on hospital admission seven days prior to death (n=147), reference group: people who were not on hospital admission for the last seven days of their lives (n=540)

<sup>2</sup> Stepwise backwards logistic regression (significant values in bold print)

<sup>3</sup> Not entered in multiple backwards logistic regression analyses

<sup>4</sup> Variables removed after 3/4 steps of the backward regression analyses

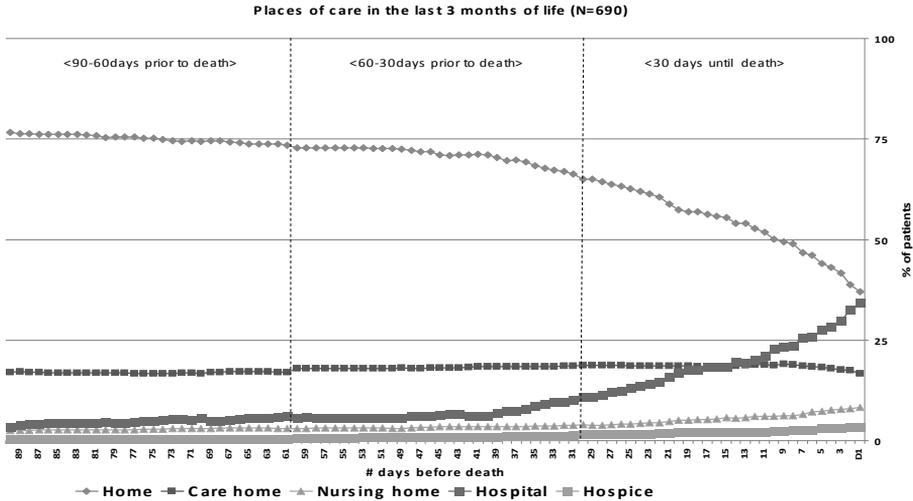


**Figure 1:** Distinct care setting trajectories in the last 3 months of life (n=690\*)

**Key:** H=Home; CH=Care home; NH=Nursing home; HOS=Hospital; PCU= Palliative care unit or Hospice

No transition = dotted lines at the extreme left (i.e. patient remained in the same setting x last 3 months of life). Trajectories with ≥10% are shaded grey.

\*3 missing cases or distinct patient trajectories. Rounded percentages. Multinomial confidence interval (95%): exact method.



**Figure 2:** Places of care in the last 3 and last month of life (N=690\*)

The X-axis represents the number of days prior to death

The Y-axis represents the percentage of patients in a particular setting

Care trajectories were missing for 3 cases.

Rounded percentages.

Multinomial confidence interval (95%): exact method.

Note that the places of care from 30 days prior to death demonstrate a steep transition gradient in the last few weeks of life.

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## Chapter 6

# Use of palliative care services and end-of-life GP visits in the Netherlands and Belgium

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## Abstract

*Context:* At the end of life, some personalised and specialised care is required. The way that general practitioner (GP) visits and palliative care services at the end of life are organised in different countries may impact the frequency of care provision. However, nationwide data on these interventions and comparisons between countries are scarce.

*Objective:* To compare the frequency of GP visits and use of palliative care services at the end of life in two European countries and identify the associated factors.

*Methods:* In 2007, two mortality follow-back studies were conducted simultaneously in the Netherlands and Belgium, using existing sentinel GP networks and similar standardised procedures. Within the one-year period, all registered patients who died at home or in a care home were selected.

*Results:* From the data of 543 registered patients, GP visits are more frequent at the end of life in the Netherlands than in Belgium: the mean number of GP visit in the last week of life was 5.1 vs. 3.2 (home) and 4.4 vs. 2.3 (care home). Conversely, palliative care services in the last three months of life are used more frequently in Belgium than in the Netherlands: 78% vs. 41% (home) and 39% vs. 5% (care home). The differences between countries remain consistent despite correcting for possible confounders. Having more frequent GP visits at home is associated with cancer-related deaths both in the Netherlands and Belgium.

*Conclusion:* Independent of the differences in patient populations (at home and care home) between countries, there are more frequent GP visits at the end of life in the Netherlands, and greater use of palliative care services in Belgium.

## Introduction

Patients with life-threatening diseases have unique needs that may require personalized (1;2) and specialized care on a continuous basis (3–5), till death. The ultimate goal of palliative care is to ensure the best possible quality of life for such patients through the entire duration of their illnesses (6;7). Given the current ageing trend in most Western populations (8), the rise in nonacute deaths (9), and the fact that the home is the preferred place of death for many (10;11), general practitioners (GPs) play a key role in end-of-life care (12). Their tasks include managing interpersonal relationships between the incurably ill, their families and a host of care providers (12–16), providing adequate support to their staff (2), and maintaining continuity of information and care (17). Home visits, which traditionally are a part of their normal routine (18;19) become more strategic (12), and often are done more frequently as conditions worsen (20). To improve overall health outcomes and guide quality efforts, collaborations are encouraged with multidisciplinary palliative care teams (3;7;21;22), even before death becomes imminent (7). Such multidisciplinary teams, comprise specially trained professionals who are well equipped to relieve patients of pain and refractory symptoms, and support primary carers in other meaningful ways (7;23). In the United Kingdom and the United States, GPs may function within standardized frameworks or policies that enable the fusion of end-of-life initiatives and resources into primary care practices (4;7). In spite of recent proliferation of palliative care services and initiatives in developed nations, specialized palliative care teams are yet unevenly distributed in some regions (24–26), between patient groups (25;27) and across care settings (28;29), and when present, patient needs (4;14), insufficient physician knowledge and misconceptions (14;15;32) and existing care policies (30;31) could dictate the frequency and extent of their use.

In the Netherlands and Belgium, there is a strong emphasis on primary care, with GPs of the former having a more restrictive gatekeeper function to secondary care access. About 95% of the entire population in both countries, have a regular GP, i.e. including residential care home residents (33;34). There is a relatively low availability of care home beds, in Flanders (Belgium) compared with the Netherlands, although the patients dying in hospital and nursing homes in the two countries have different profiles. In 2006, 57% of the Dutch population died of chronic progressive illnesses, and almost a third of all deaths occurred in a home setting (9). There was a 6% rise in nonacute deaths between 1996 and 2006 (9); and in 2008, the national statistics reflected a switch in paradigm, with the proportion of cancer deaths exceeding those from heart diseases (35). Comparative data from a 2001 death certificate study in northern Belgium (Flanders) produced a similar pattern of results, with about a quarter of all the deaths occurring at home that year (36). Although some data on traditional GP home visits do exist (18;19), the frequency of GP visits at the

end of life and use of palliative care initiatives is largely unknown. Furthermore, cross-country comparisons can be limited by differences in study design, making the results difficult to compare.

In this study, we examined terminal care in the setting where most people prefer to die, which is at home or in a regular place of residence (10;11). Using the same research instrument in the Netherlands and Belgium, we explored:

- i. The characteristics of terminally ill patients who die at home (and in care homes), the frequency of GP visits at the end of life and use of palliative care services towards death; and
- ii. The associations among these characteristics and having frequent GP visits in the last week of life, and the use of palliative care services in the last three months of life.

## Methods

### Study design & procedure

This study, the Sentinel network Monitoring End-of-Life Care study, (SENTI-MELC), is a mortality follow-back study that has sought to examine patient care from within a general population of end-of-life patients, in parts of Europe since 2005 (37–40). In 2007, we conducted two studies simultaneously in the Netherlands and Belgium using a similar nationwide health surveillance network of GPs and similar standardised procedures of data collection. Participating sentinel GPs were representative of the GPs in both countries (39;41). GPs were requested to provide data on deceased patients, and the entire data collection process was supervised by a nationally-operating public health research institute, or its equivalent. With the exception of the Dutch nursing home deaths, the samples were representative nationwide in both countries; gender and age were comparable per setting to corresponding national mortality rates (37;39). A detailed description of the SENTI-MELC study methodology is published elsewhere (39). Within one week after a patient's death, the GPs were asked to fill in a registration form providing information about care the deceased had received in the last three months of life. The completed forms were returned to NIVEL<sup>1</sup>/ IPH<sup>2</sup> where they were scrutinised for missing data and errors (34;37). Patients whose forms had multiple missing variables were excluded from the study. The Belgian patients had their information further encoded at IPH<sup>2</sup> for confidentiality purposes (39). All data were sent to the researchers for analyses.

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<sup>1</sup> NIVEL: The Netherlands Institute for health services research.

<sup>2</sup> IPH: The Belgian Scientific Institute of Public Health.

## Settings and study population

In 2007, the Dutch and Belgian sentinel GP networks consisted of 45 (including 67 GPs) and 181 (including 205 GPs) regular general practices respectively, covering approximately 1–2% of the total registered patient population in both countries (34;39). Because our focus was on those eligible to receive palliative care and those who died at home or in a care home, we excluded all patients who had died “totally unexpected and suddenly”; all those aged one year or younger (to eliminate congenital problem-related deaths); and all those who had died in a palliative care unit, hospital or in a Dutch nursing home, where care is usually taken over by a specialist (i.e., so as to provide comparable cohorts in both countries). The Dutch care home, like in Belgium is a residential care home for frail and elderly persons (42). Some Belgian care homes are adapted to meet more complex needs (40). GPs are the attending physicians and can provide a reasonable account of patient care in the period leading to death, because they remain in charge of care at home and in care homes in both countries, unlike in Dutch nursing homes where a nursing home physician takes over care after a transfer (42).

## Instrument

The research instrument (registration form) consisted of 19 items on a two-sided A4 page. There were multiple-choice and open-ended questions on patient characteristics (age, gender, ethnic group, postal code and highest education attained); the cause of death; preferred place of death; and care characteristics in the last three months of life, that is, GP awareness of preferred place of death, involvement of multidisciplinary palliative care services, the main goal of patient’s treatment in the last week of life (curative/life prolonging /palliative), the longest place of residence in the last year of life, and the actual place of death. We used internationally-accepted nomenclature, disease classifications (ICD-10), and the Edmonton Symptom Assessment Scale (ESAS) for symptoms in the last three days of life, 10 being the worst possible clinical scenario on a scale of 0–10 (43). The GPs were asked to estimate the number of visits made to a patient’s home or bedside, (excluding telephone calls and other indirect consultations), and the use of palliative care services per patient, selecting from five broad categories of existing and well-known multidisciplinary care initiatives in both countries that are accessible to patients at the end of life (40). In the Netherlands, we included: 1) a GP with palliative care training, 2) a team with a palliative care consultant (trained nurse or physician), 3) hospital-based palliative units, 4) nursing-home-based palliative units, and 5) hospice day care facility. In Belgium, there were 1) multi-disciplinary palliative support home-care teams, 2) hospital-based mobile support teams, 3) hospital-based palliative units, 4) palliative day-care centres, and 5) care home-based palliative reference nurses.

## Comparing Dutch and Belgian Primary End-of-Life Care Services

GPs in the Netherlands are strict gatekeepers to the health care system, which does not allow patients direct access to the use of specialised services. In contrast, patients in Belgium could by-pass their GP, directly accessing specialised services. Non-sudden deaths commonly occur at home, residential care homes, nursing homes, hospitals and hospices in both countries. Aside from the differences in nursing home organisation, the Dutch palliative care institution is further varied; with high-care hospices (with a physician), low-care hospices, and units for short-term terminal care in nursing homes (with a physician) or residential homes. A recent death certificate study showed significant differences in care home deaths in the Netherlands vs. Belgium (34% vs. 22%), and hospital deaths (34% vs. 52%) (36). Non-sudden deaths in the Netherlands and in Belgium (Flanders) are mainly as a result of ageing, cancers and other chronic illnesses; the deaths of persons older than 80 years in the Netherlands vs. Belgium were 47% vs. 49%, respectively. Cancer, cardiovascular-related and respiratory-related deaths occurred in the Netherlands in 27%, 25% and 10% respectively, and in Belgium in 26%, 28% and 13%, respectively.

### Statistical analysis

Using SPSS 15.0, all the non-sudden and totally expected deaths at home or care home were selected (n=543). Patient characteristics, frequency of GP home visits and the use of palliative care services were compared across countries, per setting using Pearson's  $\chi^2$  and the Mann-Whitney U test (significance level of  $\leq 0.05$ ). Separately, we used linear and logistic regression to investigate the influence of possible confounders on the differences between countries. The possible confounders were defined as the patient, disease and care-related characteristics that differed significantly between countries (see Table 1). Country was entered in hierarchical multiple linear (for GP visits) and logistic regression analyses (for palliative care service use), followed by each of the potential confounders, regarding frequency of end-of-life visits by GP and use of palliative care services as dependent variables.

Because of the skewed distribution of the data, logistic regression was again used to identify the variables that were associated with having GP home visits (dichotomized using the median) and using palliative care services in the last three months. Associated patient and care characteristics were analysed univariately, and to make a predictive model, all the variables that had a significant ( $p \leq 0.05$ ) relationship were included in a stepwise backward logistic regression, that is, variables were removed from the equation where  $p > 0.05$ .

## **Ethical Considerations**

An approval from the Ethical Review Board was not required for this study in the Netherlands because of the nature of the data collection (postmortem), whereas in Belgium, the study protocol was approved by the relevant Ethical Review Board. In both countries, patient anonymity was preserved and physician confidentiality maintained through the registration and data entry processes.

## **Results**

### **Characteristics of Study Population**

About 63% of the total 1,711 deaths registered by the sentinel GPs had been non-sudden (n=1,075). From this, we selected 570 patients who had lived for the longest part of their last year at home or in a care home, excluded 27 cases (for having predominantly missing values); this left 543 patients. Overall, the proportion of men, home deaths and palliative treatment goal were more in the Netherlands than in Belgium.

Across all home deaths, the countries differed significantly in age, mental state and main treatment goal (Table 1). The mean age was higher in Belgium. The proportion mentally incapable was more than twice as much in Belgium as in the Netherlands. About two-thirds of these patients had cancer in the Netherlands, unlike in Belgium, where the proportions with and without cancer were about half. About 14% of the Belgian patients dying at home received curative and life-prolonging care in the last week of life, whereas none did in the Netherlands.

Across the care home deaths, the cohorts differed in mental state and main treatment goal, too. In the Netherlands, the proportion of patients not capable of making decisions was about half of that in Belgium (26% vs. 51%). Over four-fifths of both cohorts did not have cancer. Cardiovascular disease was the most common singular diagnosis leading to death in the two countries.

### **Pattern of General Practitioner Home Visits per Setting per Country**

The frequency of GP home visits increased as patients approached death in both settings and in both countries (table 2). GP home visits were more frequent in the Netherlands than in Belgium ( $P<0.05$ ). In the last week of life, the Dutch mean number of GP visits to patients at home was almost twice that of Belgium (5.1 vs. 3.2 for home deaths, and 4.4 vs. 2.3 for care home deaths). However, less than a tenth of the Dutch care home patients used palliative care services in the last months of life. Age, capacity for decision-making and palliative treatment goal were identified as possible confounders that may explain the differences between countries regarding

the number of GP visits at the end of life in the three time frames. After the consecutive addition of the possible confounders into a multiple regression analysis, including country as a correlate, the possible confounders altogether only explained small amounts of additional variance (3–5%) of the variance in the number of GP visits at the end of life. The standardised regression coefficient associated with country diminished slightly after addition of the possible confounders, but the associated *t*-values remained significant.

### **Use of Palliative Care Services in the last three months of life**

Table 2 shows the frequency of palliative care service use by country, per setting. Overall, this was 41% at home vs. 5% in care homes within the Netherlands, and 78% at home vs. 39% in care homes within Belgium. There is relatively more frequent palliative care service use in Belgium than in the Netherlands. After the consecutive addition of the possible confounders in a multiple regression analysis, including country as a correlate, the possible confounders together explained only a small amount of additional variance (3–5%) of the variance in the use of palliative care services. Table 3 describes selected palliative care services and their usage in the two countries. These initiatives were used more in Belgium, and more frequently than in the Netherlands. There were more hospital-based initiatives in Belgium than in the Netherlands. Home-based services in the Netherlands often involved a GP. The Dutch sub-group more frequently used no palliative care service in both home and care home settings.

### **Associated Characteristics**

Table 4 shows the patient and care-related characteristics associated with having frequent GP visits in the last week of life. Decision-making capability, primary diagnosis and use of palliative care services had significant univariate relationships with the number of GP visits of patients dying at home in the Netherlands, whereas gender, age, primary diagnosis, main treatment goal and palliative care service use were significant univariate correlates in Belgium. After multiple regression analysis of all home deaths, primary diagnosis and decision-making capability remained significant in the Netherlands, whereas primary diagnosis, palliative care service use, and gender were significant in Belgium. The proportion of Dutch cancer patients dying at home had twice as many GP home visits in the last week of life than those with cardiopulmonary illnesses and almost three times more than those with “others”. In Belgium, the proportion of patients who died at home after cardiopulmonary illnesses was close to those with cancer, and those with “other” diagnoses were significantly least likely to have GP home visits. Of the care home deaths, univariate correlates of having more frequent end-of-life GP visits in Belgium (than in

the Netherlands) were age and gender, and age (65–84) remained in the Belgian multivariate analyses.

With respect to the use of palliative care services at home, associated factors on multiple regression analyses of the Dutch data were diagnosis and educational status, and in Belgium, having a palliative treatment care goal in the last week of life, and cancer (table 5). Factors associated with palliative care service use in care homes were age, gender, and main treatment goal in Belgium, but not in the Netherlands. However, having cancer was associated with using palliative care services in both countries.

**Table 1:** Socio-demographic, clinical and care characteristics of patients who died at home and in care homes in The Netherlands and Belgium (N=543)

Patient Characteristics	Number (%)			Number (%)		
	All home deaths: n=296			All care home deaths: n=247		
	NL 114 (21)	BE 182 (33)	p	NL 57 (10)	BE 190 (35)	p
<b>Gender</b>						
Males	63 (59)	100 (55)	0.515 <sup>1</sup>	20 (36)	49 (26)	0.125 <sup>1</sup>
Females	44 (41)	82 (45)		35 (64)	141 (74)	
<b>Age, in years</b>						
Mean (SD)	71.13 (14.8)	75.25 (14.0)	0.013 <sup>2</sup>	88.17 (6.5)	86.72 (7.4)	0.144 <sup>2</sup>
Range	24–99	21–102		71–100	52–102	
15–64	31 (30)	42 (23)		0	4 (2)	
65–84	55 (54)	92 (51)		13 (24)	58 (31)	
>=85	16 (16)	48 (26)		41 (76)	128 (67)	
<b>Educational status (as estimated by GP)</b>						
Primary or lower	39 (38)	58 (36)	0.909 <sup>1</sup>	28 (62)	90 (52)	0.465 <sup>1</sup>
Secondary	45 (44)	75 (47)		14 (31)	70 (41)	
Tertiary and higher	18 (18)	27 (17)		3 (7)	13 (7)	
<b>Level of consciousness 3 days before death {the worst possible scenario (i.e. 0) on a scale of 0–10}</b>						
Comatose	6 (5)	18 (10)	0.153 <sup>1</sup>	3 (6)	20 (11)	0.218 <sup>1</sup>
Not comatose	104 (95)	157 (90)		50 (94)	154 (89)	
<b>Capacity for decision-making 3 days before death</b>						
Totally incapable {worst case possible}	16 (14)	64 (37)	< 0.001 <sup>1</sup>	14 (26)	90 (51)	0.001 <sup>1</sup>
Capable of making decisions to some extent	95 (86)	111 (63)		40 (74)	85 (49)	
<b>Primary diagnosis leading to death</b>						

Patient Characteristics	Number (%)			Number (%)		
	All home deaths: n=296			All care home deaths: n=247		
	NL	BE	p	NL	BE	p
Cancer	79 (70)	104 (57)	0.376 <sup>1</sup>	9 (16)	26 (14)	0.607 <sup>1</sup>
Cardiovascular	12 (11)	26 (14)		14 (25)	38 (20)	
Pulmonary	5 (4)	11 (6)		5 (9)	22 (12)	
Nervous system	4 (4)	8 (4)		8 (14)	16 (8)	
CVA	3 (3)	5 (3)		6 (10)	19 (10)	
Others	10 (9)	28 (15)		15 (26)	69 (36)	
Diagnosed with cancer present or not						
Cancer	79 (70)	104 (57)	0.028 <sup>1</sup>	9 (16)	26 (14)	0.669
No cancer	34 (30)	78 (43)		48 (84)	164 (86)	
Longest place of residence in the last 12 months						
Home	111 (97)	171 (98)	0.852 <sup>1</sup>	4 (7)	27 (15)	0.108 <sup>1</sup>
Other (incl. Nursing home in NL)	3 (3)	4 (2)		53 (93)	149 (85)	
Main treatment goal in the last week of life						
Curative	-	6 (3)	< 0.001 <sup>1</sup>	-	17 (9)	0.006 <sup>1</sup>
Life-prolonging	-	19 (11)		-	14 (7)	
Palliative	108 (100)	151 (86)		53 (100)	156 (83)	

Percentages of missing observations from within the above-listed variables were between 0.3 and 11.5%  
Tests of associations: <sup>1</sup>Pearson's  $\chi^2$  test; <sup>2</sup>Mann-Whitney U test.

**Table 2:** Pattern of GP home visits in the last 3 months of life for the 543 patients who died at home and in care homes, by country

Frequency of GP home visits <sup>1</sup>	Number (%)		p	Number (%)		p
	All home deaths: n=296			All care home deaths: n=247		
	NL 114	BE 182		NL 57	BE 190	
<b>Last 2–3 months of life</b>						
0	8 (8)	11 (7)		4 (8)	7 (4)	
1	18 (19)	73 (45)		25 (51)	114 (63)	
2	31 (33)	39 (24)		12 (24)	42 (23)	
3–5	31 (33)	32 (20)		7 (14)	17 (9)	
≥ 6	6 (6)	6 (4)		1 (2)	1 (1)	
Mean # GP visits (SD)	2.67 (2.8)	2.02 (1.9)	0.001 <sup>2</sup>	1.73 (1.5)	1.51 (1.2)	0.411 <sup>2</sup>
<b>Last 2–4 weeks of life</b>						
0	8 (8)	14 (9)		4 (8)	11 (7)	
1	31 (31)	99 (63)		30 (60)	123 (76)	
2	34 (34)	23 (15)		11 (22)	22 (14)	
3–5	22 (22)	15 (9)		5 (10)	5 (3)	
≥ 6	5 (5)	7 (4)		-	-	
Mean # GP visits (SD)	2.07 (1.6)	1.49 (1.4)	< 0.001 <sup>2</sup>	1.38 (0.9)	1.07 (0.6)	0.008 <sup>2</sup>
<b>Last 7 days of life</b>						
0	4 (3)	10 (6)		1 (2)	16 (9)	
1	10 (9)	33 (19)		7 (13)	52 (28)	
2	11 (9)	49 (28)		10 (18)	42 (23)	
3–5	49 (43)	54 (30)		21 (38)	66 (36)	
≥ 6	40 (36)	31 (17)		16 (29)	9 (5)	
Mean # GP visits (SD)	5.14 (3.6)	3.23 (2.4)	< 0.001 <sup>2</sup>	4.38 (3.2)	2.30 (1.6)	< 0.001 <sup>2</sup>
<b>Last 3 months of life</b>						
Palliative care services (PCS) used	43 (38)	91 (51)	0.026 <sup>1</sup>	5 (9)	62 (34)	< 0.001 <sup>1</sup>
Not used	70 (62)	86 (49)		52 (91)	123 (66)	

<sup>1</sup>Note that the intervals vary in terms of number of days i.e.: last 2–3 months of life= 60–90 day period; last 2–4 weeks of life=14–28 day period; last 7 days of life= 7 day period  
Percentages of missing observations from within the above-listed variables were between 1.7 and 13.4%  
Tests of associations: <sup>1</sup>Pearson’s  $\chi^2$  test; <sup>2</sup>Mann-Whitney U test.

**Table 3:** Frequency of the use of palliative care services (PCS) in the last 3 months of life for the 543 patients who died at home and in care homes, by country

	Frequency of PCS use in the last 3 months in NL <sup>1</sup> N (Column %)			Frequency of PCS use in the last 3 months in BE <sup>1</sup> N (Column %)	
	Home 114	Care home 57		Home 182	Care home 190
None	70 (61)	52 (91)	None	86 (47)	123 (65)
A GP with palliative care training	20 (17)	2 (3)	A Palliative homecare team	85 (47)	10 (5)
A Palliative care consultant team	24 (21)	2 (3)	Mobile palliative care support team (hospital)	6 (3)	3 (1)
Palliative care unit in a hospital	4 (3)	0	Palliative care unit (hospital)	85 (47)	10 (5)
Palliative care unit in a nursing home	0	1 (2)	Palliative day (care) centre	1 (0.5)	0
Hospice day care facility	0	0	Palliative care reference persons in a care home	4 (2)	57 (30)

<sup>1</sup> More than one answer possible

## Discussion

We examined data obtained from 543 patients in the Netherlands and Belgium whose deaths were expected and non-sudden, and occurred at home or in a care home. Our results show GP visits at the end of life were more frequent in the Netherlands than in Belgium: the mean numbers of GP visits in the last week of life was 5.1 vs. 3.2 (home) and 4.4 vs. 2.3 (care home). Conversely, palliative care services in the last three months of life were used more frequently in Belgium than in the Netherlands: 78% vs. 41% (home) and 39% vs. 5% (care homes). Having more frequent GP visits at home was associated with cancer-related deaths in both the Netherlands and Belgium.

To the best of our knowledge, this is the first nationwide study that compares the incidence of caregiving at the end of life between two countries. To have a general non-disease specific patient population, we recruited patients through the two corresponding national GP networks. To enhance comparability, data were collected using similar representative mortality follow-back procedures undertaken simultaneously in both countries. One limitation of our study design was recall bias; a few of the questions asked depended on the GPs' abilities to remember certain details, some of which may not have been previously recorded. However, past studies have shown that patient proxies, such as GPs, do provide valid and reliable reports, especially when the questions asked are objective (44), and the study is undertaken within six weeks of the death (45). Another drawback was the lack of representativ-

ity of the nursing home deaths in the Netherlands; hence they were duly excluded from our analyses.

This study provides some useful insight on differences in the characteristics of terminally ill patients at home and in care homes in the Netherlands and Belgium. The distribution of gender and educational status were similar in both countries, particularly in the home setting. There were more women than men in the care homes in both countries, perhaps because women usually outlive their partners and are more likely to use communal care facilities than men. The patients in the Belgian care homes were significantly older and more often less capable of making decisions than in the Netherlands, obviously because of the exclusion of the Dutch nursing home deaths (40;46). The observed differences, however, did not explain the large disparity in the mean number of GP visits at the end of life and use of palliative care services (tables 2). Rather, they seem to reflect fundamental differences in public policy in general, and also in palliative care, and perhaps, GP care provision existing in the two countries (32).

Regarding GP visits, the GPs in the Netherlands appear to be more involved in patient care at the end of life. Perhaps, this is because more of them have formal palliative care training (47); they practice more bedside palliative care (48), and thus, they perceive end-of-life care as a specific part of their roles as GPs. In Belgium, on the other hand, the GPs appear to delegate more of the terminal care to the specialised teams. Probably, this is because they are confronted with more “diversity” and /or complexity in terms of their patient population (they need to cater for all patient groups, unlike in the Netherlands where most geriatric and dementia patients are seen by specialists in nursing homes and hospices (42)). Also, given that in Belgium there is a high rate of end-of-life hospital admissions (38;40), it is possible that the GPs there often lose track of their patients, following series of hospitalisations. Furthermore, in the Netherlands, being gatekeepers to the health care system, the GPs have more oversight of end-of-life care. In Belgium, even though they manage overall care (being the regular caregiver), the GPs do not “control” all aspects of palliative care, that is, visits to or by hospital specialist teams (22).

Regarding the use of palliative care services, our data show that a sizeable number of palliative care “reference persons” function in the care homes in Belgium. Though we do not know specifically what these reference persons actually do, that is, whether they function as administrators or provide hands-on care, their presence does suggest a palliative care policy in Belgian care homes. On the other hand, end-of-life care for the elderly in care homes in the Netherlands do not necessarily have a specific palliative focus.

Finally, age and gender were significant correlates associated with palliative care service use at home, in Belgium but not in the Netherlands. The Belgian result coincides with findings from a previous study (40). Aside from cancer, which are well-known indicators for palliative care referral (6;40), our results show that having cardiopulmonary disease is related to using palliative care services in the Netherlands, whereas the reverse is the case in Belgium. Again, this could be as a result of the Dutch policy which supports the training of caregivers in palliative care, such that only specific tasks are left to the “specialists” (14;42), whereas in Belgium, more attention is given to developing the palliative care units.

In conclusion, our results show terminally ill patients in general practice in the Netherlands are relatively younger and more capable of making decisions than those in Belgium. From a behavioural perspective, GPs in the Netherlands have a palliative care treatment goal more often and perform end-of-life visits more frequently, but have fewer palliative care options and use palliative services less frequently than those in Belgium. Cancer and non-use of palliative care services predict more frequent GP visits at the end of life, whereas cancer and a palliative care treatment goal predict the use of palliative care services.

### **Future research**

Our findings show the frequency of end-of-life care provision in the Netherlands and Belgium, without informing on the quality of palliative care received. Also, details about the quality of home visits and palliative care services were simply outside the limits of this study and were, therefore, not explored. These differences, if any, in quality of care, as influenced by the organisation of care in the two countries, remain to be studied. In general, epidemiological research could be conducted and the quality of palliative care studied using quality indicators (49).

**Table 4:** Characteristics associated with having had more frequent\* GP visits in the last week of life by patients who died at home, by country (N=296<sup>†</sup>)

Patient Characteristics	*Frequency of GP visits >4 in those patients who died at home in NL N (Row %)				*Frequency of GP visits >2 in those patients who died at home in BE N (Row %)			
			Logistic regression				Logistic regression	
	≤4 visits 53 (47%)	>4visits 60 (53%)	Univariate <sup>1</sup> OR (95%CI)	Multivariate <sup>2</sup> OR (95%CI)	≤2 visits 92 (53%)	>2 visits 82 (47%)	Univariate <sup>1</sup> OR (95%CI)	Multivariate <sup>2</sup> OR (95%CI)
<b>Gender</b>								
Males	25 (51)	37 (49)	0.56 (0.3–1.2)	<sup>3</sup>	57 (61)	37 (39)	<b>0.51 (0.3–0.9)</b>	<b>0.52 (0.3–1.0)</b>
Females	24 (65)	20 (35)	1		35 (44)	45 (56)	1	1
<b>Age, in years</b>								
15–64	14 (45)	17 (55)	1	<sup>3</sup>	14 (38)	23 (62)	1	<sup>5</sup>
65–84	20 (37)	34 (63)	1.40 (0.6–3.4)		55 (60)	36 (40)	<b>0.40 (0.2–0.9)</b>	
>=85	10 (62)	6 (37)	0.49 (0.1–1.7)		23 (50)	23 (50)	0.61 (0.3–1.5)	
<b>Educational status (as estimated by GP)</b>								
Primary or lower	19 (49)	20 (51)	0.67 (0.2–2.1)	<sup>3</sup>	30 (55)	25 (45)	0.77 (0.3–1.9)	<sup>3</sup>
Secondary	18 (41)	26 (59)	0.92 (0.3–2.8)		38 (54)	33 (46)	0.81 (0.3–2.0)	
Tertiary and higher	7 (39)	11 (61)	1		13 (48)	14 (52)	1	
<b>Clinical status prior to death</b>								
* Reference - worst possible scenario i.e. score 10 (versus all others)								
Complete coma	0	6 (100)	<sup>4</sup>	<sup>3</sup>	7 (41)	10 (59)	0.60 (0.2–1.7)	<sup>3</sup>
Other	50 (49)	53 (51)			81 (54)	69 (46)	1	
Completely incapable of making decisions	3 (19)	13 (81)	<b>0.23 (0.1–0.9)</b>	<b>0.08 (0.01–0.5)</b>	35 (58)	25 (42)	1.43 (0.8–2.7)	<sup>3</sup>
Other	47 (50)	47 (50)	1	1	53 (50)	54 (50)	1	
<b>Primary diagnosis leading to death</b>								
Cancer	32 (41)	46 (59)	1	1	46 (46)	53 (54)	1	1
Cardio-pulmonary	10 (59)	7 (41)	0.49 (0.2–1.4)	0.41 (0.1–1.3)	19 (51)	18 (49)	0.82 (0.4–1.8)	1.81 (0.7–4.7)
Others*	11 (65)	6 (35)	<b>0.38 (0.1–1.0)</b>	<b>0.13 (0.02–0.6)</b>	27 (71)	11 (29)	<b>0.35 (0.2–0.8)</b>	<b>0.31 (0.1–0.8)</b>
<b>Main treatment goal in the last week of life</b>								
Palliative	48 (45)	59 (55)	<sup>4</sup>	<sup>3</sup>	70 (49)	74 (51)	<b>3.17 (1.2–8.4)</b>	2.57 (0.8–7.9)
Not palliative (curative /life-prolonging)	-	-			18 (75)	6 (25)	1	1
<b>Use of Specialist palliative care initiative in last 3 months</b>								
Yes	15 (35)	28 (65)	<b>2.22 (1.1–4.8)</b>		13 (15)	76 (85)	<b>3.14 (1.7–5.8)</b>	<b>3.08 (1.5–6.4)</b>
No	38 (54)	32 (46)	1	<sup>5</sup>	31 (36)	54 (64)	1	1

<sup>†</sup> Includes 4 missing values from all home deaths; percentages of missing observations variables ranged between 0.3 and 5.8%

<sup>1</sup> Dependent variable in NL/BE: People who had > the median number of GP home-visit in the last week of life

<sup>2</sup> Stepwise backwards logistic regression not done because only one set of variable survived the 2 steps of univariate analyses. Significant values in bold print

<sup>3</sup> Not entered in multiple backwards logistic regression analyses

<sup>4</sup> Estimation terminated because parameter estimated changes <0.001

<sup>5</sup> Not retained following multiple backwards logistic regression analyses

**Table 5:** Characteristics associated with having used palliative care services (PCS) in the last 3 months in all those who died at home, by country (N=296<sup>†</sup>)

Patient Characteristics	Frequency of SPCI use in those patients who died at home in NL N (Row %)				Frequency of SPCI use in those patients who died at home in BE N (Row %)			
	No SPCI 70 (62%)	SPCI 43 (38%)	Logistic regression		No SPCI 86 (49%)	SPCI 91 (51%)	Logistic regression	
			Univariate <sup>1</sup> OR (95%CI)	Multivariate <sup>2</sup> OR (95%CI)			Univariate <sup>1</sup> OR (95%CI)	Multivariate <sup>2</sup> OR (95%CI)
<b>Gender</b>								
Males	38 (61)	25 (39)	1.51 (0.7–3.4)	<sup>3</sup>	53 (55)	43 (45)	1	<sup>5</sup>
Females	31 (70)	13 (30)	1		33 (41)	48 (59)	<b>1.79 (1.0–3.3)</b>	
<b>Age, in years</b>								
15–64	18 (58)	13 (42)	2.17 (0.6–8.2)	<sup>3</sup>	13 (33)	27 (67)	<b>2.95 (1.2–7.1)</b>	<sup>5</sup>
65–84	33 (61)	21 (39)	1.91 (0.5–6.7)		46 (50)	45 (50)	1.39 (0.7–2.8)	
>=85	12 (75)	4 (25)	1		27 (59)	19 (41)	1	
<b>Educational status (as estimated by GP)</b>								
Primary or lower	29 (74)	10 (26)	1	1	29 (54)	26 (46)	1	<sup>3</sup>
Secondary	23 (52)	21 (48)	<b>2.65 (1.0–6.7)</b>	<b>3.0 (1.1–8.1)</b>	31 (42)	42 (58)	1.51 (0.7–3.0)	
Tertiary and higher	10 (56)	8 (44)	2.32 (0.7–7.5)	2.8 (0.8–9.8)	14 (52)	13 (48)	1.04 (0.4–2.6)	
<b>Clinical status prior to death</b>								
<b>* Reference - worst possible scenario (i.e. versus all others)</b>								
Complete coma	4 (67)	2 (33)	1	<sup>3</sup>	9 (53)	8 (47)	1	<sup>3</sup>
Other	63 (61)	40 (39)	0.79 (0.4–4.5)		74 (48)	79 (52)	0.83 (0.3–2.3)	
Completely incapable of making decisions	10 (63)	6 (37)	1	<sup>3</sup>	31 (51)	30 (49)	1	<sup>3</sup>
Other	58 (62)	36 (38)	0.97 (0.3–2.9)		52 (48)	57 (52)	0.88 (0.5–1.6)	
<b>Primary diagnosis leading to death</b>								
Cancer	43 (55)	35 (45)	1	1	35 (35)	66 (65)	1	1
Cardio-pulmonary	11 (65)	6 (35)	0.67 (0.2–2.0)	0.78 (0.2–2.7)	29 (78)	8 (22)	<b>0.15 (0.1–0.4)</b>	<b>0.18 (0.1–0.5)</b>
Other*	16 (94)	1 (6)	<b>0.08 (0.01–0.6)</b>	<b>0.08 (0.01–0.7)</b>	22 (56)	17 (44)	<b>0.41 (0.2–0.9)</b>	0.62 (0.3–1.4)
<b>Main treatment goal in the last week of life</b>								
Palliative	64 (60)	43 (40)	<sup>4</sup>		59 (40)	87 (60)	<b>10.8 (3.1–37.8)</b>	<b>4.7 (1.3–17.5)</b>
Not palliative (curative/ life-prolonging)	0 (0)	0 (0)			22 (88)	3 (12)	1	1
<b>More GP visits per country in the last week of life</b>								
Yes <sup>6</sup>	32 (53)	28 (47)	<b>2.21 (1.0–4.9)</b>	<sup>5</sup>	28 (34)	54 (66)	<b>3.14 (1.7–5.8)</b>	<b>3.15 (1.5–6.5)</b>
No <sup>6</sup>	38 (72)	15 (28)	1		57 (62)	35 (38)	1	1

<sup>†</sup> Includes 6 missing values; percentages of missing observations from the listed variables ranged between 0.3 and 1.9%

<sup>1</sup> Dependent variables in NL/BE: People who had SPCI in the last 3 months

<sup>2</sup> Stepwise backwards logistic regression. Variables removed after 2 steps of the backward analyses. Significant values in bold print

<sup>3</sup> Not entered in multiple backwards logistic regression analyses

<sup>4</sup> Estimation terminated because parameter estimated changes <0.001

<sup>5</sup> Not retained following multiple backwards logistic regression analyses

<sup>6</sup> Median number GP visits per country.

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## Chapter 7

# The oldest old and GP end-of-life care in the Dutch community: A nationwide study

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## Abstract

*Background:* Provision of adequate care for the oldest old is increasingly crucial, given the current ageing trends. This study explores differences in end-of-life care of the oldest ( $\geq 85$ y) versus the younger (65–84y) old; testing the hypothesis that age could be an independent correlate of receiving specialised palliative care services (SPCS), having palliative-centred treatment, and dying in a preferred place.

*Methods:* GPs participating in the nationwide representative network in the Netherlands were asked to fill in patient, illness and care characteristics of all registered patients  $\geq 65$ y, who died non-suddenly in their practices between 2005 and 2008, using standardised forms. Associations with the palliative care variables were tested using multiple logistic regression.

*Results:* 990 patients were registered. Among the oldest old, there were more women than men, more patients with heart failure than cancer, less hospital and home deaths, and more residential care home deaths compared with the younger old. Of the oldest old, fewer received SPCS, and more preferred to die in a residential care home than the younger old. Age was independently associated with palliative care provided: compared with the younger group, the oldest old received SPCS less often (OR=0.7), and were treated with a palliative-centred goal more often (OR=2.4); but age was not related to dying in a preferred place, i.e. independent of other characteristics.

*Conclusion:* This study shows age to be independently associated with receiving SPCS in the Dutch community. Although the GPs do recognise the “palliative phase” in the oldest old, involvement of specialist teams is somewhat less.

## Introduction

In this paper, we explore some aspects of end-of-life care of the oldest of old (people  $\geq 85$  years). Adequate care provision for the oldest of old has become crucial, given current ageing (1) and chronic morbidity trends (2). In response to rapidly growing demands for end-of-life care (3), healthcare systems are adapting to meet patient-specific needs (4). The underlying goal of palliative care remains the attainment of the best possible quality of life for patients throughout the entire duration of their illness, irrespective of age (2). General practitioners (GP) manage the care of older persons resident in most communities, alongside geriatricians and other specialists who manage care in institutionalised settings (4–6). It is possible that certain demographic or care-related characteristics of these patients could be associated with their likelihood of receiving palliative care before death (7;8). For instance, age could influence a patient's ability to access specialised palliative care services (SPCS) (7;9–12), their readiness to acknowledge or discuss death (13), and their wish to die either at home (14) or in a hospital (15). Past studies were unable to effectively generate reasons for the variability in use of SPCS (7;11). Previously, research had focused mainly on older people residing in specialised settings (16–18), with specific diagnoses (13;19); somewhat overlooking the substantial proportion of older people in the community, dying from other causes (20;21).

In 2006, about half of all deaths in the Netherlands were of people over 80 years, several of whom had chronic incurable illnesses (20;21). Of the 135 thousand deaths that year, 38% occurred at home or residential care home, and 23% in a specialist nursing home (20;21). The Dutch healthcare system is arranged such that 95% of the entire community is compulsorily registered with one GP, who serves as a gatekeeper to the health system (5). In the absence of a distinct "palliative care" speciality, the Dutch government enhances the palliative care expertise of her GPs (22) through periodic training (23), and initiatives that involve specially-accredited and experienced practitioners, available to all GPs and patients, via telephone or at the patient's bedside (22–24).

This study explores differences in patient, illness and care characteristics, between the oldest ( $\geq 85y$ ) and younger old (65–84y) in the Dutch community. In addition, we will test the hypothesis: "age is related to three aspects of palliative care: (1) use of SPCS, (2) care mainly aimed at palliation or comfort, and (3) dying in the patient's preferred place". In studying age and access to services, Burt and Raine say that care needs should be taken into account (11). Also, the literature suggest that age could be related to certain factors, despite being related to diagnosis and co-morbidities (7;9;10). To illustrate this further, Burge et al. (12), in a retrospective study on among cancer patients, used cancer and co-morbidities as proxies for

needs, and registration on community-based specialised programs as outcome measures. In this study, we will use a similar step to explain the reasons behind differences that may be present.

## Methods

### Study design & population

The SENTI-MELC study (Sentinel network Monitoring End-of-Life Care), is a mortality follow-back study monitoring end-of-life patient care through continuous GP registration (25;26). In the Netherlands, data were collected from 1 January 2005 to 31 December 2008, via the Sentinel Network of GPs, and this process was supervised by the Netherlands Institute of Health Services Research (NIVEL). The Network, consisting on average of 67 regularly participating GPs, covers approximately 1% of the total registered patient population (27). The GPs are representative of all GPs in the Netherlands, and participation rate over the 4-year period (2005–8) was 75–85%. Following a patient's death, the GP was asked to provide information about the care the patient received in the last three months of life. Completed forms were returned to NIVEL, where they were scrutinised for missing data and errors, and then sent to the researchers for analyses. Given the focus in this study, we excluded patients under 65 years, all those whose deaths were judged sudden by the GPs, and all entries with multiple missing data. We selected all patients who in the last year of life, had lived mainly at home or in a residential care home (n=990).

### Definition of concepts

Based on a pre-existing internationally validated framework (28), we explored the last 3 months of life in the *terminally ill*, and whose deaths were foreseen by their GPs. Prior to registration, the forms had been piloted and rigorously tested to ensure the GPs understood the items as we intended them. The term *co-morbidity* was applied when more than one major chronic illness was present. A specialised palliative care service (SPCS) was defined as (i.) a GP with palliative care training operating in a team, (ii.) a palliative care consultant (trained nurse or physician) operating in a team, (iii.) hospital-based palliative care units, (iv.) specialist nursing-home-based palliative care units, or (v.) a hospice day care facility, all of which are readily accessible to terminally ill patients in the Netherlands. *Aim of care* in the last week of life was measured by asking the GPs for the main treatment-goal (curative, life prolonging, or palliation). *Dying in a preferred place* was assessed in two steps. First, we asked the GPs for each patient's preferred place of death (as relayed by patient, a relative or other care provider), and then we asked for the actual place of

death (from GP records). A detailed description of the SENTI-MELC study methodology, as it applies to the Netherlands, is published elsewhere (26).

### **Measurement instrument**

Using a two-paged registration form, we measured certain patient, illness and care-related characteristics i.e. age, gender; cause of death as registered in the death certificate, main treatment-goal was in the last week of life, whether SPCS was used in the last 3 months of life (yes/no); whether GP was aware of patient's preferred place of death (yes/no); source of GP's awareness (patient/relative/ other care provider-specify); and patient's actual place of death (home/ residential care home/ specialist nursing home/ hospice or palliative care unit/ other).

### **Statistical analysis**

Data were analysed using the Statistical Package for the Social Sciences version 15.0. The characteristics were compared across age sub-groups using Pearson's  $\chi^2$  (Table 1). To test whether age was independently related to the three palliative aspects (use of SPCS, care is mainly aimed at palliation and dying in the patient's preferred place), multiple logistic regression analyses were used. Variables were entered into the equation using the conditional backward elimination of independent variables method. To avoid erratic results, we applied Peduzzi et al's recommendation of EPV >10 (events per variable) (29). From our analyses, EPV was 27 and 12.9 (Tables 2 and 3 respectively). In addition, we tested for possible interaction effects, so as to rule out possible moderation of the associated factors by age.

### **Ethical considerations**

An approval from the Ethical Review Board was not required for this study in the Netherlands due to the (post-mortem) nature of the data collection process.

## **RESULTS**

The GPs registered 990 patients, aged 65–104 years; with 82.2 mean age, and SD: 9. Table 1 shows that among the oldest old, the women were twice the proportion of men, while among the younger old, the men were twice the women. Cancer ranked second as a singular cause of death, after heart failure among the oldest old; but was the commonest cause of death among the younger old (23% vs. 45%). Six percent of the oldest old did not die of a registered pathology. The residential care home versus home was most frequently the preferred place of death among the

oldest versus younger old, respectively. Hospitalisations in the last week of life were relatively fewer among the oldest old (25% vs. 37%). The use of SPCS in the last 3 months of life was relatively less frequent among the oldest, compared with the younger old (78% vs. 56%). Palliation was mainly used as a form of treatment in both age-groups in the last week of life (84–87%), and about 60% of both sub-groups had GPs who were informed of their preferred death place.

### **Factors associated with using SPCS, receiving palliation-focused treatment, and dying in a preferred place**

Table 2 shows the odds of using SPCS as being 1.5 times less frequent, among the oldest than the younger old. Cancer was the single most-frequent cause of death, and the odds of using SPCS was 2.5 times more for cancer than for heart failure patients. Having used SPCS, the chance of having terminal hospitalisation in the week of life was 0.7 times that of dying in other settings. The odds of receiving treatment focused on palliation in the last week was 2.5 times more among the oldest old (Table 3). The single most-frequent reason for receiving palliation-focused treatment in the last week was ‘cancer’, and patients with other illnesses combined, were 4 times less likely to receive mainly palliation in their last week of life. Since age and dying in a preferred place were not related in the univariate analyses, there was no basis for further logistic regression (Table 1). About 5% of the variance of SPCS-use, and 9% of palliative-centred treatment, was accounted for.

**Table 1:** Patient and care characteristics of patients studied, by age group (N=990)

Variable	Total N (%)	65–84yrs N (%)	≥85 yrs N (%)	p-value‡
	990 (100)	570 (58)	420 (42)	
Gender				
Male	460 (50)	328 (62)	130 (33)	0.001
Female	462 (50)	201 (38)	259 (67)	
Cause of death				
Cancer	320 (32)	254 (45)	66 (16)	0.001
Heart failure	166 (17)	70 (12)	96 (23)	
Stroke	96 (10)	44 (8)	52 (12)	
COPD	80 (8)	52 (9)	28 (7)	
Nervous system	37 (4)	13 (2)	24 (6)	
Old age	24 (3)	0	24 (6)	
Euthanasia	14 (1)	11 (2)	3 (1)	
Others combined*	249 (25)	122 (23)	127 (30)	
Reported co-morbidity**				
Yes	449 (45)	248 (43)	201 (48)	0.219
No	537 (55)	318 (56)	219 (52)	
Main treatment goal in the last week of life				
Curative	68 (7)	40 (7)	28 (7)	0.571
Life-prolonging	45 (5)	28 (5)	17 (4)	
Palliative	807 (85)	454 (84)	353 (87)	
Other	25 (3)	17 (3)	8 (2)	
Specialised palliative care services were used				
Yes	351 (36)	233 (41)	118 (28)	0.001
No	631 (64)	332 (59)	299 (72)	
GP informed of preferred death place				
Yes	576 (58)	318 (56)	258 (61)	0.075
No	414 (42)	252 (44)	162 (39)	
Patient preferred to die				
At home	369 (64)	249 (78)	120 (47)	0.001
In a residential care home	169 (29)	40 (13)	129 (50)	
In a hospice	21 (4)	18 (6)	3 (1)	
In a hospital	10 (2)	8 (3)	2 (1)	
In Dutch nursing home	5 (1)	2 (1)	3 (1)	
Elsewhere	2 (0.3)	1 (0.3)	1 (0.4)	
Actual place of death				
Hospital	309 (32)	205 (37)	104 (25)	0.001
Private home	336 (34)	226 (40)	110 (26)	
Residential care home	215 (22)	51 (9)	164 (39)	
Dutch nursing home	72 (7)	43 (8)	29 (7)	
Hospice or palliative care unit	37 (4)	29 (5)	8 (2)	
Other	6 (1)	5 (1)	1 (0.2)	
Patient died in a preferred place				
Yes	467 (81)	257 (81)	210 (81)	0.860
No	109 (19)	61 (19)	48 (19)	

‡ Pearson's chi-square test. Between group difference was significant (P<0.05)

\* Other causes of death include renal failure, hepatic cirrhosis, chronic cachexia.

\*\* 'co-morbidity' is >1 major chronic illness

**Table 2:** Differences in age and other characteristics associated with using specialised palliative care services (SPCS) in the last three months of life (n=990)<sup>1</sup>

Variable	Proportion that used specialised palliative care services <sup>1</sup> (column %)		Beta	Standard Error	Odds Ratio <sup>†</sup> for using SPCS or not [95%CI] <sup>‡</sup>
	Yes N=351	No N=631			
<b>Age</b>					
65–84yrs	66	53			1
≥85 yrs	34	47	-0.341	0.164	<b>0.711 (0.52–0.98)</b>
<b>Gender</b>					
Female	49	51			1
Male	51	49	-0.042	0.152	0.959 (0.71–1.29)
<b>Cause of death</b>					
Cancer	43	26			1
Heart failure	12	20	-0.854	0.237	<b>0.426 (0.27–0.68)</b>
COPD	8	8	-0.495	0.298	0.610 (0.34–1.10)
Stroke	10	10	-0.520	0.275	0.594 (0.35–1.02)
All others	27	36	-0.658	0.192	<b>0.518 (0.36–0.75)</b>
<b>Presence of a co-morbidity</b>					
Yes	45	46			1
No	55	54	-0.218	0.156	0.804 (0.59–1.09)
<b>Palliation/comfort-focused treatment</b>					
Yes	87	81			1
No	13	19	-0.087	0.224	0.917 (0.59–1.42)

<sup>1</sup> Multiple logistic regression analyses for using specialised palliative care services (SPCS) in the last three months of life (n=351) versus not (n=631). Proportion missing: 0.8–1.6%<sup>‡</sup> Odds ratio with significant results in bold. Variables entered into the equation were either significant in the univariate analyses or prompted through research: Age, gender, cause of death, co-morbidity, received palliation/comfort-focused treatment, hospital admission in the last week of life. Other interaction effects (involving Age\*gender; Age\*cause of death; Age\*co-morbidity, Age\*hospital admission in the last week of life) were not significant. Model summary results: Nagelkerke R<sup>2</sup> = 0.053; Percentage correctly predicted = 63%.

**Table 3:** Differences in age and other characteristics associated with receiving palliation/comfort-focused treatment in the last week of life (n=990)<sup>1</sup>

Variable	Proportion receiving palliation/comfort-focused treatment in the last week of life <sup>1</sup> (column %)		Beta	Standard Error	Odds Ratio <sup>†</sup> for having PC goal or not [95%CI] <sup>‡</sup>
	Yes N=807	No N=167			
Age					
65–84yrs	56	64			1
≥85 yrs	44	36	0.877	0.271	<b>2.41 (1.41–4.09)</b>
Gender					
Female	51	48			1
Male	49	52	0.083	0.239	1.087 (0.68–1.74)
Cause of death					
Cancer	36	16			1
Heart failure	15	24	-1.337	0.303	<b>0.263 (0.15–0.48)</b>
COPD	7	12	-1.441	0.354	<b>0.237 (0.12–0.47)</b>
Stroke	10	7	-0.696	0.400	0.498 (0.23–1.10)
All others	31	41	-1.293	0.270	<b>0.275 (0.16–0.47)</b>
Presence of a co-morbidity					
Yes	45	51			1
No	55	49	0.075	0.194	1.078 (0.74–1.58)
Specialised palliative care service used					
Yes	37	27			1
No	63	73	-0.277	0.204	0.758 (0.51–1.13)

<sup>1</sup> Multiple logistic regression analyses for receiving palliation/comfort-focused treatment in the last week of life (n=807) versus not (n=167). Proportion missing: 0.8–1.6%

<sup>‡</sup> Odds ratio with significant results in bold. Variables entered into the equation were either significant in the univariate analyses or prompted through research: Age, gender, cause of death, co-morbidity, specialised palliative care service used, Age\*Gender. Other interaction effects (involving: Age\*gender; Age\*cause of death; Age\*co-morbidity) were not significant. Model summary results: Nagelkerke R<sup>2</sup> = 0.086; Percentage correctly predicted = 83%.

## Discussion

These results show that the oldest old sub-group had more women than men, more patients with heart failure than cancer, less hospital- and home-, but more care home-deaths, in comparison to the younger old. Of the oldest old patients, fewer used or were referred to SPCS, fewer preferred to die at home, and more preferred to die in a care home, than the younger old. Age was an independent factor, associated with the use of palliative care: compared with the younger group, the oldest old used SPCS less often (OR=0.7), and were treated with a palliative-centred goal more often (OR=2.4); independent of other patient, illness, and treatment characteristics. However, there was no relationship between age and dying in a preferred place, independent of the other factors. Furthermore, heart failure and place of death were independently associated with the use of SPCS; heart failure and COPD were independently associated with receiving palliation-focused treatment; and

stroke and an absent palliation-focused treatment goal were independently associated with dying in a preferred place. The proportions explained variance of the analyses exploring the associated factors of SPCS-use and a palliation-focused treatment goal were low.

To the best of our knowledge, this is the first nationwide study that explores aspects of end-of-life care within the older segment of the Dutch community. We gathered information from a registered general practice patient-population, all of whom in principle, could benefit from planned end-of-life care. We enlisted experienced GPs from an existing surveillance network, and combined data over a 4-year duration in order to maintain high standards of registration, and achieve robust analyses on the oldest of old. Expectedly, nursing home residents who are predominantly  $\geq 65$ y, were under-represented in our selection, because GPs hand-over the care of these residents to specialists. However this under-representation would hardly be a problem since the results are based on proportions. Another possible limitation was the fact that the GPs provided information on the care they provided over a period of time, which may have led to some self-reporting or recall bias, although recall in itself could be enhanced by the use of patient records, and the existing relationship with the patients.

The two age-groups, 65–84y versus  $\geq 85$ y, with similar proportions dying in a preferred place, differed significantly in their actual place of death (Table 1). The oldest of old died more often in residential care homes, than home. This is hardly surprising, because care homes in the Netherlands are generally considered as ‘home’ for people with long-term care needs (5); majority of whom are very old (21). It is plausible that the very old equally rely on the social networks these residential care facilities provide (2), due to a lack of informal support.

The oldest old used SPCS less frequently and received palliative-centred treatment more frequently than the younger old patients, and these persisted in the presence of indicators of palliative care needs: diagnosis cancer and the presence of comorbidities. Like Burge et al. did in their population-based study (12), we controlled for a range of potential confounders, and again our results are comparable in that they show patients  $\geq 65$ y, (but particularly  $\geq 85$ y), to be significantly less likely to be registered with a specialised palliative care program, than those  $< 65$ y. And although these two variables are insufficient as full-blown indicators of patient-needs; yet they provide reasons for validation of our findings (13;14).

Despite a higher incidence of congestive heart failure, the oldest of old received palliative-focused treatment more frequently, than the younger old. This may suggest a palliative philosophy in the care of the oldest old in the Netherlands, that

transcends diagnoses. We do not know whether the supplementary palliative care training given to Dutch GPs could explain this finding (30). On the other hand, this could likewise imply that the GPs provide alternative life-prolonging therapies less frequently to this sub-group of patients, an apparent finding from a previous Belgian study (25). Contrary to the main treatment-goal being palliative, our results show SPCS were less-frequently used, by the oldest old.

This may be linked to the presence of trained carers in residential care homes, often suggesting that patients' needs are being met (5). However, in the absence of adequate training, certain needs may go unrecognised, depending on the inherent decline e.g. speech and cognitive problems (2;23), and unfortunately there are fewer specialised palliative units in residential homes versus specialised nursing homes, for instance (5). Albeit reasons for this pattern of SPCS-use among the oldest of old should be explored in detail in future studies.

In conclusion, our results suggest that GPs in the Dutch community recognise the "palliative phase" in the very old, but perhaps judge the use of specialist teams unnecessary (rightfully or not). This practice is consistent with the Dutch societal expectation of caring for the very frail in an 'appropriate' place of death, with familiar carers and settings. Our observations provide fresh insight into the pattern of palliative care service utilisation by the fastest growing cohort in the community, and this could inevitably inform planning, particularly from an economic perspective. Also the results stress that a needs assessment is an essential part of palliative care provision for the oldest of old.

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# Chapter 8

## Discussion

## **Nationwide monitoring of care in the last months of life**

In this dissertation, we have described patient care in the last three months of life through the registration of sentinel GPs (SENTI-MELC study). Approximately nine out of ten non-institutionalised persons in the Netherlands are registered with one GP, who is a gatekeeper to healthcare, provides care within and between settings, and manages advance care planning and decision-making at the end of life.

In this chapter, we will discuss key findings and answers to the six main research questions earlier posed (8.1), methodological considerations of the SENTI-MELC study as relates to the Netherlands (8.2), and practical implications for healthcare policy, practice and future research based on these findings (8.3). As a reminder, the main research questions were centred around the following:

1. Recognition of death in the near future
2. Communication of salient end-of-life topics with patients
3. Awareness of patients preferred place of death
4. Transitions between care settings in the last months of life
5. Home visits at the end of life and use of palliative care services
6. The oldest old and end-of-life care in the Dutch community

## **8.1 KEY FINDINGS**

Key findings have been summarised around the following:

- i. Epidemiological data on care settings, transitions in the last 3 months of life, and place of death
- ii. Epidemiological data on awareness of death in the near future by GPs, and GPs discussing relevant end-of-life issues with patients
- iii. Interesting contrasts between countries (Dutch vs. Belgian), and patient sub-groups in the community (cancer vs. noncancer; oldest vs. younger old)

### **Care settings, Care transitions and Place of death**

Care settings, i.e. place of care and place of death, are important parameters that have been used to describe the quality of end-of-life care and dying process (1;2). Our results, like some others (3–6) show that most patients prefer to die at home. The GP awareness of a patient’s wish for “place of death” suggest some advance care planning might have taken place, or the GP was at least informed of patient wishes, though we did not explore when and how (in what context) this was done. Based on the premise that preferences could change before death, depending on patient’s situation and care needs (2;3;5), we suggest GPs and primary caregivers seek to be aware of patient preferences, but remain open to possible changes in the

weeks leading to death. Another finding was that most patients whose preferences were known died there, which shows that the GPs often upheld patient preferences when these were known. We observe that of the majority of those with known preferences, and who had preferred to die at home (versus elsewhere), the cause of death was cancer. This may reflect the ethos of home care and pattern of use by terminally ill patients in this community (3;5;7).

We found transitions in the last month of life to be frequent, many resulting in hospitalisation for the last seven days of life. Admittedly, GPs whose patients had long-term treatment in hospitals may have been out of touch with ongoing care, because these GPs more frequently did not recognise death in the near future and initiated important end-of-life discussions in the last week of life. Also, the multiplicity of transitions, albeit away from home was associated with the absence of GP awareness of patient preferred place of death, especially among non-cancer patients. The frequency of transfers between settings in the last months underscores the need for systematic and structured discussions and planning while patient condition is stable. Although acute episodes often respond to aggressive hospital-based therapies, the benefits of transitions should be considered when transferring patients, especially if there is an explicit wish about place of death. Furthermore, supportive care takes time to organise, and its effects may not be well maximised by patients in transition.

### **Awareness and communication about patients' condition**

By definition, palliative care should be based on impeccable and timely assessment patient's condition (7), irrespective of their age, diagnosis or setting. Our findings show GPs frequently did not recognise that death was in the near future, or they recognised it only in the last week of life, giving the patient little or no time to experience planned end-of-life care. It is likely this result was due to the substantial disease variation represented in general practice today, given the unpredictability of many illness trajectories. According to McKinley's study, GPs were less likely to identify a "terminal" status if the underlying illness was of a non-malignant nature, (than when malignant), even when patients with both categories of illness visited their practices the same number of times in the last seven days of life (8). Like previously noted, GP awareness of preferred place of death oftentimes preceded dying in preferred places, which is indicative of quality of care and dying. End-of-life issues were discussed most frequently with cancer patients, and this again perhaps was because of the clear pattern or trajectory accompanying most cancers. It would be interesting though, to explore whether the frequency of discussing these issues are related to the type, primary site, or stage of the cancer, since different cancers of a fact behave differently. Regarding the timing of the discussions, it is possible some GPs "delayed" discussing certain issues based on their broad knowledge of patients

(pre-morbid health, family and socioeconomic situation). For instance, a GP may consider patient's religious affiliation and preferences regarding discussing end-of-life issues. Some people require more time in adjusting or coming to terms with their illness, and "timely" discussions about prognosis and palliative care options may end up being unproductive, or even harmful. Moreso, communication may be enhanced while a patient is stable mentally, in a condition that does not warrant frequent hospital admissions as yet. We found that discussing some topics was sequel to recognising death in the near future, and the GP seemed to play a more decisive role in managing care thereafter, i.e. they made more contact (and home visits), facilitated fewer transitions in the last month, fewer hospital deaths, more dying in a preferred place, and discussed specific end-of-life issue more frequently in the last seven days with patients. It comes as a surprise though that the GPs did not discuss certain issues, i.e. palliative care and treatment options, more often than we found, especially with the pragmatic and open-minded nature of the Dutch, and recently reported end-of-life (euthanasia) debates (9). An in-depth exploration of plausible reasons for this finding was beyond the scope of the study, but could be considered in the future. Finally, it is possible there were no gaps in communication needs after all, since patients discussed with other professionals in the last months, but this again was outside the scope of this study.

### **Important differences between countries and other patient populations**

Comparing results between the Netherlands and Belgium, congruence between the preferred and actual place of death in both countries was 80%, suggesting similar care outcomes despite differences in practice (1;2;6). Multiple transitions were frequent in the last three months of life in the two countries, although hospital deaths were more frequent in Belgium. The ratio of hospitalised to home patients in the last days of life in Belgium exceeded those of patients in the Netherlands (Chapter 5). These emergent trends may as a result of existing policies in the Netherlands which prevent transfer of nursing home patients (regardless of treatment need), and the presence of Dutch nursing home specialists that obviously reduce the need for hospitalisation. According to Florien et al, Dutch GPs have a work culture that includes visiting very ill patients at home – a practice which is more common in the northern parts of Holland (10). This in itself may explain the higher frequency of home visits in the Netherlands versus Belgium. Furthermore, the frequency and content of palliative care training for GPs in the Netherlands may also influence the practice of home visits (11), though the content of such training is yet to be synchronised or analysed in this context. Also, studies show GPs in the Netherlands frequently enjoy the support of palliative care advisors, via telephone or at patient's bedside (10;12). On the other hand, it would seem that GPs in Belgium may hand-over the care of terminally ill patients to teams that specialise in palliative care

(Chapter 6). However, it would be presumptuous to judge which system works out best at this point.

Altogether, cancer was the main reason for GP awareness of preferred place of death, recognising imminent death, discussing end-of-life issues with patients, and dying in a preferred place, although less than 40% of the samples selected in all six studies (non-sudden and expected deaths) died of cancer. Also we observe GPs maintained a palliative approach more often and facilitated fewer multiple transitions in the last months when managing cancer patients. These underscore the need for increased awareness amongst GPs and all professionals caring for patients in the last phase of life, that patients with other illnesses such as heart failure, COPD, HIV etc will likewise benefit from planned end-of-life care in their last months. In addition, raising public and patient awareness is also important because as seen from this research, the cancer patients themselves, given their diagnosis and related suffering, were perhaps more prepared to discuss death with their GPs as well as others. An important aspect which could not be explored here was the influence of multiple morbidities on end-of-life outcomes and indeed cancer care (13).

Within the ageing community, the oldest old mostly preferred to die in care homes or residential facilities. These are considered 'home' in most part of this dissertation (based on GP involvement), although we know for a fact that there are important differences, such as the communal nature of care homes and presence of trained caregivers. Although not explored, the presence of caregivers may have somewhat contributed to less frequent use of palliative care services in the Netherlands, and the relatively less frequent use of these services among the oldest old. Also we notice there were more late recognition of death in the near future for patients who resided in care homes versus home, and it's unclear whether this was because the GPs visited the oldest patients residing at home more frequently than those in care homes, and whether this in itself was related to the presence of informal carers in the latter, but this was not explored.

### **Concluding remarks: all patients should have a chance to end-of-life care**

We started by selecting patients whose GPs considered had died "non-suddenly and expectedly" from all the registration. For these, we asked the GPs for the main goal of treatment, and a "palliative care" treatment goal in the last days was frequently present. This was associated with age (the oldest vs. younger old OR=2.4), higher GP-awareness odds, discussing all the end-of-life issues more (except social and spiritual issues), and not being hospitalised in the last 7 days of life. It seems therefore that the care at the end of life may be enhanced if palliation is actively done for all patients. Also, GPs could be assisted in recognising the terminal phase of dying in

patients with less odds of recognition. In conclusion, there is a potential for increasing timely recognition of approaching death, reaching patients with or without cancer, minimising transitions (particularly to the hospital) in the last weeks of life, and using more palliative care services on a more regular basis; and to achieve this, we suggest the use of a “palliative care” treatment goal, for all incurably ill patients. In this context, GPs could be assisted, to recognise death in the near future in cancer and non-cancer patients, more systematically.

## **8.2 METHODOLOGICAL CONSIDERATION**

This dissertation examined end-of-life care, an increasingly important health issue in Europe. Its focus on the society, rather than on individual patients is particularly useful for public health planning and policy. A mortality-follow back design was used in each of the six studies over the four-year registration period.

### **Strengths**

#### **Nationwide registration**

To the best of our knowledge, this is the first nationwide study that explores these aspects of end-of-life care among patients who had died nonacutely, from within a general patient population in the Netherlands. The coverage was uniform and widespread along the distribution of sentinel stations in the network (Fig. 3; Chapter 1), the registration was systematic, regardless of age group, setting, or diagnoses, and the entire exercise was actively supervised by NIVEL (14).

#### **Representative data (excluding nursing homes)**

Our data was representative of all registered GP patients in the Netherlands, which by definition and function, already excludes nursing home residents. In addition, the Network was representative of all practising GPs in the Netherlands by age, gender, geographic distribution and population density. Hence, the findings from this study may be generalised for the population represented, unlike if a convenient sampling method had been used. However, there is need for caution when doing this, given the Dutch context of nursing home and other practice.

#### **Network of Trained GPs**

Participating sentinel GPs were trained to collect accurate data via a continuous registration (of morbidity and mortality) process. The non-sudden and progressive

nature of the patient's illness and the "gate-keeping" role of the GPs meant the GPs were often familiar with the course of illness leading to death. As informants, they might not have been the perfect proxies as stated in Chapter 4, however given the circumstances, we assume the data they provided were reliable, particularly since most were from prospectively-documented records (Chapter 6). This Network maintained a low GP drop-out rate throughout the 4-year registration period (14).

### **Research instrument**

Questions were developed in the Dutch language, piloted and rigorously tested among GPs for readability and comprehensibility. We informed the GPs when changes were introduced to the forms (i.e. at the start of each new year), and gave clear operational guidelines, including definitions, illustrative examples, to ensure they understood the items as we intended. Paper forms were used because they were already in use by NIVEL, and they were efficient and very easy-to-fill.

### **One-week retrospective data collection**

GPs registered data on patients they had cared for themselves. To minimize recall bias, data were collected within one week of patient's death, and reminders were sent when necessary. A retrospective collection was advantageous in this case because the deaths were captured upfront, unlike in prospective studies where very ill patients are sought, and patient drop-out rates could be high. We avoided recruiting patients with three-month life expectancy for instance, because this technique would present more opportunities for missing out on certain groups, especially noncancer patients (unlike beginning with people who had actually died).

### **Quality assurance by NIVEL**

The entire data collection exercise was supervised by NIVEL, using stringent quality assurance protocols. Completed registration forms were returned to the Research Institute, where they were scrutinised for errors and missing values, photocopied, and copies were then sent to the researchers for data entry and analyses. When necessary, NIVEL assisted in retrieving missing data from the GPs.

### **Cross-national comparison**

Country comparison was possible with Belgium (Chapter 6), using the same research instrument and methodology, and this can be applied to other countries.

## **Limitations**

### **Self-reporting GPs**

It is possible the GPs provided some socially-desirable responses, because they reported on care they had provided themselves. Naturally, people avoid reporting information that could reflect badly on them. Also, it is possible that responses sometimes reflected GP (or care-giver), rather than patient-perspectives.

### **Limited representative-ness**

A logical consequence of this research design was our inability to explore the Dutch nursing home which is an equally important end-of-life care setting. As mentioned in every chapter, the results are not representative of nursing home residents and all those whose care in the last weeks of life were outside the purview of their GPs. By virtue of this selection, there is need for caution when interpreting these results.

### **Insufficient power**

Being a population-based registration, we generated a relatively large sample size over the four years. Hence it was possible to pool data together, e.g. the study on the oldest old, producing robust analyses. However, we could not explore care within interesting sub-populations, i.e. patients with HIV, dementia, diabetes, heart failure, migrant communities etc in more detail. This is likely to change in the future.

### **Terminologies**

A retrospectively derived concept like “non-sudden and expected death”, could in reality be difficult to understand and measure because there’s a tendency to resist death, both in thoughts and deed, thereby not recognising it soon enough, especially if a good relationship existed between GP and patient. Otherwise, well

## **8.3 IMPLICATIONS FOR POLICY, PRACTICE AND FURTHER RESEARCH**

Between 2005-2008, the SENTI-MELC methodology generated robust population-based data on salient aspects of end-of-life care in the Netherlands, some of which can be used by researchers, patient groups, policy makers, health insurers, GPs and other clinicians involved in end-of-life care provision, and can yet provide a platform for further research endeavours.

## **Policy and practice implications**

Our findings point at ongoing care practices in the last months in the Netherlands. Naturally, the next step would be to monitor and properly evaluate this care. Based on our results, the Dutch government could assist national monitoring systems in evaluating end-of-life care in all recognised care settings, encouraging consistent and complementary approaches. Guidelines could be developed to enforce the systematic use of a treatment plan with specified goals per time, particularly for the nonacute and incurably ill patient. Also, there is a need for an inventory of existing palliative care services (specialised or not, multidisciplinary etc) and the content of palliative care training programmes for all GPs in the Netherlands, followed by the exploration of further training needs, if any. To improve end-of-life care at home and care homes, and enhance practice, results from this and related studies could be made available to practising GPs nationwide. The benefits of timely recognition of ‘approaching death’ cannot be overemphasised (see Chapters 2–5), and to achieve this, GPs are key. They could be supported in the use of a practical tool like the Gold Standards Framework, which allows structured assessment and care organisation for persons with any end-stage condition, residing in any setting (15;16).

## **Further research implications**

From our findings, it would appear that there is a need for more research into why several GPs were unaware of their patients end-of-life preferences (i.e. place of death), although the question of whether the patients actually retained the same preferences in the last months to weeks of life, would remain an issue. Also, it may be interesting to examine how unnecessary or unwanted transitions at the end of life could be recognised and managed, without jeopardising optimal care provision. Based on findings from the article on discussing end-of-life issues, some research could be done to explore communication needs of different patient groups (including non-westerners), and meaningful ways of communicating topics exploring social, and spiritual /existential issues with patients at the end of life. As earlier mentioned, there is the need to research the contents and curricula of current palliative care training programs, policies guiding GP end-of-life practices in the Netherlands, and GP use of existing protocols and end-of-life assessment tools. Given the differences in organisation of end-of-life care in the Netherlands and several other European countries, some research could be done to explore the similarities and differences, which arrangements produce better outcomes, are cost effective and beneficial to patients, especially in the light of current medical advancements and national greying trends. Finally, our results show a substantial proportion of patients preferred to die in hospices – this might reflect the growing number of ageing migrants in the Netherlands, and should be researched in detail, for the purpose of future planning.

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# Summary

## SUMMARY OF DISSERTATION

This is a research on patient care in the last months of life via a representative network of general practitioners. Data from GPs on all patients in the network aged > 1year, whose deaths had been non-sudden and expected, were collected between 2005-2008 through registration forms which were filled within one week of dying. Data were collected on demographic characteristics, place of death, nature and purpose of care, wishes of patients and some other aspects of end-of-life care.

Chapter 2 examined how long before death the patients who were likely die in the near future were recognised, from a selection of non-sudden and expected deaths. Our results showed that most patents died at home or in a care home (twice as many as those who died in hospital). Recognising death before a patient's last week of life was found to be related with fewer hospital deaths, more GP-patient contacts in the last week, more deaths in a preferred place, and more GP-patient discussions about specific end-of-life issues in the last seven days of life. Cancer was the main reason for recognising death in the near future, and recognising death in the near future preceded aspects of end-of-life care, i.e. GP-patient discussing end-of-life topics such as possible complications, physical problems, psychosocial problems, and palliative care options. We reasoned that if GPs could systematically recognise the dying phase, particularly among non-cancer populations at home, there would be more desirable end-of-life care outcomes. A practical tool that has been used for facilitating this practice in the UK is the Gold Standards Framework (GSF).

Chapter 3 explored the incidence and timing of GPs discussing ten end-of-life issues - primary diagnosis, incurability of illness, life expectancy or prognosis, possible medical complications, physical symptoms, psychological problems, social problems, spiritual or existential problems, palliative care options and treatment burdens with terminally ill patients. We found that physical and psychological problems were discussed most frequently; while social and spiritual problems were least discussed with GPs. Having cancer, being educated and absence of dementia were important correlates of GPs ever discussing the ten issues with their patients before death. Generally, issues were discussed more often with younger, female, more educated, and mentally competent patients, and those with a clear palliative care treatment goal. Primary diagnosis and incurability were discussed more frequently with men than women. Although patient-needs were not assessed in this study, our data shows that current practice in the Netherlands does not completely reflect the new models of palliative care, which dictate that supportive care be given alongside curative therapies. Cancer was the main reason for GP-patient communication about all end-of-life issues in all the three time intervals.

Chapter 4 examined GP awareness of patients' preferred place of death in the last months, and the incidence of patients dying in a preferred place. Forty-six percent of the patients had GPs who were not aware of their preferred places of death. Of those GPs that were aware of their patients preferred POD, most had informed by the patients themselves. Four-fifth of the patients with known preferred POD died there. A higher social status, having a palliative care or life-prolongation treatment goal, and using palliative care services were associated with higher GP-awareness odds. We concluded that there is a potential for improving awareness among GPs, of patient wishes such as preferred POD. Such awareness can be enhanced when palliation is an active part of end-of-life patient care.

Chapter 5 examined the nature and prevalence of care setting transitions in the last 3 months of life, and the results showed 690 patients made 709 transitions in the last 3 months, which involved a hospital two out of every three times, covering 43 distinct care trajectories within the two-year study period. The commonest trajectory was home-hospital (48%). Two out of every three transitions involved hospital at some point. Having a transition in the last 30 days of life was associated with being male, having multi-morbidities, and absent GP-awareness of a patient's preferred place of death. Terminal hospitalisation for the last 7 days of life, was associated with age ( $\leq 85$  years), infection, and absent palliative care treatment goal. We observed that transitions to hospitals were relatively frequent, though most 'non-sudden and expected' deaths occurred at home. We therefore conclude that timely recognition of the palliative phase of dying, is important in minimizing abrupt or frequent transitions before death.

Chapter 6 compared the frequency of GP visits and palliative care service utilisation in two European countries, and identified associated factors. GP visits were more frequent in the Netherlands than in Belgium: the mean number of GP visit in the last week of life was 5.1 vs. 3.2 (home) and 4.4 vs. 2.3 (care home). Conversely, palliative care services were more often used in the last three months of life in Belgium than the Netherlands: 78% vs. 41% (home) and 39% vs. 5% (care home). Having more frequent GP visits at home were associated with cancer-related deaths in the Netherlands and Belgium. The differences between countries remained consistent despite correcting for possible confounders. They appear to have resulted from existing policies and the organisation of healthcare in the two countries, but these should be studied in some more detail.

Chapter 7 examined the oldest old and GP end-of-life care. Many of the oldest of old in the Netherlands reside at home and in residential care homes, and remain under the care of their GPs, (unlike those cared for by specialists in nursing homes and hospitals). There were more women than men, more patients with heart failure

than cancer, less hospital and home deaths, and more residential care home deaths among the oldest old (>85y) compared with the younger old group (65-84y). Comparatively, fewer oldest old patients received PCS, and more preferred to die in a residential care home than the latter. Age was independently associated with using palliative care services: the oldest old received PCS less often (OR=0.7), and were treated with a palliative-centred goal more often (OR=2.4) than the younger old; but was not related to dying in a preferred place, i.e. independent of other characteristics. This results shows age to be independently associated with receiving PCS in the Dutch community. And although the GPs did recognise the “palliative phase” in the oldest old, their involvement of specialist teams for them was somewhat less.

Chapter 8 is the last chapter and it provides the discussion of all findings in a general context. In conclusion, the non-sudden and expected nature of death resulting from advanced progressive illnesses (e.g. cancer, heart failure, COPD, end-stage renal disease, AIDS), and advanced ageing allows for better care management at the end of life. Monitoring the pattern of GP recognition of the need for palliative care, communication of salient issues with patients, their awareness of place of death preferences, and the knowledge of transitions between care settings, could provide cues for forward planning and adequate end-of-life care provision by all concerned.

## **Samenvatting (summary in Dutch)**

## NEDERLANDSTALIGE SAMENVATTING

Dit is een studie over zorg in de laatste levensmaanden via een representatief huisartsennetwerk. Gegevens van huisartsen over alle patiënten in het netwerk ouder dan 1 jaar van wie het overlijden verwacht en niet-plotseling was, zijn verzameld tussen 2005 en 2008 met behulp van registratieformulieren. Gegevens zijn verzameld over plaats van overlijden, aard en doel van de zorg en wensen en ervaren problemen van de patiënten.

In de studie gerapporteerd in Hoofdstuk 2 is onderzocht hoe lang vóór het overlijden de patiënten die waarschijnlijk binnen korte tijd zouden overlijden zijn geïdentificeerd. Het identificeren van deze patiënten meer dan een week voor hun overlijden was gerelateerd aan minder ziekenhuisoverlijdens, meer contacten tussen huisarts en patiënt in de laatste week, en vaker overlijden in de gewenste plaats van overlijden dan wanneer patiënten korter dan een week voor overlijden zijn geïdentificeerd. Bij patiënten die langer dan een week voor overlijden zijn geïdentificeerd waren ook meer gesprekken tussen huisarts en patiënt over specifieke levenseindeonderwerpen in de laatste week, zoals mogelijke complicaties, lichamelijke en psychologische problemen en mogelijke opties voor palliatieve zorg. De diagnose kanker was de belangrijkste reden voor het identificeren van overlijden in de nabije toekomst. We concludeerden dat als huisartsen de stervensfase systematisch zouden herkennen, zeker bij niet-kankerpatiënten thuis, wenselijke levenseindeuitkomsten waarschijnlijk zouden zijn. Een praktisch instrument om dit proces te vergemakkelijken is de Gold Standards Framework.

In Hoofdstuk 3 is gerapporteerd hoe vaak en op welk tijdstip huisartsen belangrijke onderwerpen rond de levenseindezorg met de patiënten bespraken. De onderwerpen waren diagnose, ongeneeslijkheid van de ziekte, levensverwachting, mogelijke medische complicaties, lichamelijke problemen, psychologische problemen, sociale problemen, spirituele / existentiële problemen, opties voor palliatieve zorg en door de patiënt ervaren last. Uit de resultaten blijkt dat lichamelijke en psychologische problemen het meest werden besproken, terwijl sociale en spirituele problemen het minst werden besproken tussen huisarts en patiënt. De diagnose kanker, een hoge opleiding en de afwezigheid van dementie waren gerelateerd aan het ooit hebben besproken van de onderwerpen. Over het algemeen werden de onderwerpen vaker besproken met jonge patiënten, vrouwen, patiënten met een hogere opleiding, wilsbekwame patiënten, en patiënten met een palliatief behandeldoel. Diagnose en ongeneeslijkheid van de ziekte werd relatief minder vaak besproken met vrouwelijke patiënten. Onze gegevens laten zien dat in Nederland het model voor palliatieve zorg, dat voorziet in het geven van symptoomgerichte zorg tegelijk met ziektegerichte zorg, niet geheel wordt toegepast.

De in Hoofdstuk 4 gerapporteerde studie had als onderwerp de mate waarin huisartsen zich bewust waren van de door patiënten gewenste plaats van overlijden, en het aantal patiënten dat overlijdt op de gewenste plaats. Zesenvertig procent van de patiënten had huisartsen die zich niet bewust waren van de gewenste plaats van overlijden. De meeste van deze patiënten hadden zelf hun huisarts hierover geïnformeerd. Rond 80% van de patiënten met een bekende gewenste plaats van overlijden overleden daar ook. Bij patiënten met hogere sociaal-economische status, behandeling gericht op palliatie of levensverlenging en het inzetten van palliatieve zorgdiensten, was er een hogere kans op bewustzijn van de huisarts over de gewenste plaats van overlijden. We concludeerden dat er ruimte is voor verbetering van bewustzijn van de huisarts over wensen van patiënten rond het levenseinde, zoals gewenste plaats van overlijden.

In Hoofdstuk 5 is gerapporteerd over de aard en het aantal zorgverplaatsingen van patiënten in de laatste drie levensmaanden. Uit de resultaten blijkt dat 690 patiënten 709 verplaatsingen maakten in de laatste drie maanden. Er was sprake van 43 verschillende trajecten van verplaatsingen; bij tweederde van de verplaatsingen was een ziekenhuis betrokken. Het meest voorkomende traject was huis – ziekenhuis. Manlijke patiënten, patiënten met meerdere aandoeningen en patiënten bij wie de huisarts niet op de hoogte was van hun wensen hadden vaker een verplaatsing dan andere patiënten. Verplaatsing naar het ziekenhuis gevolgd door overlijden was gerelateerd aan leeftijd van de patiënten ( $\leq 85$  jaar), het hebben van infecties, en het ontbreken van een behandeldoel gericht op palliatie. Het tijdig herkennen van de stervensfase is nodig om het aantal verplaatsingen aan het levenseinde zo veel mogelijk te beperken.

Nederland en België werden in Hoofdstuk 6 vergeleken met betrekking tot het aantal huisbezoeken van huisartsen en het gebruik van palliatieve zorgdiensten. Huisartsen in Nederland bezochten hun patiënten aan het levenseinde vaker dan in België. In de laatste week van het leven kwam de huisarts gemiddeld 5,1 keer thuis op bezoek in Nederland en 3, 2 keer in België. Het gemiddeld aantal bezoeken in verzorgingshuizen is respectievelijk 4,4 en 2,3. In de laatste drie levensmaanden werden palliatieve zorgdiensten in België vaker ingezet dan in Nederland bij patiënten thuis (78 vs 41%) en in verzorgingshuizen (39 vs 5%). Zowel in Nederland als in België is de diagnose kanker gerelateerd aan frequente huisbezoeken van de huisarts. De verschillen tussen de landen reflecteren de verschillen in zorgbeleid tussen de landen; de Nederlandse huisarts wordt meer dan in België geacht zelf invulling te geven aan de palliatieve zorg van zijn of haar patiënten.

In Hoofdstuk 7 wordt gerapporteerd over een studie naar de levenseindezorg voor de alleroudste patiënten die thuis of in een verzorgingshuis verblijven. Onder de

alleroudste patiënten (ouder dan 85 jaar) waren er in vergelijking met jongere patiënten (65-85 jaar) meer vrouwen, meer patiënten met hartfalen, minder ziekenhuisoverlijdens en meer overlijdens in verzorgingshuizen. De oudere patiënten wensten vaker in een verzorgingshuis te overlijden. Leeftijd was gerelateerd aan het gebruik van palliatieve zorgdiensten: de alleroudsten hadden 1,4 keer minder kans op zorg van een palliatieve zorgdienst en werden 2,4 keer vaker met een behandeldoel gericht op palliatie behandeld dan de jongere patiënten. Leeftijd was niet gerelateerd aan het overlijden op de gewenste plaats.

Hoofdstuk 8 is het laatste hoofdstuk van dit proefschrift, waarin de bevindingen in een algemeen perspectief worden geplaatst.

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# Curriculum Vitae

## ABOUT THE AUTHOR

Ebun Abarshi was born on 29<sup>th</sup> of June, 1966 at the Hammersmith Hospital, London. She obtained her secondary school diploma (GCSE) at the Queen's College, Lagos, followed by a Bachelors in Medicine & Surgery (MBBS) from the prestigious Obafemi Awolowo University, Ile-Ife in Nigeria. After about eight years of practising clinical medicine in Nigeria, Ebun veered into the field of Public Health, and gained hands-on experience in qualitative and quantitative research methods by working on several projects in Africa and abroad. One of such projects was the WHO Local government and health sector decentralisation project undertaken in Nigeria.

Ebun has a Masters in Env. Epidemiology and Public Health Policy from the London School of Hygiene & Tropical Medicine (University of London). In May 2005, she worked part-time as a researcher in the Department of Public and Occupational Health of the VUMC, and was formally employed by the EMGO Institute in October 2006, where she performed the research that is reported in this dissertation.

Ebun is an ordained pastor of the Redeemed Christian Church of God (RCCG), and she volunteers her time in teaching and empowering people based on Biblical principles. Her interests include the end-of-life care needs of cancer and non-cancer patients (HIV, CHF, COPD, RF), improving patient decision-making especially among non-western cultures, and spiritual care provision at the end of life.

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## **DISSEMINATION OF RESEARCH FINDINGS**

1. EAS requests and cancer types in the Netherlands: is there a relationship? 4<sup>th</sup> Research forum of the EAPC. Venice, Italy. 24-27/05/2006. Poster presentation.
2. End-of-life care registration in the Netherlands via General Practice: a process in progress. Agora Meeting (Palliative Care network), Amsterdam, Netherlands. 15/03/2007. Speaker.
3. Monitoring end-of-life care via general practice in Europe: a study with the Sentinel Surveillance Networks of General Practitioners. Care in the last three months of life in The Netherlands. 13<sup>th</sup> WONCA Europe Congress. Paris, France. 17-20/10/2007. Oral presentation.
4. Transitie in zorgsetting aan het levenseinde in Nederland: resultaten van de Senti-Melc studie. *Wetenschap in de palliatieve zorg*, Onderzoekforum Nederland-Vlaanderen, Antwerpen, België. 17/11/2007. Oral presentation.

5. Multiple care setting transitions at the end of life in the Netherlands: results from the Senti-Melc Study. 9th Public Health Symposium: Public Health at the End of Life. Brussels, Belgium. 14/12/2007. Oral presentation.
6. Care setting transitions at the end-of-life in the Netherlands: a nationwide study. 5th Research forum of the EAPC. Trondheim, Norway. 29/05/2008. Poster presentation.
7. Transitions between Care Settings at the end of life in the Netherlands: results from the Senti-melc study. Werkbespreking. The EMGO Institute for Health and Care Research, VUMC, Amsterdam. 4/05/2009. Oral presentation.
8. Methodology & Results: Senti-melc nationwide mortality follow-back study. Huisartsgeneeskunde/ Epidemiologie: Keuzevak Extramuraal geneeskundig onderzoek. VUmc Amsterdam, Netherlands. 3/06/2009. Oral presentation.
9. Transitions between care settings at the end of life: results from a nationwide study. 15th WONCA Europe 2009 Conference. Basel, Switzerland (16/09/2009). {Abarshi et al. Transitions between care settings at the end of life in the Netherlands: results of a nationwide study. Swiss Medical Weekly, The European Journal of Medical Sciences; Sept 2009;175(139):33-34}. Oral presentation.
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12. The oldest old and GP end-of-life care in the Dutch community: a nationwide study. 6th Research forum of the EAPC. Glasgow, UK. 10-12/06/2010. Poster presentation.
13. Use of Palliative Care Services and GP visits at the end of life in the Netherlands and Belgium. 6th Research forum of the EAPC. Glasgow, UK. 10-12/06/2010. Poster presentation.
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