DYING WELL WITH DEMENTIA
IN NURSING HOMES
IN FLANDERS, BELGIUM.

An Vandervoort

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DYING WELL WITH DEMENTIA
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Department of Family Medicine and Chronic Care
Faculty of Medicine and Pharmacy
Vrije Universiteit Brussel

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An Vandervoort

Promoter: Prof. dr. Luc Deliens
Co-promoter: Prof. dr. Lieve Van den Block

Examination committee
President: Prof. dr. Dirk Devroey
Other members:
Prof. dr. Joachim Cohen
Prof. dr. Reginald Deschepper
Prof. dr. Chantal Van Audenhove
Prof. dr. Agnes van der Heide

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Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L.
Nursing home residents dying with dementia in Belgium: the research protocol of the Dying Well with Dementia study.

CHAPTER 3

Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Volicer L, Houttekier D, Deliens L. Nursing home residents dying with dementia in Flanders, Belgium: a nationwide post-mortem study on clinical characteristics and quality of dying. Journal of Medical Directors Association; 2013.14(7):485-492.

CHAPTER 4

Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Deliens L. The incidence of palliative care and life-prolonging treatments in nursing home residents dying with dementia. (submitted)

CHAPTER 5

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CHAPTER 6

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CHAPTER 7

Vandervoort A, Van den Block L, van der Steen JT, Vander Stichele R, Bilsen J, Deliens L. Advance directives and physicians’ orders in nursing home residents with dementia in Flanders, Belgium: prevalence and associated outcomes. International Psychogeriatrics. 2012 Jul;24(7):1133-43.

CHAPTER 8

Vandervoort A, Houttekier D, Vander Stichele R, van der Steen JT, Van den Block L. Quality of dying in nursing home residents dying with dementia: does advanced care planning matter?
A nationwide postmortem study. PLoS One (in press)

VOORWOORD

If I have seen further, it is by standing on the shoulders of giants. Deze uitspraak van Isaac Newton is zeker van toepassing als ik terugkijk op het proces van dit PhD. Het was een fijne tijd waarvan ik bewust heb genoten van de uitdaging maar het was ook hard labeur, waarin ik mijn grens meerdere malen heb kunnen en moeten verleggen. Het maken van dit PhD was een grootse uitdaging voor me, waarin verschillende mensen in verschillende fases belangrijk zijn geweest. Ik ben aan hun allen dank verschuldigd, een aantal "giants" wil ik in het bijzonder bedanken.

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PART I

INTRODUCTION

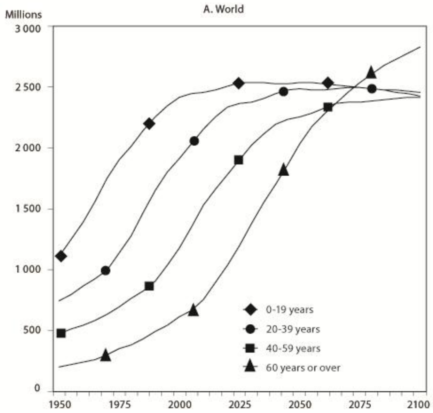
CHAPTER 1:

BACKGROUND AND RESEARCH QUESTIONS

AGEING AND DYING WITH DEMENTIA IN NURSING HOMES

Worldwide there is a continuously growing number of people living to old age (figure 1). In the EU the population aged 65 and above will almost double from 87 million in 2010 to 153 million in 2060[1, 2]. Moreover, the number of people aged 80 years and above is projected to almost triple from 24 million in 2010 to 62 million in 2060[1, 2]. This significant change in age structure is driven by advances in medical knowledge, improved living conditions and hygiene, hereby changing the pattern of disease and dying from acute infectious diseases to chronic and degenerative diseases such as dementia.

Figure 1: Worldwide population by broad age groups



SOURCE: own figure based on figure published by the population division of the department of economic and social affairs of the united nations secretariat: population ageing and development 2012, http://esa.un.org (accessed 16/01/2014)

Dementia is one of the biggest global public health challenges facing our generation[1]. There are currently 36 million people living with dementia in the world and this is predicted to almost double every 20 years[1-4]. A “tsunami” of dementia is predicted worldwide, with 66 million in 2030 to 115 million in 2050[1, 2]. Newly available data suggests that the current burden and future impact of the dementia epidemic has been underestimated[1]. Considering the growing prevalence of dementia, end-of-life care for people with dementia has also become a major public health concern[2].

Dying has become more institutionalized. The number of people dying in nursing homes is almost certain to increase with the ageing population[5, 6]. Most people with early-stage dementia reside at home; however more than 95% need 24-hour care when the illness progresses, making home care until death fairly unusual. Epidemiological evidence shows dementia as a risk factor for nursing home admission; between 50% and 92% of people with dementia in Europe die in a nursing home as do 67% in the US[5, 6]. The median time from dementia diagnosis to nursing home admission is three to four years[7]. In Belgium, 11.4% of people with dementia died at home, 22.7% in hospital and 65.9% in nursing homes[5]. When studying trends in place of death, home deaths remained stable; however, hospital deaths decreased from 55.1% to 51.7% and nursing home deaths rose from 18.3% to 22.6%[5]. Despite a shift in priority to community service provision, residential care is still a significant feature of long-term care for people with dementia, and it may be the most appropriate and effective way of meeting someone’s needs when community support (formal and informal) is insufficiënt[2] meaning that nursing homes play an increasing role in caring for frail older people, such as people with dementia, at the end of life.

While we are aware of this increase in people with dementia in nursing homes, we lack reliable data on how many nursing home residents with dementia are currently actually dying in and outside nursing homes, what care they received and what the quality of the dying process is.

QUALITY OF DYING WITH DEMENTIA AND PALLIATIVE CARE

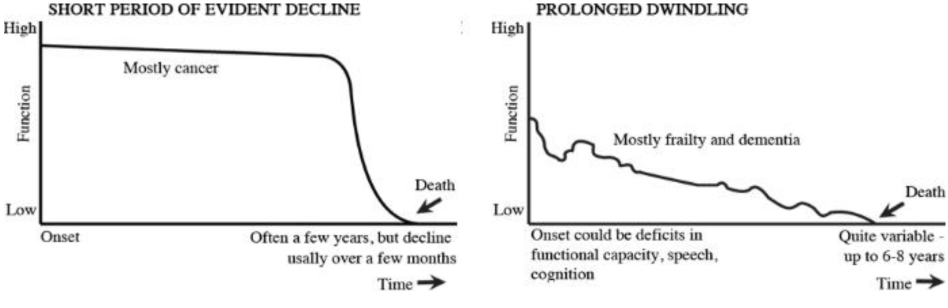
The World Health Organisation (WHO) defines dementia as follows:

“ Dementia is a syndrome due to disease of the brain – usually of a chronic or progressive nature- in which there is a disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capacity, language, and judgement.[2]” (WHO, dementia a public health priority, 2012).

Dementia follows a “frailty” pattern of decline with a steady “prolonged dwindling” due to the progression of the illness[8-10]. People with dementia become gradually dependent on others and suffer severe disability throughout the last years? of life with an increased activities of daily living

(ADL) dependency in the last months of life (eg memory loss, problems with communication, loss of mobility, eating and weight loss, problems with continence, unusual behaviour etc)[8-10]. Patients reaching the advanced stages of dementia experience these disabilities longer and usually throughout the last year of life[8-10]. Male gender and ADL dependency are the strongest predictors of 6-month mortality for patients with advanced dementia with no acute disease[10-13]. Survival with dementia is variable, between 5 and 9 years (median survival)[10, 14-17]. Comparing disease trajectories for dementia and cancer patients there are some important differences (figure 1). While cancer patients experience a substantial decline in function in the last months or weeks of life, people with dementia have progressive impairments (cognitive, functional and physical); however they may life for a long time (prolonged "dwindling")[18]. Cancer patients therefore have a more predictable dying course with a short period of evident decline which makes identifying the palliative and end of life phase easier; people with dementia experience prolonged "dwindling" which may persist for years, which makes prognosis difficult[19]. Moreover, in addition to physical and cognitive problems, behavioural problems or neuropsychiatric symptoms (eg depression) present further challenges in end of life care[18, 19].

Figure 2: Illness trajectories for people with progressive chronic illness



SOURCE: Adapted from Lynn and Adamson, 2003[22]; Murray et al., 2005[54]

Although people with advanced dementia are often bed bound, incontinent and unable to communicate, they are usually not perceived as having a terminal illness and professionals have a poor understanding of the pathophysiology of dementia[20]. The WHO stated that a growing number of people suffer from serious eventually fatal chronic illnesses such as dementia and this requires understanding end-of-life care in new ways[21, 22]. According to the World Health Organization

(WHO), palliative care is an approach that "improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment, and treatment of pain and other problems, physical, psychosocial and spiritual"[18, 23]. Traditionally, palliative care predominantly focused on cancer patients and on the last phase of life. However, the concept that palliative care is only relevant to the last weeks of life (when no other treatment is beneficial) is, it is suggested, outdated, and a more appropriate concept therefore is that palliative care is offered from the time of diagnosis, alongside potentially curative treatment, through disease progression until the end of life. Palliative care is a component of healthcare that can be needed at any time in life, starting at a low base and rising to eventually become the predominant theme for people with dementia[21, 22]. A recent white paper on palliative care for people with dementia affirms this viewpoint and elaborates by indicating that dementia is a potentially terminal disease for which palliative care may be beneficial.

It has been suggested that end-of-life care for people with dementia is currently inadequately adapted to their needs. A limited number of studies, mainly from the US and the Netherlands, have shown that people with dementia appear to be at risk of overtreatment with burdensome and potentially non-beneficial treatments[10, 18, 19] and that futile and distressing admissions to acute hospitals are common[20, 24] Also, caregivers consistently overestimate prognosis in advanced dementia: for example at nursing home admission only 1.1% of residents were thought to have a life expectancy of less than 6 months though 71% died within that period[11, 20]. An important study on nursing home residents dying with advanced dementia in the US (CASCADE study) reported that they suffer from a range of symptoms, similar to those found in the terminal stages of cancer; however they are often under recognized or inadequate addressed[10, 20, 25]. However, while most end of life studies are restricted to the specialist nursing homes in the Netherlands or to advanced dementia in a limited number of nursing homes in the US or other countries, several gaps remain in our knowledge of how people with dementia are dying, especially those who did not progress to an advanced stage. Robust epidemiological studies providing public health data on how nursing home residents die in a country, the extent to which palliative care is provided and valid measurements of the quality of end-of-life care and dying are lacking.

PALLIATIVE CARE IN FLEMISH NURSING HOMES

Belgium has many structures and services for palliative patients[26]. In the case of nursing homes, the Belgian Law on Palliative Care (26/10/2002) and the Decree on Residential Care (13/03/2009) indicate the right to palliative care for all and requires each nursing home to have a palliative care function. Nursing homes are required to join a palliative care network (15 regional networks cover the whole country) and have a functional relationship with a palliative care unit (not further specified in the law). Furthermore, each nursing home is required to have palliative caregivers supporting the regular caregivers by giving advice and if requested by taking over some aspects of care. These consist of a coordinating and advisory physician of the nursing home - a general practitioner who is among other things responsible for the development of a strategy regarding end-of-life care (no formal training in palliative care required) - or an in-house reference nurse for palliative care (registered nurse with bachelor degree and an obligatory basic palliative care training) or a palliative care task group[27-29]. They are asked to introduce a palliative care culture, provide palliative care consultation for regular caregivers and improve staff members' knowledge/skills in palliative care. Additionally, specialist home palliative care teams (ie mobile home care teams coming into the nursing home) can provide advice and training to regular and palliative care staff in relation to a specific resident (bedside or not). Before the present study was performed, we had no data on the involvement of these palliative care services/structures in the end-of-life care for nursing home residents with dementia.

ADVANCE CARE PLANNING AND GENERAL PRACTITIONERS' TREATMENT ORDERS

One of the key aspects of good quality palliative care is that the provided care is in accordance with the patient's wishes[30, 31]. Since communication at the end-of-life can be difficult for patients – especially for those suffering from cognitive deficiencies such as dementia – it is important to become aware of wishes or preferences regarding care in advance and engage in advance care planning. Advance care planning concerns the discussion with the resident and/or his/her representative about the goals and desired direction of care, particularly end-of-life care, in the event that the residents is or becomes incompetent to make decisions[32].

In addition to advance care planning, general practitioners' treatment orders (GP orders) are used in end-of-life care[33]. GP orders are instructions from the GP placed in the resident's medical file governing the use of specific treatments toward the end of life[33, 34]. Only when they have been discussed with the resident themselves they can be considered as patient-centred advance care planning[33, 34]. However, so far, no studies have described with whom such GP orders are discussed and when[33].

Societal developments such as the ageing of society, changing disease patterns from acute to more progressive and chronic diseases (eg cancer, cardiovascular and neurological diseases), more liberal attitudes (personal autonomy and self-determination) and an increasing recognition of the importance of focusing on patient-centred care have contributed to making advance care planning an issue of great clinical and public health concern[31, 35-43]. Additionally, for people with dementia, early exploration of their wishes and preferences is of particular importance since at the end of their life, most patients are not able to communicate their preferences[44-48]. In the USA, the trend towards advance care planning is supported by the Patient Self Determination Act which made it mandatory to inform all patients of their rights regarding decisions on their own medical care such as the right to accept or reject medical treatments, to authorize a representative and to complete written advance directives[49-51]. Ever since, there has been a growing awareness of the need to consider advance care planning in other countries[31]. In Belgium, since 2002, the Patients' Right Act gives patients the right to accept or reject medical treatments and to authorise a representative; however Belgian legislation does not regulate how institutions should implement these rights in practice[31, 33, 52].

The process of advance care planning can be documented in written advance directives. A written advance directive or living will refers to a document in which a person indicates their health care preferences while he or she is cognitively and physically able to make decisions[31]. These preferences mostly relate to withholding or withdrawal of potentially life-prolonging medical procedures such as cardiopulmonary resuscitation, artificial food or fluid administration, transfer to a hospital etc[31]. Written advance patient directives can consist of advance treatment directives (eg do-not-hospitalize or do-not-resuscitate orders) or the authorization of a legal representative in case the resident loses capacity. Written advance directives can be an aid to stimulate and facilitate the process of ongoing end-of-life care communication or facilitate transition of information to different health care workers in one care setting[31]. However, communication about future care does not always result in a written record but may involve conversations with the residents, or residents expressing their wishes to professional caregivers. Several models of advance care planning state how it could be initiated and maintained, for example the three step model by Teno proposed a stepwise approach that can be integrated flexibly into routine clinical encounters by the practitioner or other health care providers[31, 51, 53].

At the onset of the studies discussed in this dissertation, no data were available on a nationwide and population-based level describing advance care planning (written and verbal) and general practitioners' treatment orders for nursing home residents with dementia in Flanders, Belgium. Existing research has tended to focus on written outcomes of advance care planning only (eg advance directives). Moreover rather than studying associations between advance care planning and patient outcomes, research to date focused on associations between advance care planning and the use of care.

RESEARCH QUESTIONS

This dissertation has two overall aims:

1. To describe the proportion of nursing home residents dying with dementia in a representative sample nursing homes in Flanders, Belgium, and to describe their quality of dying and the care received at the end of life.
2. To describe the frequency and content of advance care planning for nursing home residents dying with dementia and for their families, and its relationship with resident outcomes.

More specifically, we have outlined the following research questions.

PART II Quality of dying, use of palliative care and life-prolonging treatments at the end of life of nursing home residents with dementia

1. What is the proportion of nursing home residents dying with dementia in Flanders, Belgium and what are their clinical characteristics and quality of dying? (Chapter 3)
2. How often and which type of palliative care do deceased nursing home residents with dementia receive in Flanders, Belgium and how many and which type of potentially life-prolonging treatments are provided? (chapter 4)
3. How often are deceased nursing home residents with dementia hospitalized in the last phase of life? (chapter 5)

PART III Advance care planning among nursing home residents with dementia

4. What is the prevalence and content of advance care planning and GP orders among deceased nursing home residents with dementia and what is the level of congruence between general practitioners, nurses and relatives? (chapter 6)
5. How are advance care planning and GP orders among deceased nursing home residents with dementia related to place of death and quality of dying? (chapter 7 and 8)

METHODOLOGY

In order to answer the research questions, two different studies were performed.

Dying Well with Dementia in 2010

The Dying Well with Dementia study answers the research questions 1 to 4 and part of 5. For the Dying Well with Dementia study this section presents the main characteristics of this study; the method is described in more detail in chapter 2 of this thesis.

The Dying Well with Dementia study was designed to investigate the quality of dying and end-of-life care in a representative sample of nursing home residents with dementia in Belgium, and to identify structural elements and processes of care that are associated with improved or worsened outcomes. To obtain representativity, we performed a cross-sectional retrospective study in Flanders, Belgium (2010) using random cluster-sampling. Based on a list of all nursing homes in Flanders in 2010 (provided by the national health insurance agency in Belgium, RIZIV) we randomly selected nursing homes from several strata (based on province, bed capacity, and ownership –public, private/nonprofit, private/profit). In the participating nursing homes, all residents with dementia who died in a three month period were reported. A structured questionnaire was filled in by the nursing home administrator, the nurse most involved in care, the general practitioner, and the most involved relative.

The study protocol was approved by the Medical Ethical Committee of UZ Brussel (University Hospital of Brussels).

Study on Advance Care Planning in Nursing Homes in 2006

To answer research question 5 we also performed a secondary analysis on previously collected data ie using the study on Advance Care Planning in Nursing Homes that was conducted at the end of 2006 by De Gendt et al [33]. Based on a list from the Flemish Ministry of Health, addresses and institutional characteristics of Flemish nursing homes were obtained and all care homes for the elderly recognized as high care nursing homes were included in the study (N=594). The nursing home administrator of each nursing home received a structured questionnaire by mail and was asked to list the number of residents who had died during September and October 2006. For each deceased residents the nursing home administrator was asked to pass a four-page questionnaire to the nurse most involved in the resident's care, or to the head nurse in case the nurse could not be identified. The nurse was asked to fill in questions about the resident's characteristics (age, gender, level of dependency), the prevalence of hospital transfers at the end of life, palliative care provision and the prevalence of documented advance care plans (advance directives and physician's orders) and the authorization of a legal representative. Non-responders (and those who reported more deceased residents during September and October 2006 than the researcher received questionnaires for) received a follow-up letter after one month and for those who had still not responded a telephone call after another three weeks.

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

In this dissertation, we have studied data of 764 nursing home residents with dementia (secondary analyses).

OUTLINE OF THIS DISSERTATION

Part II of this dissertation provides an overview of the quality of dying, the use of palliative care and life-prolonging treatments at the end of life of nursing home residents with dementia. Chapter 3 focuses on the clinical characteristics and quality of dying. Chapter 4 shows the incidence of palliative care and life-prolonging treatments while chapter 5 studies hospitalizations in the last phase of life in detail.

Part III concerns a more profound description of advance care planning among nursing home residents with dementia. Chapter 6 is devoted to advance care planning and physicians' orders from the perspective of the nurse, general practitioner and relatives. Chapter 7 examines the prevalence and associated outcomes of advance directives and physicians' orders. Chapter 8 examines whether advance care planning is related to the quality of dying.

Part IV entails a summary of the most important findings of the study, followed by a general discussion. Also attention will be given to challenges for practice and policy and recommendations for future research.

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CHAPTER 2:

DYING WELL WITH DEMENTIA IN NURSING HOMES: STUDY PROTOCOL OF A NATION WIDE CROSS-SECTIONAL STUDY

An Vandervoort, Lieve Van den Block, Jenny T. van der Steen, Robert Vander Stichele, Luc Deliens

ABSTRACT

BACKGROUND

The World Health Organization recently emphasized the overwhelming impact of dementia and stated that it should be considered a public health priority. The Dying Well with Dementia study was designed to investigate the quality of dying and end-of-life care in a representative sample of nursing home residents with dementia in Belgium, and to identify structural elements and processes of care that are associated with improved or worsened outcomes.

METHODS/DESIGN

To obtain representativity, we performed a cross-sectional retrospective study in Flanders, Belgium (2010) using random cluster-sampling. In selected nursing homes, all residents with dementia who died in a three month period were reported. A structured questionnaire was filled in by the nurse most involved in care, the general practitioner, and the most involved relative. We identified 205 deceased residents with dementia in 69 nursing homes, representative of all nursing homes in Flanders. Age distribution was representative for the population of nursing home residents dying with dementia. Response rates for general practitioners, nurses, nursing home administrators and relatives were 52.9%, 88.4%, 95.0% and 53.2% respectively. Non-response analysis showed no significant differences when comparing responding with non-responding general practitioners and responding with non-responding relatives on several important characteristics such as treatment and care at the end-of-life and residents' outcomes. The only observed difference was that nurses perceived more consensus among relatives on care and treatment of the resident (p=0.004) in case the general practitioner participated compared to when the general practitioner did not participate.

DISCUSSION

Using the design of the Dying Well with Dementia study we will be able to provide representative population-based data on how well nursing home residents with dementia die in our country, those with advanced dementia as well as those who die before dementia reaches an advanced stage. Dissemination of nationwide research results is currently in preparation and data are being merged with analogous data from The Netherlands in order to make cross-national comparisons. The study

also creates opportunities for comparison with other countries in and outside the EU. A preliminary analysis of the possible strengths, weaknesses and opportunities of our research is outlined.

BACKGROUND

Dementia is one of the greatest global health care challenges. A significant increase in the numbers of people with dementia and of those dying with dementia is expected in the forthcoming years[1-4]. The World Health Organization recently emphasized the overwhelming impact of dementia and stated that it should be considered a public health priority[4]. Dementia is a risk factor for institutionalization, especially when it progresses to an advanced stage and the need for care increases[5-8]. On average, 40% of the population in nursing homes in Belgium have dementia. However, research regarding the end of life of nursing home residents dying with dementia is scarce. This study was designed to investigate the quality of dying and care in the last phase of life of nursing home residents with dementia and to identify the processes of care that determine improved outcomes.

Almost all earlier work concerning the end of life for people with dementia has limitations, eg using small sample sizes[9,10], being conducted only in a hospital[10], being based on analyses of secondary databases with difficulties in identifying residents with dementia[9,11,12] or being limited to specific populations such as those with advanced dementia only[12,13]. Moreover, most of these studies originate from the US and are limited to specific regions or institutions, hence generalising is difficult[14]. One important recent US study of nursing home residents dying with advanced dementia (CASCADE study) described the clinical course of advanced dementia and identified important areas for improvement[15]. However, not all residents progress to an advanced stage and it is unclear how many die before reaching that stage and how different their dying process is. Also, due to the use of a prospective design, people with dementia living the longest were not followed up until death in this study, preventing to obtain a representative sample of this population[13]. Finally, many other studies have not focused on identifying how the care provided relates to improving or worsening outcomes for these residents though this would provide important information on which to base the interventions necessary to achieve preferred outcomes.

The research questions of the Dying Well with Dementia study in Belgium are to:

1. Describe the prevalence and characteristics of a representative sample of deceased nursing home residents with dementia

2. Describe the health, clinical characteristics, quality of dying and quality of end-of-life care for nursing home residents dying with dementia and for their families
3. Identify structural elements and processes of care associated with improved or worsened outcomes.

In this paper we present the protocol of the study and report the number of cases, the response rates obtained, the results of a non-response analysis and the possible strengths and weaknesses of the study.

METHODS

DESIGN

We performed a cross-sectional retrospective study in 2010 in Flanders, Belgium using random cluster-sampling. In selected nursing homes, all residents with dementia who died in a period of three months were reported. For each case a structured questionnaire was filled in by the nurse most involved in care, the general practitioner (GP) and the relative most involved in the resident's care.

There are several reasons why we used a retrospective rather than a prospective design. A retrospective design more easily allows the identification of a distinct study population[16-18]. It also, allows identifying a population-based sample of deaths on a nationwide level, while prospective studies are often not representative due to censoring[16-18].

Study population

A two-stage screening protocol was used to identify eligible residents:

1. as a first step, in each care home willing to participate, a contact person identified all residents who had died, in the nursing home or elsewhere, in the past three months and identified residents who met one of the criteria used by the Belgian health insurance system to allocate financial resources[19] the criteria for (1)'category Cdementia' i.e. 'being completely care dependent or needing help for bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space', OR (2) disorientation in time and space (KATZ scale≥3 or having 'almost daily a problem with disorientation in time and space'). These first selection criteria minimized the risk of missing out eligible residents with dementia but risked including false positives so GPs and nurses of residents fulfilling these criteria were sent questionnaires in which additional eligibility criteria were surveyed.
2. in the second step – in order to exclude false positives or residents who did not have dementia according to the GP or nurse - additional eligibility criteria required that the GP or nurse indicated that the resident 'had dementia' or 'was diagnosed with dementia'.

Based on the Cognitive Performance Scale and Global Deterioration Scale (as scored by the nurse), residents were classified into three groups (Box1). Advanced dementia was measured in the same way as by Mitchell et al[13].

Box 1: Classification of dementia severity one month before death

Very severe or advanced dementia	CPS* ≥ 5 and GDS† = 7
Severe dementia	(CPS ≥ 5 and GDS <7) or (CPS <5 and GDS = 7)
Moderate or mild dementia	CPS <5 and GDS <7

*Cognitive Performance Scale [27], † Global Deterioration Scale [28]

Based on earlier studies, our power analyses showed that obtaining a minimum sample of 100 subjects with advanced dementia would produce an 80% likelihood (or power of 80%) that the study would yield a statistically significant effect on important outcomes measures (eg to find a mean difference of four points between respondents[20] (such as advanced vs mild to severe dementia) or to find a mean difference of five points between countries[21] in SM-EOLD,calculated using Power and Precision,4.1,2011). On the basis of a previous study of deceased residents in Flemish nursing homes, we estimated that 65% of residents dying in Flemish nursing homes would suffer from a form of dementia (estimated by nurses)[22]. However, no reliable data exist on the number of people dying with advanced dementia. Nurses' clinical judgments suggested that 41% of all deaths involve severe dementia[22]. Hence, we decided we needed a minimum of 400 deceased nursing home residents in our study using a conservative estimate of 25% (100/25*100) in order for it to include 100 deceased nursing home residents with advanced dementia.

OBSERVATIONAL UNITS AND SAMPLING PROCEDURE OF NURSING HOMES

To be representative of all Flemish nursing homes, all homes in Flanders in 2010 – identified using the data available from the national health insurance agency in Belgium (RIZIV)– were stratified by region (five provinces) and subsequently by bed capacity (up to or more than 90 residents) and ownership (public, private/nonprofit, private/profit) and then randomly sampled per stratum. Bed capacity and ownership are factors related to the quality of end-of-life care[23,24]. Where an institution declined to participate, another nursing home was randomly selected in that stratum until the targeted number of nursing homes was reached. After data collection, we verified the relative distribution of participating nursing homes in terms of the umbrella organisations, indicating that the identified sample of homes was representative for all major umbrella organisations in the country.

Based on a previous study of De Gendt et al(2006), we know that in each nursing home on average five residents die over a period of three months so we estimated that we needed to include 80 nursing homes to identify 400 deceased residents. We expected a 58% response rate as was the case in De Gendt et al[22].

DATA COLLECTION PROCEDURE

A letter introducing the research project was sent to the board of directors asking for their participation. If they wanted to participate, the board of directors and the coordination and advisory physician, (who is responsible for overall policy of end-of-life care in Belgian nursing homes but not for the care of individual patients) of the facility received the full research procedure by letter. Where there was no initial response, the researcher contacted the nursing home two weeks after sending the first invitational letter.

In each participating home, the board of directors and/or coordination and advisory physician appointed one contact person for the study (a nursing home administrator or head nurse). The researcher visited each nursing home and assisted the contact person in identifying eligible residents. Using a checklist the nursing home administrator listed all the residents who had died in the last three months. Deaths were recorded between May and October 2010; a three-month flashback limits the recall bias and has been tested and used previously[25].

The contact person checked residents for inclusion criteria (step 1 of the two-stage screening protocol by the use of a checklist). The researcher only received the part of the checklist containing the unique coded number and the inclusion criteria (Part B, not containing any names). Part A of the checklist, containing the names of the patients, GPs, and the relative, remained in the institution. All this information was provided using the residents’ administrative files (without using the medical files).

For the selected individuals with dementia the contact person identified three key persons:

- nurse most closely involved in the resident’s care. This could be the head nurse or another nurse in the institution. If this nurse was not willing to cooperate, the head nurse was asked to fill in the questionnaire instead

- resident’s GP (the GP is the treating physician of nursing home residents in Belgium)
- relative ie most closely involved family member or friend.

The contact person of each institution sent questionnaires to all three respondents, linked to the unique code of the resident, accompanied by a letter from the nursing home explaining why and how they were participating in the study. All respondents received an informational letter and were asked to participate on a voluntary basis. The relatives received the questionnaire no earlier than two weeks after the resident’s death. It has been shown that there is no difference in distress or response rate for the family at two weeks in comparison with a period of six weeks[26].

The completed questionnaires with coded identifiers were sent back to the researcher. The researcher contacted the reference person regarding non-responding nurses, GPs and relatives (identified through the unique code), and the reference person then sent a maximum of two reminders.

The study design, all steps in the data collection procedure and the measurement instrument were tested in 5 nursing homes.

ETHICAL CONSIDERATIONS

The research procedures outlined in the method section ensure confidentiality and respect for the privacy of patients and respondents, using unique anonymous codes and a mediating contact person of the home. The study protocol was approved by the Medical Ethical Committee of UZ Brussel (University Hospital of Brussels).

MEASUREMENT INSTRUMENT

To develop the questionnaires, we selected questions and instruments used in other (Dutch, Flemish, US) retrospective and prospective studies[13,14,22]. When possible, we selected measures specifically designed for use in people with dementia. Table 1 provides an overview of the data collection elements, instruments that were used, the respondents and the time frame.

Demographic and background data on the resident included:

- age, sex, religious affiliation, education, marital status, whether or not there was a relative/friend involved in their care, length of nursing home stay, reason for nursing home admission, prior living situation, place of death, type of nursing home unit at time of death.

Data on dementia included:

- type of dementia, time of onset of dementia, diagnosis of dementia, stage of dementia at time of nursing home admission, stage of dementia at time of death, mild/moderate/severe dementia as judged by the nurse and GP at time of admission and death.

Stage of dementia was measured with:

- Cognitive Performance Scale (CPS) a validated measure that assigns residents to cognitive performance categories from intact cognition=0,borderline intact=1 ,mild impairment=2, moderate impairment=3, moderately severe impairment=4,severe impairment=5 to very severe impairment=6 consisting of five items: coma, short-term memory, cognitive skills for daily decision making, understanding by others and ADL self-performance in eating[27]
- Global Deterioration Scale (GDS) classifying dementia into seven stages based on deficits in cognition and function[28]. Stage seven of the GDS is described as very severe cognitive decline with minimal to no verbal communication, assistance needed with eating and going to the toilet, incontinence for urine and stool and loss of basic psychomotor skills such as the loss of the ability to walk.

Health status at admission, in last month and last week of life measures included:

- competence: ability to express wishes and competence in medical decision-making at admission, in last month and last week of life
- Mini-Mental State Examination (MMSE), last measured score[29]
- Katz Index of Independence in Activities of Daily Living (ADL) last measured score[30].

Health status in last month of life:

- medical comorbidity
- fall incidence

- Bedford Alzheimer Nursing Severity Scale (BANS-S) a scale to evaluate dementia stage[31].

Health status in last week of life:

- stage of decubitus: Braden scale[32]
- degree of urine and faeces incontinence
- level of consciousness.

Health status at time of death:

- nutritional status
- cause of death
- type of death (death was expected, death was sooner than anticipated, death was neither expected nor unexpected, death was unexpected)[33]
- Manner of death (passed away quietly or died in his or her sleep, was disturbed by or was aware of symptoms, he or she suffered till the end or death was a struggle, died alone)[33].

Interventions at time of death including:

- indwelling bladder catheter, PEG (or Jejunal) tube, hypodermoclysis, intravenous therapy, upper body or limb restraints and resuscitation.

Sentinel events in the last month of life were defined as illnesses or events leading to a significant change in health status (e.g. pneumonia, febrile episodes other than pneumonia, problems with eating or drinking, hip fracture, stroke, gastro-intestinal bleeding, cancer)[13].

End-of-life care surveyed in last month and last week of life:

- keeping of a palliative care record, palliative care from GP, inhouse palliative care (coordinating/advisory physicians, PC reference nurse, PC task group), external palliative home care service, palliative or symptomatic medical or nursing care, psychosocial interventions, administration of religious last rites before death, frequency of visits from family, friends or others, perceived burden of caregiving by nurse, estimated prognosis, treatment goal.

Transfers and hospitalizations in the last three months, last month and last week of life[25]:

- hospitalizations (to general ward, intensive care ward, palliative care unit) and reason, parties involved in decision-making, information transfer, involvement of hospital-based palliative care support team.

Advance care planning and communication:

- ability to express wishes, written advance directive, authorization of proxy decision-maker, GP-orders documented in resident's medical record and parties involved in decision-making, communication with relative concerning medical treatment and desired direction of care, presence of a contact person in resident file, accessibility of GP, medical procedures inconsistent with the resident's wishes, consensus about care and medical treatments, counselling of relatives about expected health problems.

End-of-life decision-making in last month and last week of life: non-treatment decisions, medical treatments (e.g. artificial food & fluid administration, antibiotics), continuous deep sedation, morphine usage.

Quality of dying and quality of care in last month and last week of life[34]:

- Comfort Assessment in Dying-End-of-Life in Dementia (CAD-EOLD) in the last week of life[35]
- Quality of Life in Late Stage Dementia (QUALID) in the last week of life[36]
- Symptom Management End-of–Life in Dementia (SM-EOLD) in last month of life[35]
- Quality of Dying in Long Term Care Facilities (QOD-LTC)[35]
- Quality of Care : Satisfaction With Care in Dying-End-of-Life in Dementia (SWC-EOLD)[35].

Respondent (GP, nurse, the relative) assessment included:

- demographics (age, gender), years of experience, formal training in palliative care, in charge of number of patients with dementia, perceived burden of caregiving, confidence in caregivers, satisfaction with nursing home care.

Nursing home characteristics included

- type and size of institution, coordinating and advisory physician (is he the overall physician, hours per week in institution), FTE palliative reference nurses, number of deceased residents, institutional guidelines on palliative care, institutional guidelines on advance care planning, individual patient-specific planning forms regarding ACP.

Table 1. Dying Well with Dementia, data collection elements.

Data collected	Instrument	From				Timeframe
		Nurse	GP	Relative	NHA *	
Resident assessment						
Demographics and background on resident		X		X	X	-
Dementia		X	X	X		Admission, time of death
Stage of dementia	CPS	X				Last month of life
	GDS	X				Last month of life
Health status		X	X	X		
Competence		X	X			Admission, last month and last week of life
	MMSE				X	Last measured score from resident file
Medical comorbidity			X			Last month of life
Fall incidence		X				Last month of life
Functional status	BANS-S	X				Last month of life
	KATZ-scale				X	Last measured score from resident file
Stage of decubitus	Braden	X				Last week of life
Incontinence		X				Last week of life
Level of consciousness		X				Last week of life
Nutritional status		X				Time of death
Cause of death			X			Time of death
Type of death		X	X			Time of death
Manner of dying		X				Time of death
Interventions		X				Time of death
Sentinel events		X				Last month of life
End-of-life care		X				Last month and last week of life
Transfers and hospitalizations		X				Last 3 months, month and last week of life
Advance care planning and communication		X	X	X		Ever
End-of-life decision making			X	X		Last month and last week of life
Quality of Care and Quality of Dying	SM-EOLD	X		X		Last month of life
	CAD-EOLD	X		X		Last week of life
	QUALID	X				Last week of life
	SWC-EOLD	X		X		Last month of life
	QOD-LTC			X		Last week of life
Respondent assessment						
Demographics		X	X	X		-
Years of working experience		X	X			At time of assessment
Religion				X		At time of assessment
Education in palliative care			X			At time of assessment
Nursing home characteristics					X	-

Abbreviations SM-EOLD Symptom Management at the End-of-Life, CAD-EOLD Comfort Assessment in Dying, CPS Cognitive Performance Scale, GDS Global Deterioration Scale, BANS-S Bedford Alzheimer Nursing Severity scale, Braden scale for assessing pressure ulcer risk, QUALID Quality of Life in Late-Stage Dementia, SWC-EOLD Satisfaction With Care, QOD-LTC Quality of Dying in Long-Term Care.

*Nursing home administrator

DATA MANAGEMENT AND PLAN OF STATISTICAL ANALYSIS

Data was entered with several control measures to ensure data quality ie consistency checks during data-entry and range and skip checks prevented key-punching errors (MS Acces). Data cleaning and data analysis were performed using PASW statistical software, 17.0 (SPSS Inc., Chicago, IL). All operations were done via SPSS syntax-files creating a working data file.

To answer the research questions, we used descriptive statistics (valid percentages, 95 Confidence Intervals). Differences in distribution between very severe/advanced dementia, severe dementia and moderate dementia are calculated using Fisher-Exaxt test, Kruskall-Wallis and Anova. Respondents’ levels of agreement are tested using Kappa values. Multivariate logistic regression analysis is used to study associations with outcome measures. Representativity of the sample (age and gender) is tested by comparing the sample to the population of nursing home residents dying with dementia insured by the two largest insurance companies in Flanders. Responders and non-responders are also compared to evaluate the representativity of the data.

RESPONSE

We contacted 134 nursing homes of which 14 reported no deaths in the study period. Sixty-nine out of 120 nursing homes reporting at least one deceased resident (58% response rate) participated, representative of all nursing homes in Flanders in terms of size, region and ownership. Response rates for questionnaires were for GPs 52.9%, nurses 88.4%, nursing home administrators 95.0% and relatives 53.2%. The median time between death of the resident and completion of the questionnaire was 65 days (interquartile range 37-91days) for nurses, 82 days (IQR 48-137days) for GPs, 134 days (IQR 45-104days) for relatives and 65 days (IQR 34-92days) for the nursing home administrator.

In the participating homes, we identified 477 residents who had died within the past three months, of whom 241 met the inclusion criteria in the first step of the screening procedure (Figure1). After screening the returned questionnaires in the second step, 205 deceased residents with dementia remained. Of all identified deaths 46.7% had dementia at the time of death according the GP or nurse. Of all deaths of residents with dementia, 106 (52.2%) had very severe or advanced dementia, 62 (30.0%) severe dementia, and 36 (17.7%) moderate dementia (for one case the stage of dementia could not be determined due to missing data) based on GDS and CPS criteria (Box 1). The age distribution was representative (p-value=.55) for the population of nursing home residents dying with dementia insured by the two largest insurance companies in Flanders insuring more than 70% of the population. Men were overrepresented in our sample (p=.02).

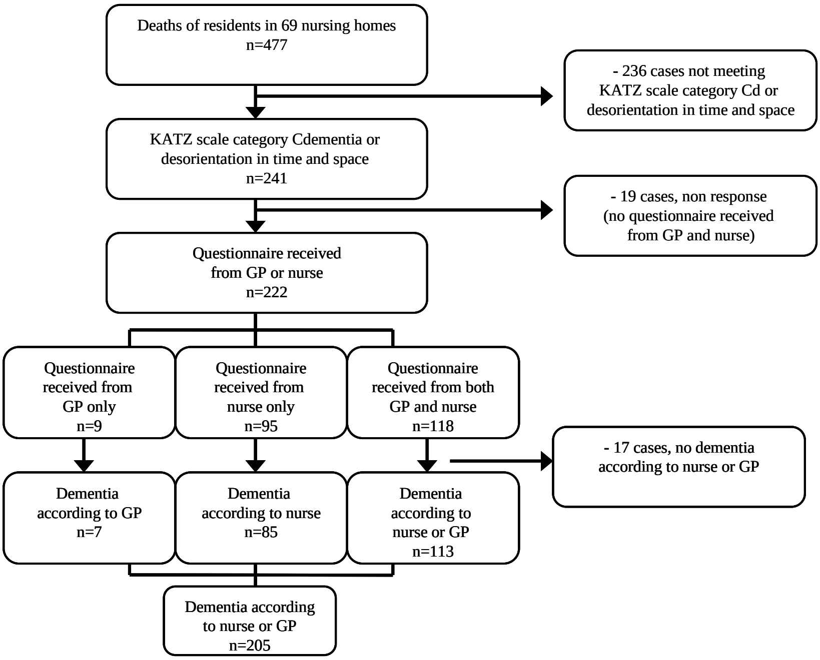

Figure 1: Identification of deceased nursing home residents with dementia.

NON-RESPONSE ANALYSIS

Since we obtained high response rates for the nurses' and nursing home administrators questionnaires, we were able to perform a thorough non-response analyses to assess a possible response bias.

Of 205 eligible cases, 120 GPs participated and 85 did not. Table 2 shows no significant differences in demographic and stay, cognition, BANS-S, nursing care and the nurse's perspective on end-of-life care and dying as judged by the nurses. The only observed difference was that nurses perceived more consensus among relatives on care and treatment of the resident (p=0.01) in cases where the GP had participated then when he had not.

Of 205 eligible cases, 116 relatives participated and 89 did not. Table 3 shows no significant differences in demographic and stay, cognition, BANS-S, nursing care and the nurse’s perspective on end-of-life care and dying and consensus on care and treatment as judged by the nurses.

Table 2 Characteristics of residents of participating and non-participating general practitioners in the "Dying Well with Dementia" study (n=205) *

Total	**Participants** **120**	**Non-participants** **85**	**P-value †**
Resident's demographics and stay			
Female, %	72 (63.7)	46 (57.5)	0.38
Age at death, mean number of years (SD)	85.2 (7.1)	88.8 (6.2)	0.20
Length of stay, median number of years (SD)	3.2 (3.8)	3.4 (3.3)	0.86
Place of death, %			
Nursing home	104 (90.4)	73 (90.1)	0.97
General hospital ward or intensive care unit	10 (8.7)	7 (8.6)	
Palliative care unit	1 (0.9)	1 (1.2)	
Hospitalization in last month of life, %	22 (19.8)	16 (19.1)	0.64
Resident's cognition			
Stage of dementia (based on CPS/GDS), %			
Moderate dementia	21 (17.8)	15 (17.6)	0.40
Severe dementia	32 (26.9)	30 (35.3)	
Very severe/advanced dementia	66 (55.9)	40 (47.1)	
Resident functional status, mean (SD)			
BANS-S	21.15 (4.04)	20.44 (3.78)	0.32
Nursing care, %			
Mouth care provided near death	92 (81.4)	67 (78.8)	0.65
Prevention of decubitus near death	92 (81.4)	70 (82.4)	0.86
Decubitus ulcers last week	27 (25.0)	25 (29.4)	0.49
Nurses perspective on end-of-life care and dying			
Nurse expected resident's death	55 (50.5)	52 (63.4)	0.07
Death perceived as peaceful, %	82 (77.4)	62 (77.5)	0.93
Nurses perspective on family involvement, relationship and decision-making			
Family visited daily	75 (67.6)	55 (67.1)	0.94
Consensus care and treatment among staff	98 (98.0)	73 (93.6)	0.13
Consensus care and treatment among relatives	91 (96.8)	63 (84.0)	0.01
Consensus care and treatment among staff and relatives	92 (95.8)	68 (89.5)	0.10

* Missing values are for gender n=12, age n=4, length of stay n=10, place of death n=9, hospitalization in last month of life n=10, stage of dementia n=1, BANS-S n=7, mouth care n=7n, prevention of pressure ulcers n=7, pressure ulcers n=12, nurse expected resident's death n=14, death perceived as peaceful n=19, family visited daily n=12, consensus care and treatment among staff n=27, consensus care and treatment among relatives n=36 and consensus care and treatment among staff and relatives n=33.

Measured by the nursing home administrator: age, gender, place of death, length of stay. Measured by the nurse: stage of dementia, BANS-S, nursing care, nurses perspective on end-of-life care and dying, nurses perspective on family involvement, relationship and decision-making.

† Differences between participating and non-participating GP's. Differences are tested using Chi-Square, significance level at 0.05. Differences or mean age and BANS-S are tested using t-test.

Abbreviations: CPS Cognitive Performance Scale, GDS Global Deterioration Scale, BANS-S Bedford Alzheimer Nursing Severity Scale.

Table 3: Characteristics of residents of participating and non-participating relatives in the "Dying Well with Dementia" study (n=205) *

	Participants	**Non-participants**	**P-value †**
Total	**116**	**89**	
Resident's demographics and stay			
Female, %	62 (56.9)	56 (66.7)	0.17
Age at death, mean number of years (SD)	86.9 (7.1)	86.4 (6.8)	0.60
Length of stay, median number of years (SD)	2.1 (3.8)	2.4 (3.0)	0.88
Place of death, %			
Nursing home	99 (90.0)	78 (90.7)	0.44
General hospital ward or intensive care unit	9 (8.2)	8 (9.3)	
Palliative care unit	2 (1.8)	0 (0.0)	
Hospitalization in last month of life, %	22 (20.2)	16 (18.6)	0.62
Resident's cognition			
Stage of dementia (based on CPS/GDS), %			
Moderate dementia	21 (18.1)	15 (16.9)	0.96
Severe dementia	31 (26.7)	25 (28.1)	
Very severe/advanced dementia	64 (55.2)	49 (55.1)	
Resident functional status, mean (SD)			
BANS-S	20.8 (3.8)	20.9 (4.2)	0.78
Nursing care, %			
Mouth care provided near death	88 (80.0)	71 (80.7)	0.90
Prevention of decubitus near death	89 (80.9)	73 (83.0)	0.71
Decubitus ulcers last week	24 (22.4)	28 (32.6)	0.11
Nurses perspective on end-of-life care and dying, %			
Nurse expected resident's death	58 (54.2)	49 (58.3)	0.57
Death perceived as peaceful	83 (79.8)	61 (74.4)	0.41
Nurses perspective on family involvement, relationship and decision-making, %			
Family visited daily	75 (70.8)	55 (63.2)	0.27
Consensus care and treatment among staff	93 (97.9)	78 (94.0)	0.18
Consensus care and treatment among relatives	87 (93.5)	73 (92.4)	0.77
Consensus care and treatment among staff and relatives	82 (91.1)	72 (91.1)	0.994

* Missing values are for gender n=12, age at death n=13, length of stay n=0, place of death n=9, hospitalization in last month of life n=10, stage of dementia n=0, BANS-S N=7, mouth care provided near death n=7, prevention of decubitus near death n=7, decubitus ulcers last week n=12, nurse expected resident's death n=14, death perceived as peaceful n=19, family visited daily n=12, consensus care and treatment among staff n=27, consensus care and treatment among relatives n=36 and consensus care and treatment among staff and relatives n=33.

Measured by the nursing home administrator: age, gender, place of death, length of stay. Measured by the nurse: stage of dementia, BANS-S, nursing care, nurses perspective on end-of-life care and dying, nurses perspective on family involvement, relationship and decision-making.

† Differences between participating and non-participating relatives. Residents who had no relative (n=15) were counted with participating relatives. Differences are tested using Chi-Square, significance level at 0.05. Differences or mean age and resident outcomes are tested using t-test.

Abbreviations: CPS Cognitive Performance Scale, GDS Global Deterioration Scale, BANS-S Bedford Alzheimer Nursing Severity Scale.

DISCUSSION

The Dying Well with Dementia study is a cross-sectional retrospective study surveying three people key to the care of a resident dying with dementia in a representative sample of Flemish nursing homes. We aimed to study residents with advanced dementia as well as those with dementia who died before they reached an advanced stage.

The study has several potential strengths but also some limitations

STRENGTHS

Firstly this is, to our knowledge, the first study on a nationwide and population based level describing the quality of care in the last phase of life and the quality of dying of nursing home residents dying with dementia. We were able to obtain a representative sample of Flemish nursing homes using a random cluster sampling procedure, dividing homes into strata related to end-of-life care quality in nursing homes.

Secondly, by using of a retrospective research design and obtaining satisfactory response rates on an institutional level and for the respondents, we were able to study a representative sample of deceased nursing home residents in Flanders. The lowest response rates were for GPs (52.9%) and for relatives (53.2%), though they were higher than the average response rates for physician postal surveys and for most medical surveys in Belgium[37,38] In our non-response-analysis we were able to compare responding with non-responding GPs and responding with non-responding relatives. No significant differences were found in important characteristics such as demographics and stay, cognition, BANS-S, nurses perspective on end-of-life care and dying. The only observed difference found was in consensus among relatives on care and treatment of the resident in cases where the GP participated compared with those where he did not. These findings confirm previous research [17,18] in which the superiority of retrospective over prospective designs in identifying population-based information has also been shown.

Thirdly, by using a two-step screening protocol we were able to identify our study population of deceased nursing home residents with dementia reliably. Fourthly, validated scales were used to identify residents with advanced dementia, for the first time providing reliable estimates of the number of nursing home residents dying with advanced dementia in one country and allowing for comparisons with other countries using the same scales for identifying advanced dementia[13]. Finally, by using the perspective of the nurse, GP and relative we gained a privileged insight into end-of-life care of nursing home residents with dementia.

WEAKNESSES

Studying the end-of-life of people with dementia requires us to rely on the perceptions of proxies, which may differ from self-reports. Given that we used a retrospective research design, memory bias cannot be ruled out. We minimized a possible bias by leaving little time between death and the completion of questionnaires and also by focusing on the final months of life. Furthermore, the number of deaths in nursing homes is rather low, on average five residents per nursing home die over a period of three months[22] implying that providing care to these patients at the end of life is not an every-day experience for professional caregivers. Nevertheless, details about symptom prevalence in the final month of life or other more subjective reports might be prone to memory bias.

Another limitation is the use of a quantitative approach in this study and our aim of gathering basic information in several broad domains in measuring end-of-life care, a qualitative in-depth insight in a number of issues may not have been achieved. Finally, causality cannot be inferred with certainty from this study when identifying structures and processes of care assumed to be associated with improved or worsened outcomes.

DISSEMINATION AND OPPORTUNITIES FOR FURTHER RESEARCH

Several important opportunities emerge from the Dying Well with Dementia study. As many other European countries face similar challenges in providing high quality end-of-life care for people with dementia in long term care settings, an international collaboration combining comparable data may provide very valuable insights. In this context, a collaborative research between Flanders and the Netherlands (Dutch End of life in Dementia study, DEOLD) was initiated in order to compare health systems and quality of care and dying of nursing home residents die in each country. Data have been merged to make cross-country comparisons possible (results forthcoming in 2014). Additionally, some of the instruments used in this study have been developed and used in US studies – mainly among people with advanced dementia – making interesting comparisons possible between Europe and the US where health systems are organized very differently. Other countries such as Switzerland, Italy, Poland and the UK have expressed interest in studying long term care facilities using this methodology in the future and preliminary consortia have been set up coordinated by the End of Life Care Research Group in Belgium.

Additionally, the data can provide important opportunities for identifying and developing interventions that might positively affect the care of nursing home residents dying with dementia. This study will focus on investigating the areas where most improvement is needed, and also identify the structures and processes of care that influence improved or worsened outcomes and are amenable to change.

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PART II

QUALITY OF DYING, USE OF PALLIATIVE CARE AND LIFE-PROLONGING TREATMENTS AT THE END OF LIFE OF NURSING HOME RESIDENTS WITH DEMENTIA

CHAPTER 3:

NURSING HOME RESIDENTS DYING WITH DEMENTIA IN FLANDERS, BELGIUM: A NATIONWIDE POST-MORTEM STUDY ON CLINICAL CHARACTERISTICS AND QUALITY OF DYING

An Vandervoort, Lieve Van den Block, Jenny T. van der Steen, Robert Vander Stichele, Ladislav Volicer, Dirk Houttekier, Luc Deliens

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ABSTRACT

OBJECTIVES

There is a lack of large-scale, nationwide data describing clinical characteristics and quality of dying of nursing home residents dying with dementia. We set out to investigate quality of end-of-life care and quality of dying of nursing home residents with dementia in Flanders, Belgium.

DESIGN/SETTING/PARTICIPANTS

To obtain representativity, we conducted a post-mortem study (2010) using random cluster-sampling. In selected nursing homes, all deceased residents with dementia in a period of three months were reported. For each case a structured questionnaire was filled in by the nurse most involved in care, the family physician and nursing home administrator. We used the Cognitive Performance Scale and Global Deterioration Scale to assess dementia. Main outcome measures were health status, clinical complications, symptoms at the end of life and quality of dying.

MEASUREMENTS

Health status, clinical complications, symptoms at the end of life and quality of dying.

RESULTS

We identified 198 deceased residents with dementia in 69 nursing homes (58% response rate). Age distribution was the same as all deceased residents with dementia in Flanders, 2010. Fifty four percent had advanced dementia. In the last month of life, 95.5% had one or more sentinel events eg eating/drinking problems, febrile episodes or pneumonia; most frequently reported symptoms were pain, fear, anxiety, agitation and resistance to care. In the last week, difficulty swallowing and pain were reported most frequently. Pressure sores were present in 26.9%, incontinence in 89.2% and cachexia in 45.8%. Physical restraints were used in 21.4% of cases and 10.0% died outside the home. Comparing stages of dementia revealed few differences between groups regarding clinical complications, symptoms or quality of dying.

CONCLUSIONS

Regardless of the dementia stage, many nursing home residents develop serious clinical complications and symptoms in the last phase of life, posing major challenges to the provision of optimum end-of-life care.

INTRODUCTION

An increasing number of elderly people will suffer from dementia in Europe, from about six million in 2010 to about 14 million in 2050.[1] Epidemiological evidence shows dementia as a risk factor for nursing home admission.[2, 3] In Belgium 43% of people with dementia live in nursing homes, rising to 76% of those with advanced dementia.[4]

Several barriers to providing high quality end-of-life care for people with dementia have been described eg dementia has a relatively unpredictable course compared with cancer[5, 6] and most patients with dementia are not able to communicate their preferences, leaving them at increased risk of prolonged suffering at the end of life.[7] Hence, management of problems in the final stages poses challenges for nursing homes in particular because, while many reside at home for a large part of their illness, many end up in nursing homes as they reach the final phases of dementia.[8]

However, large scale and nationwide empirical studies describing how people with dementia are currently dying in nursing homes are lacking. Earlier studies were often limited in scope and populations, investigating those who progress to a very advanced stage of dementia only, in specific regions or institutions or focusing on type or place of care rather than on clinical characteristics and quality of dying.[6, 8-15] One important study from the U.S. Boston region (CASCADE) reported the clinical trajectory of nursing home residents with advanced dementia.[16] They found that distressing symptoms were common, as were clinical complications such as eating problems, pneumonia, and febrile episodes.[17] However, several gaps in our knowledge of how well people with dementia are dying remain, especially of those not progressing to an advanced stage. Also, in order to provide population-based insights regarding their quality of dying, large-scale representative studies are needed. To describe the final phase of life in a representative sample of deaths, it has been recommended to use a retrospective study design[18, 19].

In this study we present findings from what is, to our knowledge, the first European nationwide population-based study describing the end of life of nursing home residents with dementia. Our main objectives are to study how many deceased nursing home residents had dementia in Flanders, Belgium and to describe their clinical characteristics and quality of dying.

METHODS

STUDY DESIGN

A retrospective cross-sectional study was conducted in Flanders, the Dutch-speaking part of Belgium where 6.3 million people (58% of the Belgian population) live. Structured questionnaires were completed by the nurse most involved in care for the resident, the family physician (FP) and nursing home administrator regarding deceased nursing home residents with dementia, in a representative sample of Flemish nursing homes i.e. high care nursing homes for elderly people. There are several reasons why we used a retrospective rather than a prospective design to study nursing home residents dying with dementia[18, 19]. A retrospective design more easily allows to identify a clear study population. It also allows to identify a population-based sample of deaths on a nationwide level, while prospective studies are often not representative due to censoring[18, 19].

STUDY FACILITIES

A random cluster sampling procedure was used, starting with a random sample of Flemish nursing homes. To be representative, homes were randomly sampled and stratified by region (five provinces) and subsequently by bed capacity (up to or more than 90 residents) and ownership (public, private/nonprofit, private/profit) ie factors found to be related to end-of-life care quality in nursing homes in previous research.[20, 21] Where an institution declined to participate, another was randomly selected until the targeted number per strata was reached.

STUDY SUBJECTS

All deaths were recorded between May and October 2010. A two-stage screening protocol was used to identify eligible subjects.

(1) as a first step, the nursing home administrator identified all residents dying, in the nursing home or elsewhere, in the past three months and identified residents who met one of the criteria used by the Belgian health insurance system to allocate financial resources[22]; the criteria for (1) ‘category Cdementia’ i.e. ‘being completely care dependent or needing help for bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space’, OR (2) disorientation in time and space (≥3 or ‘almost daily a problem with disorientation in time and space’). These broad first selection criteria minimized the risk of missing out eligible residents

with dementia but risked including false positives. Therefore, FPs and nurses of residents fulfilling these criteria were sent questionnaires in which additional eligibility criteria were surveyed.

(2) in the second step – in order to exclude false positives or residents who did not have dementia according to the FP or nurse – additional eligibility criteria required that the FP or nurse indicated that the resident 'had dementia' or 'was diagnosed with dementia'.

DATA COLLECTION

A letter introducing the research project and asking for participation was sent to the board of directors and the "coordinating and advisory physician" –responsible for end-of-life care in Belgian nursing homes– of each selected nursing home. In cases of no reply, the researcher contacted the nursing home after two weeks. In each participating home, the board of directors appointed one contact person for the study (ie nursing home administrator or head nurse). The researcher visited each nursing home and assisted the contact person in identifying eligible residents, the nurse who was 'most closely involved in resident's care' and the resident's FP.

The nurse, FP, and nursing home administrator were sent a structured standardized questionnaire no later than three months after the death. If the identified nurse was not willing to cooperate, the head nurse was asked to fill in the questionnaire. Non-responders received a reminder after three weeks, with the administrator as a mediator to guarantee anonymity.

MEASUREMENTS

After-death questionnaires surveyed socio-demographic characteristics, health status, clinical complications and, quality of dying. A feasibility study preceding the main study tested design and measurements. Because nursing home filing systems differed considerably the questionnaires of nurses and FPs were completed on the basis of the respondent's memory.

FP questionnaires: resident's health status: cause of dementia, co-existing conditions

Nurse questionnaires:

- whether or not there was a family caregiver/friend involved in the resident's care
- time of onset of dementia
- resident's health status:
    - at the time of admission
        - stage of dementia

        - ability to express wishes and competency in medical decision-making
    - functional and cognitive status one month before death
        - Bedford Alzheimer Nursing Severity Scale (BANS-S)[23]
        - Global Deterioration Scale (GDS)[24] classifying dementia into seven stages based on deficits in cognition and function[16]
        - Cognitive performance scale (CPS)[25] a validated measure that assigns residents to cognitive performance categories[16, 25]
        - Sentinel events: i.e. illnesses or events: pneumonia, febrile episodes (other than pneumonia), problems with eating or drinking, hip fracture, stroke, gastro-intestinal bleeding, cancer, or other[17]
        - quality of dying: presence of distressing symptoms in last month of life measured by the Symptom Management End-of–Life in Dementia (SM-EOLD)[26]
    - last week before death
        - quality of dying: Comfort Assessment in Dying End-of-Life in Dementia (CAD-EOLD)[26] and, Quality of life in late stage dementia (QUALID)[27]
        - stage of decubitus[28]
        - degree of urine and faeces incontinence
        - upper body or limb restraints
    - nutrition and hydration status at time of death
- type of death judged by the nurse: expected, expected but faster than thought, neither expected nor unexpected, unexpected

Nursing home administrator questionnaire:

- place of residence before nursing home admission, length of stay, open or a closed unit, place of death
- last measurement of the Mini Mental State Examination in the patient's administrative file.[29]

STATISTICAL ANALYSIS

Analyses were performed with PASW statistical software, 17.0 (SPSS Inc.,Chicago,IL). Based on the Cognitive Performance Scale and Global Deterioration Scale, residents were classified in three groups (Box1). Advanced dementia was defined as by Mitchell et al.[16] Differences in distribution between very severe/advanced dementia, severe dementia, and moderate/mild dementia were calculated using Fisher-Exact Tests. Medians and averages were tested using Kruskall-Wallis and Anova with post hoc LSD (significance level p=.05).

Box 1: Classification of dementia severity one month before death

Very severe or advanced dementia	CPS* ≥ 5 and GDS† = 7
Severe dementia	(CPS ≥ 5 and GDS <7) or (CPS <5 and GDS = 7)
Moderate or mild dementia	CPS <5 and GDS <7

*Cognitive Performance Scale; † Global Deterioration Scale

ETHICAL ASPECTS

The study protocol was approved by the Medical Ethical Committee of UZ Brussel (University Hospital of Brussels). Anonymity was guaranteed for residents and respondents by using unique anonymous numbers and a mediating contact person of the nursing home.

RESULTS

SAMPLE DESCRIPTION

Sixty nine nursing homes (58% response rate) participated, representative of all nursing homes in Flanders in terms of size, region, and ownership because of the proportionate sampling. Main reasons for not participating were: lack of time because of high work pressure, staff shortage or overload of requests for research participation. Response rates for FPs, nurses, and nursing home administrators were 52.9%, 88.4% and 95% respectively. The median time between death of the resident and completion of the questionnaire was 65 days (interquartile range 37-91 days) for nurses, 82 days (IQR 48-137 days) for GPs, 134 days (IQR 45-104 days) for relatives and 65 days (IQR 34-92 days) for the nursing home administrator. Using data gathered by the professional caregivers, non-response analysis showed no differences for important resident (age, gender, length of stay, place of death, cognitive status, disease severity) and care characteristics (end-of-life treatments, nursing care) between participating and non-participating FP's except for the nurse's perspective on end-of-life care and dying where nurses perceived more consensus among relatives on care and treatment of the resident (p=0.004) in case the FP participated than when he did not.

In participating homes, we identified 477 residents who had died within the past three months, of whom 241 met the inclusion criteria in the first step of the screening procedure (Figure1). After screening the returned questionnaires in the second step we identified 205 deceased residents with dementia. Of all identified deaths 46.7% had dementia at the time of death. Seven of the 205 cases were excluded because of too much missing data, leaving 198 for analysis; 106 (53.5%) cases of very severe or advanced dementia: 56 (28.3%) of severe dementia and 36 (18.2%) of moderate or mild dementia.

Analysis (not in table) showed that age distribution was representative (p=.55) for the population of nursing home residents dying with dementia insured by the two largest insurance companies in Flanders insuring more than 70% of the population. Men were overrepresented in our sample (p=.02).

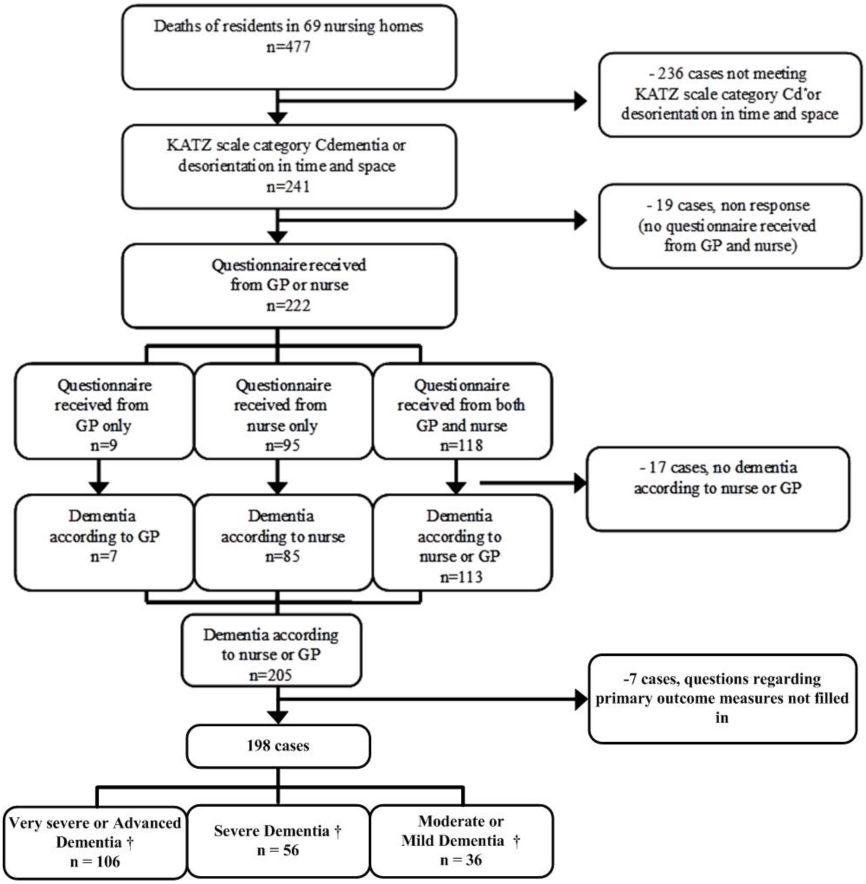

Figure 1: Overview of data gathered in this study

Age distribution of the sample was representative for nursing home residents dying with dementia in Flanders, Belgium in 2010.

* Cd or category Cdementia. KATZ scale: Katz S: Assessing self-maintenance: activities of daily living, mobility and instrumental activities of daily living. J Am Geriatr Soc 1983, 31:721-727.

† Very Severe or Advanced Dementia= Cognitive Performance Scale (CPS) ≥ 5 + Global Deterioration Scale (GDS) 7

Severe Dementia= CPS ≥ 5 + GDS <7 OR CPS <5 + GDS 7 Moderate or Mild dementia= CPS <5 AND GDS <7

Mean age at time of death in our sample was 86.7 years and more than half (61.5%) were female (Table1). Median length of nursing home stay was 2.4 years and median survival time after onset of dementia was three years. Whereas differences in length of nursing home stay were not statistically significant between dementia groups, median survival time after onset of dementia was lower for residents with mild/moderate dementia (one year) compared with residents with very severe/advanced dementia (four years). Almost half of subjects lived in a closed special care unit for dementia (47.9%) and 96.5% had a family caregiver.

Table 1. Deceased Nursing Home Residents with Dementia in Flanders, Belgium: Description of the Sample (N=198)

	Residents with Dementia N (%)	Very Severe or Advanced dementia N (%)	Severe Dementia N (%)	Moderate or Mild Dementia N (%)	P value §
Total N (%) *	198 (100.0)	106 (53.5)	56 (28.3)	36 (18.2)	
Age - yr					
<90	118 (63.4)	62 (63.9)	34 (60.7)	22 (66.7)	0.83
≥90	68 (36.6)	11 (36.1)	22 (39.3)	35 (33.3)	
mean ±SD	86.7 ±7.0	86.3 ±7.2	87.0 ±7.4	87.3 ±5.9	
Gender					
Male	72 (38.5)	39 (39.8)	22 (39.3)	11 (33.3)	0.81
Female	115 (61.5)	59 (60.2)	34 (60.7)	22 (66.7)	
Motivation for nursing home admission †					
Behavioral problems	37 (19.1)	25 (24.5)	7 (12.5)	5 (13.9)	0.14
Physical disease	52 (27.2)	26 (25.5)	10 (18.5)	16 (45.7)	0.02
Burden in family caregiver	68 (35.4)	44 (43.1)	17 (30.9)	7 (20.0)	0.03
Problems with care	45 (23.9)	27 (26.5)	14 (25.9)	4 (12.5)	0.25
Lack of self management	92 (48.9)	42 (41.2)	31 (57.4)	19 (59.4)	0.07
Cognitive problems	31 (16.0)	16 (15.4)	12 (21.4)	3 (8.8)	0.29
Other	11 (5.6)	3 (2.8)	5 (8.9)	3 (8.6)	0.12
Median length of nursing home stay median yr (interquartile range)	2.4 (1.2-4.6)	2.4 (1.2-4.5)	3.2 (1.4-5.2)	2.1 (0.5-3.2)	0.16
Median survival after onset of dementia median yr (interquartile range)	3.0 (2.0-5.0)	4.0 (2.0-5.0)	4.0 (2.0-5.0)	1.0 (0.8-2.0)	<0.001
Type of unit at time of death					
Living in closed special care unit for dementia	90 (47.9)	52 (52.5)	25 (44.6)	13 (39.4)	0.28
Living in an open unit not delivering specialist dementia care	82 (43.6)	36 (36.4)	28 (50.0)	18 (54.5)	
Other type of unit ‡	16 (8.5)	11 (11.1)	3 (5.4)	2 (6.1)	
Having an involved family caregiver †					
Child	145 (73.2)	76 (71.7)	40 (71.4)	29 (80.6)	0.61
Partner	35 (17.7)	19 (17.9)	12 (21.4)	4 (11.1)	0.49
Other	61 (30.8)	31 (29.2)	18 (32.1)	12 (33.3)	0.86
None	7 (3.5)	1 (2.8)	3 (5.4)	3 (2.8)	0.78
Cognitive Performance Scale one month before death (CPS)					
Intact, Borderline intact, Mild impairment (score 0-1-2)	8 (4.1)	-	9 (1.9)	7 (20.5)	<0.001
Moderate impairment (score 3)	27 (13.9)	-	6 (11.1)	21 (61.8)	
Moderately severe impairment (score 4)	9 (4.6)	-	3 (5.6)	6 (17.6)	
Severe impairment (score 5)	61 (31.4)	33 (31.1)	28 (51.9)	-	
Very severe impairment (score 6)	89 (45.9)	73 (68.9)	16 (29.6)	-	
Global Deterioration Scale one month before death (GDS)					
Stage 7	105 (57.7)	96 (100.0)	9 (17.3)	-	<0.001

* Missing values: age n=12, gender n=11, motivation for nursing home admission n=11, length of stay n=14, survival time n=69, type of unit n=10, involved caregiver n=0, CPS n=4, GDS n=16.

† Multiple answers possible.

‡ Other type of unit ie living in an open special care unit or living in a closed unit not delivering specialist dementia care.

§ Differences between Very Severe/Advanced Dementia, Severe dementia and Moderate/Mild dementia are tested using Fisher-Exact test, Anova or Kruskall Wallis.

HEALTH STATUS IN LAST MONTH OF LIFE

Alzheimer’s disease was the cause of dementia in 50% of cases (Table2). Residents with dementia at time of death were at the time of admission able or partly able to express their wishes in 84.3% of cases and competent or partly competent for medical decision-making in 60.7%. Most (70.3%) had one or more co-existing condition at time of death, of which cardiovascular diseases were reported most frequently. They were also severely functionally and cognitively disabled one month before death (mean BANS-S 20.8). Nursing severity was lower in those with moderate/mild dementia (BANS-S p<.001). Fewer co-existing conditions were reported in those with very severe/advanced dementia (p=.02).

CLINICAL COMPLICATIONS IN LAST MONTH OF LIFE

Nurses reported that 95.5% of residents who died with dementia had one or more sentinel event in the last month of life ie eating or drinking problems in 65.7%, febrile episodes in 42.9% and pneumonia in 32.3% of cases (Table2). The only significant difference between groups was that prevalence of eating/drinking problems in the last month of life increased with severity of dementia (p=.03).

DISTRESSING SYMPTOMS IN LAST MONTH OF LIFE

Pain (mean 1.9), fear (mean 2.3), anxiety (mean 2.4), resistance to care (mean 3.0) and agitation (mean 2.9) were most frequently reported using the SM-EOLD scale (lower scores refer to more symptoms) during the last month of life (Table2). Presence of symptoms did not differ significantly in stages of dementia.

Table 2. Health Status, Clinical Complications and Distressing Symptoms in the Last MONTH of Life of Nursing Home Residents with Dementia. (N=198)

	Residents with Dementia	Very Severe or Advanced dementia	Severe Dementia	Moderate or Mild Dementia	P value **
Total N*	198	106	56	36	
	N(%)	N (%)	N (%)	N (%)	
HEALTH STATUS					
Cause of dementia †					
Alzheimer dementia	49 (50.0)	34 (55.7)	7 (30.4)	8 (57.1)	0.12
Vascular dementia	34 (34.7)	20 (32.8)	10 (43.5)	4 (28.6)	0.62
Other type of dementia	11 (11.2)	9 (14.8)	2 (8.7)	0 (0.0)	0.35
Functional and cognitive status					
Bedford Alzheimer Nursing Severity Scale (BANS-S)one month before death ‡					
mean (SD)	20.8 (3.9)	22.5 (2.8)	20.6 (3.5)	16.3 (3.8)	<0.001 ††
Mini Mental State Examination (last measurement) §					
≥ 25	3 (1.5)	1 (0.9)	2 (3.6)	0 (0.0)	0.13
24-21	6 (3.0)	3 (2.8)	2 (3.6)	1 (2.8)	
20-11	52 (26.3)	25 (23.6)	12 (21.4)	15 (41.7)	
≤10	115 (58.1)	69 (65.1)	30 (53.6)	16 (44.4)	
No measurement in patient file	22 (11.1)	8 (7.5)	10 (17.9)	4 (11.1)	
Was able to express wishes at time of nursing home admission					
Yes	77 (39.1)	31 (29.5)	24 (42.9)	22 (61.1)	<0.001
Partly	89 (45.2)	47 (44.8)	28 (50.0)	14 (38.9)	
No	31 (15.7)	27 (25.7)	4 (7.1)	0 (0.0)	
Was competent for medical decision-making at time of nursing home admission					
Yes	51 (26.0)	23 (21.9)	13 (23.2)	15 (42.9)	<0.001
Partly	68 (34.7)	29 (27.6)	21 (37.5)	18 (51.4)	
No	77 (39.3)	53 (50.5)	22 (39.3)	2 (5.7)	
Co-existing conditions ‖					
Malignant tumor	12 (10.8)	5 (7.6)	4 (16.0)	3 (15.0)	0.35
Cardiovascular	32 (28.8)	14 (21.2)	11 (44.0)	7 (35.0)	0.08
Respiratory	15 (13.5)	9 (13.6)	4 (16.0)	2 (10.0)	0.87
Neurological	17 (15.3)	12 (18.2)	3 (12.0)	2 (10.0)	0.67
Urogenital system	9 (8.1)	4 (6.1)	4 (16.0)	1 (5.0)	0.30
Other	18 (16.4)	10 (15.4)	4 (16.0)	4 (20.0)	0.94
None of the above	33 (29.7)	26 (39.4)	5 (20.0)	2 (10.0)	0.02
CLINICAL COMPLICATIONS					
Sentinel events during last month of life registered the nurse					
Pneumonia	64 (32.3)	33 (31.1)	19 (33.9)	12 (33.3)	0.92
Febrile episode (other than pneumonia)	85 (42.9)	42 (39.6)	27 (48.2)	16 (44.4)	0.54
Eating or drinking problem	130 (65.7)	76 (71.7)	37 (66.1)	17 (47.2)	0.03
Other sentinel events	73 (36.9)	39 (36.8)	21 (37.5)	13 (36.1)	>0.99
No sentinel event	9 (4.5)	4 (3.8)	2 (3.6)	3 (8.3)	0.53
DISTRESSING SYMPTOMS					
SM-EOLD during last month of life Range: 0 (worst) to 5 (best) mean (SD) ¶					
Pain	1.9 (1.9)	2.1 (2.0)	1.8 (1.9)	1.7 (1.7)	0.44
Shortness of breath	3.2 (2.0)	3.3 (1.9)	3.2 (2.1)	2.8 (2.1)	0.51
Skin breakdown	4.1 (1.8)	4.1 (1.7)	3.9 (2.0)	4.2 (1.8)	0.71
Calm	3.4 (2.0)	3.5 (2.0)	3.2 (2.1)	3.2 (2.1)	0.62
Depression	3.6 (2.0)	3.8 (1.9)	3.7 (2.0)	2.9 (2.1)	0.06 ‡‡
Fear	2.3 (2.0)	2.2 (1.9)	2.3 (2.0)	2.6 (2.0)	0.47
Anxiety	2.4 (2.0)	2.3 (2.0)	2.7 (2.1)	2.3 (2.1)	0.55
Agitation	2.9 (2.1)	2.9 (2.1)	2.9 (2.1)	2.8 (2.0)	0.99
Resistiveness to care	3.0 (2.1)	2.7 (2.1)	3.2 (2.1)	3.5 (1.9)	0.09

* Missing values: cause of dementia n=100 (of which 85 because no questionnaire was received from the FP), BANS-S n=0, MMSE n=96, expressing wishes n=1, competence at nursing home admission n=2, co-existing conditions n=87 (of which 85 because no questionnaire was received from the FP), sentinel events n=87, pain n=8, shortness of breath n=19, skin breakdown n=9, calm n=29, depression n=18, fear n=4, anxiety n=9, agitation n= 11, resistiveness to care n= 6, total SM-EOLD n=10.

† Multiple answers possible. Don't know cause of dementia n=13.

‡ Scores on the Bedford Alzheimer's Severity Subscale range from 7 to 28; higher scores indicate greater functional disability.

§ Assessment was on average 8 months before death.

‖ Multiple answers possible. The answer to this question was reported by FP's only. In 85 cases we received no questionnaire from the FP, these cases were reported as missing, so n=113.

¶ SM-EOLD All items were (re)coded so that higher scores means better symptoms management. Total score is constructed by summing the value of each item and ranges from 0 to 45 with higher scores indicating better symptom control, missing SM-EOLD items were imputed with resident means in case there were three or fewer missing items.

** Statistical significant difference between Very Severe/Advanced Dementia, Severe dementia and Moderate/Mild dementia..

†† Statistical significant difference found between Very Severe/Advanced Dementia and Severe dementia, and between Very Severe/Advanced dementia and Moderate/Mild dementia.

‡‡ Statistical significant difference found between Very Severe/Advanced Dementia and Moderate/Mild dementia.

CLINICAL CHARACTERISTICS AND OUTCOMES IN LAST WEEK OF LIFE

In the last week of life (Table3), low levels of comfort, measured by CAD-EOLD scale (range 0 worst to 3 best), were reported for difficulty swallowing (mean 1.9), pain (mean 2.0) lack of serenity (mean 1.9), lack of peace (2.0), and lack of calm (2.0). Mean quality of life during the last week (QUALID scale, range 11 best to 55 worst) was 28.9, similar in all three groups; pressure sores were present in 26.9% of cases, incontinence for urine or faeces in respectively 89.2% and 85.6%, cachexia or severe cachexia in 45.8% and dehydration or severe dehydration in 38.6%. Physical upper body or limb restraints were used in 21.4% of cases in the last week of life. Death was expected for 50.3% of those with very severe/advanced dementia and proportions of expected death were similar for the other dementia stages. Place of death was hospital in 8.9% of cases. We found statistically significant differences between stages of dementia with respect to problems with choking (p<.001), swallowing (p<.001), incontinence (p<.001) and dehydration in the last week of life (p<.01), all being more common with more severe dementia.

Table 3. Clinical Characteristics and Outcomes in the Last WEEK of Life of Nursing Home Residents with Dementia (N=198)

	Residents with Dementia	Very Severe or Advanced Dementia	Severe Dementia	Moderate or Mild Dementia	P value §
Total N*	198	106	56	36	
CAD-EOLD Range during last week of life: 0 (worst) to 3 (best) mean (SD) †					
Discomfort	2.1 (0.7)	2.1 (0.7)	2.1 (0.8)	2.1 (0.7)	0.97
Pain	2.0 (0.7)	2.1 (0.7)	1.9 (0.7)	2.0 (0.7)	0.28
Restlessness	2.1 (0.7)	2.1 (0.8)	2.0 (0.8)	2.1 (0.7)	0.55
Shortness of breath	2.2 (0.8)	2.2 (0.7)	2.2 (0.8)	2.1 (0.8)	0.72
Choking	2.1 (0.8)	1.9 (0.7)	2.3 (0.8)	2.5 (0.7)	<0.001 ‖
Gurgling	2.3 (0.8)	2.3 (0.8)	2.3 (0.8)	2.5 (0.7)	0.58
Difficulty swallowing	1.9 (0.8)	1.8 (0.7)	2.0 (0.8)	2.4 (0.8)	0.001 ¶
Fear	2.1 (0.7)	2.0 (0.7)	2.2 (0.8)	2.1 (0.7)	0.63
Anxiety	2.2 (0.7)	2.2 (0.7)	2.2 (0.8)	2.1 (0.7)	0.74
Crying	2.7 (0.6)	2.6 (0.7)	2.7 (0.6)	2.8 (0.4)	0.57
Moaning	2.3 (0.7)	2.3 (0.7)	2.3 (0.7)	2.5 (0.6)	0.43
Serenity	1.9 (0.7)	1.9 (0.7)	1.9 (0.7)	2.0 (0.8)	0.96
Peace	2.0 (0.7)	2.0 (0.7)	2.0 (0.7)	2.0 (0.8)	0.95
Calm	2.0 (0.7)	2.1 (0.7)	2.1 (0.7)	1.9 (0.8)	0.44
Total	30.0 (6.0)	29.8 (6.4)	30.0 (5.6)	30.8 (5.7)	0.70
Quality of life in late-stage dementia (QUALID) scale during last week of life ‡					
Mean (SD)	28.9 (8.6)	29.4 (8.2)	29.1 (8.4)	27.0 (9.8)	0.34
Decubitus during last week of life	52 (26.9)	29 (28.2)	15 (27.3)	8 (22.9)	0.88
Urine incontinence during last week of life N (%)					
Incontinent	174 (89.2)	101 (96.2)	52 (92.9)	21 (61.8)	<0.001
Faeces incontinence during last week of life N (%)					
Incontinent	167 (85.6)	100 (95.2)	47 (83.9)	20 (58.8)	<0.001
Nutrition status at time of death as evaluated by the nurse N (%)					
Very cachectic	32 (17.9)	16 (16.2)	12 (23.5)	4 (13.8)	0.27
Cachectic	50 (27.9)	28 (28.3)	17 (33.3)	5 (17.2)	
Normal	72 (40.2)	37 (37.4)	17 (33.3)	18 (62.1)	
Adipose	17 (9.5)	13 (13.1)	3 (5.9)	1 (3.4)	
Very adipose	8 (4.5)	5 (5.1)	2 (3.9)	1 (3.4)	
Hydration status at time of death N (%)					
Normal	39 (21.2)	14 (13.7)	10 (19.6)	15 (48.4)	0.01
Little dehydrated	74 (40.2)	47 (46.1)	18 (35.3)	9 (29.0)	
Dehydrated	55 (29.9)	33 (32.4)	17 (33.3)	5 (16.1)	
Very dehydrated	16 (8.7)	8 (7.8)	6 (11.8)	2 (6.5)	
Use of upper body restraints or limb restraints during last week of life N (%)					
Used	41 (21.4)	26 (25.0)	10 (18.5)	5 (14.7)	0.42
Type of death N (%)					
Expected	96 (50.3)	53 (51.0)	29 (54.7)	14 (41.2)	0.43
Other	95 (49.7)	51 (49.0)	24 (45.3)	20 (58.8)	
Place of death N (%)					
Nursing home	171 (90.0)	94 (93.1)	49 (87.5)	28 (84.8)	0.28
General hospital ward or intensive care unit	17 (8.9)	6 (5.9)	7 (12.5)	4 (12.1)	
Palliative care unit	2 (1.1)	1 (1.0)	0 (0.0)	1 (3.0)	

* Missing values: discomfort n=19, pain n=9, restlessness n=15, shortness of breath n=,12, choking n=16, gurgling n=18, difficulty swallowing n=11, fear n=13, anxiety n=14, crying n=17, moaning n=16 serenity n=16, peace n=18, calm n=19, SM-CAD total n=16, Qualid n=4, decubitus n=5, urine incontinence n= 3, faeces incontinence n=3, nutrition status n=19, hydration status n=14, restraints n=6, type of death n=7, place of death n=8.

† CAD-EOLD. All items were (re)coded so that higher scores means better symptoms management. The CAD-EOLD total score is constructed by summing the value of each item. It ranges from 14 to 42 with higher scores indicating better symptom control, missing CAD-EOLD items were imputed with residents' means in case there were four or fewer missing scores on the scale.

‡ Qualid. Total scores range from 11 points to 55 points with lower scores reflecting a higher quality

§ Differences between Very Severe/Advanced Dementia, Severe dementia and Moderate/Mild dementia.

‖ Statistical significant difference found between Very Severe/Advanced Dementia and Severe dementia, and between Very Severe/Advanced dementia and Moderate/Mild dementia.

¶ Statistical significant difference found between Very Severe/Advanced Dementia and Moderate/Mild dementia.

DISCUSSION

This study shows that nearly half of all nursing home residents in Flanders, Belgium, die with dementia and half of these have very severe or advanced dementia at the time of death. Regardless of the stage of dementia, many residents develop serious clinical complications and symptoms in the terminal phase of life.

To our knowledge, this is the first nationwide population-based study describing the clinical characteristics and quality of dying of nursing home residents with dementia. The random cluster sampling procedure, high response rates, and representativity of age distribution contribute to the quality of the data. Non-response analyses showed no differences between residents whose FP's did or did not respond, except for the item of consensus among relatives on care. Using a retrospective design we could identify a population based sample in this setting. The use of a retrospective research design has been proven to be superior to a prospective design in identifying population based information[18, 19]. In Flemish nursing homes, where residents with and without dementia live together and move between different care levels according to their needs, selection of those with dementia is difficult. Therefore we used a two-step screening protocol to select the study population and validated clinical scales to identify subgroups. Hence we were able to study all deceased nursing home residents with dementia and compare advanced dementia with other stages. Using a combination of different observers we could provide a good epidemiological view of the circumstances of dying with dementia in Flanders.

Nevertheless, the study has several limitations. Since a retrospective research design was used, memory bias cannot be ruled out. However, this was limited by minimizing the time between death and the completion of questionnaires and by focusing on the final month of life. Also, even though representativity was difficult to test because of lack of population data, men appear overrepresented in our sample. Finally, when interpreting the results, we take into account that we needed to rely on FPs' and nurses' reports and perception of health status, clinical complications and distressing symptoms which may differ from what residents themselves would have reported however self-reporting is not possible in this patient population.[30]

From a public health point of view, our study provides important data concerning the magnitude of the problem of dying with dementia in nursing homes. Of all deaths in Flemish nursing homes, about half concern residents with some form of dementia most of whom experience serious limitations and complications at the end of life. Moreover, median nursing home stay was 2.4 years and median survival time after onset of dementia was three years. Considering the future increase in people developing dementia[31], our results confirm that dying well with dementia in nursing homes is one of the most important public health challenges.

Also, many residents dying with moderate/mild or severe dementia appear to encounter similar end-of-life problems to those with very severe/advanced dementia. As was previously observed in the US[16], nursing home residents with advanced dementia suffer from important clinical complications. However, we additionally found that the prevalence of clinical complications in the last month of life (eg pneumonia or other infections), levels of comfort and quality of life in the last week did not differ significantly between groups, nor did the presence of distressing symptoms in the last month. Hence, nursing homes face major challenges in caring for residents dying with dementia regardless of the stage.

Overall, the most common clinical characteristics in the last week of life were incontinence for urine or faeces, pressure sores and cachexia/dehydration. The most common clinical complications in the last month of life were eating or drinking problems (65.7%), febrile episodes (42.9%) and pneumonia (32.2%). These three complications are also cited as highly prevalent in US and Italian studies limited to advanced dementia.[32, 33] In the prospective US Boston study among nursing home residents with advanced dementia (323 residents of whom 177 died during the study), an eating or drinking problem was reported in 85.8%, febrile episodes in 52.6% and pneumonia in 41.4% during the study period of 18 months.[33] Eating/drinking problems were the most prevalent clinical complications across all dementia stages and particularly common among residents with advanced dementia. This reinforces the need to pay particular attention to this end of life complication. It might be one of the most common end points for which family members need to be prepared, particularly since far-reaching end of life decisions concerning forgoing food or fluid might need to be made in the final days of life. It can also be one of the main issues to discuss with residents early in their disease course as part of an advance care planning process.

Across all dementia stages, the most commonly reported symptoms in the last month of life were pain, fear and anxiety. Although comparison with other studies is difficult due to differences in population and research procedures, these findings do not seem surprising. In other studies from other EU countries or the US[32-37], people with dementia also appear to experience a number of burdensome physical, emotional or psychosocial symptoms. Interestingly, while some other studies report that anxiety seems to decrease in the severe stages of dementia[35], the nurses in our study indicated fear and anxiety to be one of the most prevalent symptoms in residents with dementia regardless of the stage.

It is remarkable that survival time after diagnosis was shorter in case of mild/moderate dementia than in case of severe or advanced dementia. This might be explained by the fact that co-existing conditions such as cardiovascular diseases were more often reported by the family physicians among residents with mild/moderate dementia than among the more advanced residents. Residents with dementia seem to either die earlier with more comorbid conditions or die later with more severe or advanced dementia.

Finally, we found that 21.4% of residents with dementia at time of death were physically restrained (upper body or limb restraints) during the last week of life. The use of these restraints is controversial and often associated with stress, agitation and a higher risk of falls.[38] Also, on average one in ten nursing home residents with dementia died in a hospital, indicating that burdensome terminal transitions remain an issue. Further research is needed concerning the best approach to these problems.

CONCLUSION

In conclusion, considering our finding that half of nursing home residents die with dementia - a number only increasing in the future - dying well with dementia in nursing homes is one of the most important public health challenges for end-of-life care. Serious clinical complications and distressing symptoms were reported regardless of the stage of dementia. This suggests that research addressing the challenge of providing high quality end-of-life care for residents with dementia should not only focus on residents with advanced dementia. It also suggests that end of life care practices in nursing homes might benefit from a regular and systematic assessment of symptoms and problems among residents with dementia, and from preparing caregivers, residents and their families for the clinical complications that might occur at the end of life and the accompanying end of life decisions.

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CHAPTER 4:

THE INCIDENCE OF PALLIATIVE CARE AND LIFE-PROLONGING TREATMENTS IN NURSING HOME RESIDENTS DYING WITH DEMENTIA

An Vandervoort,, Lieve Van den Block, Jenny T. van der Steen, Robert Vander Stichele,, Luc Deliens

Submitted

ABSTRACT

IMPORTANCE

Although contemporary palliative care models suggest that life-prolonging treatments can to a certain extent co-exist with a palliative care approach, there is a dearth of population-based nationwide data describing the incidence of palliative care and its relationship with life-prolonging treatments, in particular for non-cancer populations.

OBJECTIVE

To describe the incidence of different types of palliative care provision and potentially life-prolonging treatments and the extent to which they co-exist at the end of life of nursing home residents dying with dementia in Belgium.

DESIGN/SETTING/PARTICIPANTS

In a nationwide representative post-mortem study in Flanders, Belgium (2010), nursing homes reported all deceased residents with dementia over a three-month period. Nurses most involved in care and family physicians completed structured questionnaires for each death.

MAIN OUTCOMES MEASURES

Palliative care provision (involvement of in-house palliative care staff - reference nurses/physicians for palliative care with minimal palliative care training - or external specialist multidisciplinary palliative care services); presence of a palliative treatment goal and potentially life-prolonging treatments.

RESULTS

We identified 205 deceased residents with dementia (106 with advanced dementia) in 69 nursing homes (response rate 58%). Palliative care was provided by in-house palliative care staff and external specialist services in respectively 81.9% and 11.0% of cases. A palliative treatment goal was present in 89.2%. In the last week of life, 30.8% of residents with dementia received one or more potentially life-prolonging treatment, of which 19.5% consisted of antibiotics and 20.6% of administration of artificial food/fluids. Although residents with a palliative treatment goal were less likely to receive potentially life-prolonging treatments overall than those without this treatment goal (adjusted OR 0.16; CI, 0.03-0.78), 7.8% received artificial food/fluid in the last week of life and 16.2% were hospitalized in the last month of life.

CONCLUSIONS/RELEVANCE

Most but not all nursing homes residents dying with dementia receive some type of palliative care in Belgium, mainly from in-house staff and a few from specialist multidisciplinary palliative care services. Residents being treated with a palliative intent were less likely to receive potentially life–prolonging treatments although possibly burdensome treatments co-existed with a palliative care approach in a minority of people.

INTRODUCTION

Considering the growing prevalence of dementia, end-of-life care for people with dementia has become a major public health concern[1]; between 50% and 92% of people with dementia in Europe die in a nursing home and 67% in the US[2, 3]. Recent studies of nursing home residents dying with dementia have shown that clinical complications at the end of life are prevalent in this population and there is room for improvement in the quality of dying[4-6]. There is also an increasing consensus that people with dementia can benefit from palliative care, not only at the very end of life but also earlier in the disease trajectory, in terms of optimizing psychological and physical wellbeing, advance care planning, supporting caregivers and ensuring appropriate access to healthcare[7-11]. As defined by the World Health Organization (WHO), palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and assessment and treatment of pain and other physical, psychosocial and spiritual problems. It intends neither to hasten nor to postpone death. According to this contemporary model of palliative care, life-prolonging treatments can to a certain extent co-exist with a palliative care approach, although burdensome and futile treatments are limited at the very end of life[11-13].

There is a dearth of population-based and nationwide data describing palliative care and treatments provided to people with dementia in nursing homes in the final phase of life. We lack robust and large-scale data describing the incidence of different types of palliative care and potentially life-prolonging treatments for nursing home residents with dementia[6-9, 14]. Moreover, very little research has been conducted on the co-existence of palliative care and life-prolonging treatments[15, 16] in particular for non-cancer populations.

In this study we identify a representative nationwide sample of nursing home residents dying with dementia in Belgium in order to address the following research questions:

- how often do nursing home residents dying with dementia receive palliative care, and of what type, in Flanders, Belgium?
- how many and which type of potentially life-prolonging treatments are provided to nursing home residents dying with dementia in Flanders, Belgium?
- to what extent do potentially life-prolonging treatments coexist with a palliative treatment goal in this population?

METHOD

STUDY DESIGN

To obtain a representative sample of all nursing home residents dying with dementia, we conducted a retrospective cross-sectional study to describe end-of-life care of nursing home residents dying with dementia in 2010 in Flanders, Belgium (Dying Well with Dementia study)[6, 17].

A structured questionnaire was completed by the nurse most involved in the resident's care, the family physician and the nursing home administrator of all residents dying with dementia identified over a three month inclusion period.

SETTING AND SELECTION OF STUDY SUBJECTS

A random cluster-sampling procedure was used. For the sample to be representative of all Flemish nursing homes, homes were stratified by region (five provinces) and subsequently by bed capacity (up to or more than 90 residents) and ownership (public, private/nonprofit, private/profit) and then randomly proportionally sampled.

A two-stage screening protocol was used to identify eligible residents:

In the first step residents were included if they met the criteria for (1) 'category C dementia' ie 'being completely care dependent or needing help for bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space', or (2) disorientation in time and space (KATZ scale ≥ 3 or having 'almost daily a problem with disorientation in time and space')[18].

In the second step additional eligibility criteria required that the family physician or nurse indicated that the resident 'had dementia' or 'was diagnosed with dementia'.

According to their score on the Cognitive Performance Scale (CPS) and Global Deterioration Scale (GDS) scored by the nurse, residents were classified into three groups[19]:

- moderate dementia ($CPS<5$ and $GDS<7$)
- severe dementia [($CPS\geq 5$ and $GDS<7$) or ($CPS<5$ and $GDS=7$)]
- very severe or advanced dementia ($CPS\geq 5$ and $GDS=7$)

DATA COLLECTION

In each participating nursing home, the board of directors appointed one contact person for the study (ie the nursing home administrator or head nurse). The researcher visited each nursing home and assisted the contact person in identifying eligible residents, the nurse who was ‘most closely involved in the resident’s care and the resident’s family physician. The nurse, family physician and nursing home administrator were sent a structured standardized questionnaire no more than three months after the death. Non-responders received a reminder after three weeks, with the administrator as a mediator to guarantee anonymity.

MEASUREMENTS

The after-death questionnaires surveyed socio-demographic characteristics, health status, medical end-of-life treatments and palliative care.

Family physician

- Health status: co-existing conditions, cause of death
- Main treatment goal in the last week of life (palliative, life prolonging, preservation/recuperation of function, no global treatment goals set)
- Potentially life-prolonging treatments in last week of life: antibiotics, artificial food or fluid administration, intravenous therapy, subcutaneous rehydration, other

Nurse

- Health status: median survival time after onset of dementia, Bedford Alzheimer Nursing Severity-Scale (BANS-S)[20] measuring dementia , level of dementia using Cognitive Performance Scale (CPS) and Global Deterioration Scale (GDS)[21, 22]
- Sentinel events (pneumonia, febrile episodes, eating or drinking problems or other) in last month of life
- Types of palliative care provision:
    - palliative care from family physician as perceived by the nurse: yes/no – in Belgian nursing homes, nursing care is provided by skilled nurses 24/7; medical care (including end-of-life care) is provided by a visiting family physician who is chosen by the resident and who is often their long-term family physician
    - in-house palliative care provided by nursing home staff with minimal palliative care training: according to the Belgian Law on Palliative Care (2002) and the Decree on Residential Care (2009)23-25 each nursing home is required to have palliative caregivers supporting the regular caregivers by giving advice and if requested by taking over some aspects of care eg a coordinating and advisory physician of the nursing home—a family physician who is among other things responsible for the development of a strategy regarding end-of-life care—or an in-house reference nurse for palliative care (registered nurse with bachelor degree), or a palliative care task group. The formal education for these

physicians/nurses is not yet well developed hence the quality of the palliative care provided is unclear

  - external specialist palliative care services: a palliative multidisciplinary home care team coming into the nursing home or a admission to a palliative care unit in the last three months of life
  - palliative care record in the nursing home: ie, a formal supplement to the resident's nursing home file linked to governmental financial support for the resident.
- Additionally, we surveyed:
  - psychosocial interventions during the last month of life: adjustment of environment (to support reduced sensory, cognitive and motor ability), activity programs
  - palliative or symptomatic medical or nursing care in the last week of life: regular assessment of pain (with or without scale), prevention of decubitus, wound care
  - Potentially life-prolonging treatments:
  - last month of life: transfer to hospital (excluding palliative care unit)
  - at time of death: cardio pulmonary resuscitation (CPR)

Nursing home administrator

- Demographics: age, gender
- Length of nursing home stay, whether the residents lived in a special care unit for dementia (ie a closed unit within the nursing home), place of death

ANALYSES

Analyses were performed with PASW statistical software, 17.0 (SPSS Inc., Chicago, IL). Based on the CPS&GDS, residents were classified into three groups. Very severe/advanced dementia similarly defined as such by Mitchell et al[19].

Differences in distribution between very severe/advanced dementia, severe dementia and moderate dementia were calculated using Fisher-Exact Tests. Medians and averages were tested using Kruskall-Wallis and Anova (significance level p<.05).

We used multivariable logistic regression analysis to calculate odds ratios correcting for resident characteristics, level of dementia and sentinel events. We examined associations between palliative treatment goal as dependent (reference = no palliative treatment goal) and antibiotics treatment in the last week of life (reference = no antibiotics), artificial food or fluids in the last week of life (reference = no artificial food or fluids) and transfer to hospital in the last month of life (reference = no transfer to hospital) as independent variables.

ETHICAL ASPECTS

The research procedures respected privacy/confidentiality of patients and respondents. The study protocol was approved by the Medical Ethics Committee of UZ Brussel (University Hospital of Brussels).

RESULTS

SAMPLE DESCRIPTION

Sixty-nine nursing homes (58% response rate) participated, representative of all nursing homes in Flanders in terms of size, region and ownership. Response rates to the questionnaires for family physicians were 52.9%, for nurses 88.4% and for nursing home administrators 95.0%. The median time between the completion of the questionnaire and death of the resident was 65 days (interquartile range 37-91 days) for nurses, 82 days (IQR 48-137 days) for family physicians, and 65 days (IQR 34-92 days) for nursing home administrators. Non-response analysis showed no differences for important resident characteristics (age, gender, length of stay, place of death, cognitive status, disease severity).

In participating homes, we identified 477 residents who had died within the past three months of whom 241 met the inclusion criteria in the first step of the screening procedure. After screening the returned questionnaires in the second step we identified 205 (46.7%) deceased residents with dementia. Of these, 106 had very severe or advanced dementia, 61 severe dementia and 36 moderate dementia (Table 1).

Sixty four percent (64.2%) of all residents with dementia were aged 85 or older and 61.1% were women. The median length of stay was 2.4 years. Half of the residents (52.1%) died in a special care unit for dementia within the nursing home; 8.7% died in a hospital.

Most residents with dementia were severely functionally and cognitively disabled one month before death (mean score on BANS was 20.8). The cause of death was labelled old age or overall decline by the family physician in 41.2%.

Table 1. Nursing Home Residents Dying With Dementia in Flanders, Belgium: Description of the Sample (N=205)

	Residents with Dementia N(%)	Very Severe or Advanced Dementia N (%)	Severe Dementia N (%)	Moderate Dementia N (%)	P value §
Total N*	205	106	61	36	
PATIENT CHARACTERISTICS					
Age – yr					
<80	36 (17.9)	21 (20.6)	8 (13.1)	6 (16.7)	0.89
80-84	36 (17.9)	15 (14.7)	12 (19.7)	9 (25.0)	
85-89	59 (29.4)	31 (30.4)	18 (29.5)	10 (27.8)	
90-94	46 (22.9)	23 (22.5)	16 (26.2)	6 (16.7)	
≥95	24 (11.9)	12 (11.8)	7 (11.5)	5 (13.9)	
Gender					
Male	75 (38.9)	39 (39.8)	25 (41.0)	11 (33.3)	0.78
Female	118 (61.1)	59 (60.2)	36 (59.0)	22 (66.7)	
Median length of nursing home stay Median yr (interquartile range)	2.4 (1.1-4.5)	2.4 (1.2-4.5)	3.2 (1.2-5.1)	2.1 (0.5-3.2)	0.21
Living in special care unit for dementia	101 (52.1)	58 (58.6)	28 (45.9)	15 (45.5)	0.10
Place of death					
Nursing home	177 (90.3)	94 (93.1)	54 (88.5)	28 (84.8)	0.30
General hospital ward or intensive care unit	17 (8.7)	6 (5.9)	7 (11.5)	4 (12.1)	
Palliative care unit	2 (1.0)	1 (1.0)	0 (0.0)	1 (3.0)	
BANS-S one month before death (mean ± SD) †	20.8 ±3.9	22.5 ±2.78	20.6±3.53	16.3 ±3.78	<0.001
HEALTH STATUS					
Co-existing conditions ‡					
Malignant tumour	13 (11.0)	5 (7.6)	4 (13.3)	3 (15.0)	0.48
Cardiovascular	33 (28.0)	14 (21.2)	12 (40.0)	7 (35.0)	0.14
Respiratory	16 (13.6)	9 (13.6)	5 (16.7)	2 (10.0)	0.87
Neurological	20 (16.9)	12 (18.2)	5 (16.7)	2 (10.0)	0.74
Urogenital system	9 (7.6)	4 (6.1)	4 (13.3)	1 (5.0)	0.50
Other	19 (16.2)	10 (15.4)	5 (16.7)	4 (20.0)	0.89
None of the above	36 (30.5)	26 (39.4)	7 (23.3)	2 (10.0)	0.024
Cause of Death					
Malignant tumour	13 (10.9)	5 (7.7)	3 (9.7)	4 (19.0)	0.76
Cardiovascular	19 (16.0)	9 (13.8)	4 (12.9)	6 (28.6)	
Stroke (CVA)	12 (10.1)	7 (10.8)	3 (9.7)	2 (9.5)	
Neurological	4 (3.4)	3 (4.6)	1 (3.2)	0 (0.0)	
Respiratory	13 (10.9)	7 (10.8)	5 (16.1)	1 (4.8)	
Old age / overall decline	49 (41.2)	28 (43.1)	14 (45.2)	6 (28.6)	
Other	9 (7.6)	6 (9.2)	1 (3.2)	2 (9.5)	

* Missing values are for age n=4, gender n=12, median length of nursing home stay n=10, median survival time after onset dementia n=76, living in special care unit for dementia n=11, place of death n=9, BANS-S n=7, co-existing conditions n=87 (of which 85 because no questionnaire was received from the family physician), cause of death n=86 (of which 85 because no questionnaire was received from the family physician).

† Scores on the BANS-S (Bedford Alzheimer’s Nursing Severity-Scale) range from 7 to 28; higher scores indicate greater dementia severity.

‡ Multiple answers possible

§ Differences between Very Severe/Advanced Dementia, Severe dementia and Moderate dementia.

PALLIATIVE CARE PROVISION

According to the family physician the treatment goal in the last week of life was palliative in 89.2% of cases and did not differ significantly between dementia stages (table 2). According to the nurse, overall, palliative care was provided by the family physician in 84.5% of cases and more frequently with more severe dementia (p=0.049). In-house palliative care staff members were involved in 81.9% of cases, varying between 70.8% and 89.0% (p=0.02), consisting of the involvement of a palliative care reference nurse (66.3%), discussion by a palliative care task group (48.8%) or the involvement of the coordinating and advisory physician (26.5%). The advisory physician provided a bedside consultation in 22.1% of cases and the reference nurse in 60.7%. External specialist palliative care services were involved in 11.2% of cases, 3.1% admission to a palliative care unit and 9.6% involvement of a palliative home care team, and did not differ significantly between dementia stages. Taking in-house or external palliative care together, palliative care was more often provided to residents with advanced (90.1%) compared with severe (72.9%) or moderate dementia (77.8%) (p=0.02).

According to the nurse six in ten residents dying with dementia (61.7%) had a formal palliative care record in the nursing home, varying between 69.5% of those with very severe/advanced dementia and 48.6% of those with moderate dementia (p=0.045).

Table 2. Palliative care provision among nursing home residents dying with dementia in Flanders, Belgium. (N=205)

	Residents With Dementia	Very severe or Advanced Dementia	Severe Dementia	Moderate Dementia	P value ‖
Total N*	205	106	61	36	
			N (%)		
Palliative treatment goal in last week of life according to the family physician†	107 (89.2)	62 (93.9)	26 (83.9)	17 (81.0)	0.12
Palliative care from the family physician at any point in time	136 (84.5)	78 (90.7)	38 (79.2)	20 (74.1)	0.049
In-house palliative care initiatives ‡	136 (81.9)	81 (89.0)	34 (70.8)	21 (77.8)	0.02
PC from the coordinating and advisory physician of the nursing home	44 (26.5)	28 (30.8)	8 (16.7)	8 (29.6)	0.18
Bedside consultation provided	32 (22.1)	20 (23.3)	7 (19.4)	5 (21.7)	0.96
Palliative care reference nurse	110 (66.3)	67 (73.6)	28 (58.3)	15 (55.6)	0.08
Bedside consultation provided	88 (60.7)	52 (60.5)	24 (66.7)	12 (52.2)	0.54
Palliative care task group	81 (48.8)	44 (48.4)	24 (50.0)	13 (48.1)	0.98
External specialist palliative care initiatives	22 (11.2)	13 (12.3)	6 (10.9)	3 (8.3)	0.91
Palliative home care team	16 (9.6)	9 (9.9)	5 (10.4)	2 (7.4)	<0.99
Bedside consultation provided	15 (10.3)	8 (9.3)	5 (13.9)	2 (8.7)	0.74
Admission to palliative care unit in last three months of life	6 (3.1)	4 (3.8)	1 (1.9)	1 (2.8)	0.86
In-house or external palliative care provided at any point of time§	138 (83.1)	82 (90.1)	35 (72.9)	21 (77.8)	0.02
Palliative care record in nursing home	121 (61.7)	73 (69.5)	31 (55.4)	17 (48.6)	0.045
Psychosocial interventions during last month of life					
Adjustment of environment	19 (9.6)	12 (11.3)	2 (3.6)	5 (13.9)	0.14
Activity programs	25 (12.6)	9 (8.5)	6 (10.7)	10 (27.8)	0.02
Palliative or symptomatic medical or nursing care in last week of life					
Pain assessment	124 (62.6)	65 (61.3)	38 (67.9)	21 (58.3)	0.63
Prevention of decubitus	162 (81.8)	91 (85.8)	47 (83.9)	24 (66.7)	0.04
Wound care	45 (22.7)	24 (22.6)	14 (25.0)	7 (19.4)	0.85

* Numbers of categories of variables may not add up to 205 because of missing values.

† Missing values are for treatment goal n=87, of which 85 because no questionnaire was received from the family physician.

‡ Inhouse palliative care initiatives are those provided within the nursing home by regular caregivers of the nursing home.

§ Sum of inhouse and external palliative care initiatives.

‖ Differences between Very Severe/Advanced Dementia, Severe dementia and Moderate dementia.

POTENTIALLY LIFE-PROLONGING TREATMENTS

The most common potentially life-prolonging treatments in the last week of life were antibiotic treatment (19.5%), artificial food/fluid administration (10.6%), and intravenous therapy (6.4%; table 3). CPR was performed in three cases. Overall, 19.5% were transferred to a hospital in the last month of life, varying from 14.4% in very severe/advanced dementia to 30.6% in moderate dementia (p=0.09).

Table 3. Potentially life prolonging treatments among nursing home residents dying with dementia in Flanders. Belgium. (N=205)

	Residents with Dementia	Very severe or Advanced Dementia	Severe Dementia	Moderate Dementia	P value §
Total N*	205	106	61	36	
			N (%)		
Transfer to hospital in last month of life (excl palliative care unit)	38 (19.5)	15 (14.4)	12 (21.8)	11 (30.6)	0.09
Potentially life prolonging treatments in last week of life					
Treatments in last week of life †	36 (30.8)	15 (23.4)	11 (36.7)	9 (42.9)	0.16
Antibiotics	22 (19.5)	12 (19.0)	5 (17.2)	5 (25.0)	0.81
Artificial food or fluid administration	12 (10.6)	5 (7.9)	4 (13.3)	3 (16.7)	0.44
Intravenous therapy	7 (6.4)	3 (4.9)	1 (3.4)	3 (17.6)	0.12
Subcutaneous rehydration	6 (5.6)	2 (3.3)	3 (10.3)	0 (0.0)	0.34
Other	6 (5.3)	3 (4.8)	1 (3.4)	1 (5.3)	<0.99
Resident underwent CPR at time of death	3 (1.6)	1 (1.0)	2 (3.8)	0 (0.0)	0.27

* Numbers of categories of variables may not add up to 205 because of missing values.

† For treatments in last week of life missing values are=90, of which 85 because no questionnaire was received from the family physician.

‡ Multiple answers possible

§ Differences between Very Severe/Advanced Dementia, Severe dementia and Moderate dementia are tested using Fisher-Exact test, Anova or Kruskall Wallis, significance level at 0.05

PALLIATIVE CARE CO-EXISTING WITH POTENTIALLY LIFE-PROLONGING TREATMENTS

Residents having a palliative treatment goal received antibiotic treatment in 18.6% of cases compared with 27.3% for those without (p=0.69) (Table 4). Those with a palliative treatment goal were less likely to receive artificial food or fluids treatments (7.8%) or to be transferred to hospital (16.2%) than those without (respectively 36.4% and 50%). Residents with a palliative treatment goal receiving life-prolonging treatments (n=31) had advanced dementia in 43.3% of cases. Residents with a palliative treatment goal receiving antibiotics or artificial food or fluids had advanced dementia in respectively 52.6% and 37.5% of cases. Residents with a palliative treatment goal being transferred to hospital had advanced dementia in 43.8% of cases (not shown in tables).

Within the group of residents receiving external specialist palliative care services (n=22), possibly life-prolonging treatments were provided in 13 cases, two receiving antibiotics and one artificial food/fluid (not shown in tables).

Table 4. Potentially life-prolonging treatments for residents with and without a palliative treatment goal for nursing home residents dying with dementia in Flanders, Belgium (N=205) *

	Palliative treatment goal †	No palliative treatment goal†	Bivariable P-value §	Multivariate AOR ‖
	N %	N %		
	107 (89.2)	13 (10.8)		
Treatments in last week of life (total score)‡	31 (29.2)	5 (45.5)	0.31	0.47 [0.1-2.25]
Antibiotics	19 (18.6)	3 (27.3)	0.69	0.29 [0.06-1.58]
Artificial food or fluid administration	8 (7.8)	4 (36.4)	0.017	0.16 [0.03-0.78]
Transfer to hospital in last month of life	16 (16.2)	6 (50.0)	0.013	0.20 [0.05-0.78]

* Numbers of categories of variables may not add up to 205 because of missing values.

† Palliative treatment goal in last week of life according to the family physician

‡ For treatments in last week of life there were 90 missing values, of which 85 because no questionnaire was received from the family physician.

§ Differences between palliative treatment goal and no palliative treatment goal are tested using Fisher-Exact test, significance level at 0.05.

‖ Odds ratios based on logistic regression analysis with palliative treatment goal as dependent variable (ref = no palliative treatment goal) and as independent variables antibiotics (ref= no antibiotics), food/fluids (ref= no food/fluids) and transfer to hospital (ref= no transfer to hospital). We controlled for resident characteristics, level of dementia and sentinel events.

DISCUSSION

This nationwide representative post-mortem study in nursing homes in Flanders, Belgium, demonstrates that palliative care was provided by in-house palliative care staff and external specialist services in respectively 81.9% and 11.0% of cases, varying overall between 72.9% for moderate and 90.1% for advanced dementia. In the last week of life, 30.8% of residents with dementia received one or more potentially life-prolonging treatments. Although residents being treated with a palliative intent were less likely to receive potentially life-prolonging treatments, some possibly burdensome treatments co-existed with a palliative care approach in a minority of people ie 7.8% received artificial food/fluid in the last week of life and 16.2% were hospitalized in the last month.

To our knowledge, this is the first nationwide, population-based study describing and relating palliative care and medical end-of-life treatments among nursing home residents dying with dementia and comparing this in different stages of dementia. We obtained a representative sample of Flemish nursing homes using a random cluster sampling procedure, dividing homes into different strata. The use of a retrospective research design has been shown to be superior to a prospective design in identifying population-based data[26-28]. Also, by using proxy measurements we were able to study the last days and weeks of life in a population usually no longer able to self-report[26, 27]. The high response rates contributed to the quality of the data, the lowest response rates being for family physicians (52.9%) although this is higher than the average response rates for physician postal surveys and for most medical surveys in Belgium[29, 30]. Non-response analyses showed no differences between residents whose family physicians did or did not respond in important characteristics such as demographics, cognition, decision-making capacity, treatment and care. By using a two-step screening protocol we were able to identify reliably our study population of nursing home residents with dementia. We considered all residents dying with dementia, those dying with advanced dementia as well as those with dementia who died before they reached an advanced stage, allowing for comparisons between dementia stages. For this we used validated clinical scales to identify the subgroups of dementia. By using the perspective of the nurse and family physician we gained a privileged insight into the end-of-life care of nursing home residents with dementia.

However, this study also has limitations. Studying the end of life is dependent on the perceptions of proxies in a retrospective research design; memory bias cannot be ruled out, although it might be limited by focusing on the last phase of life. Additionally, using a quantitative approach to study palliative care is limited in that it cannot provide in depth insights into the way care was delivered by different caregivers. Measuring the presence of in-house or external specialist palliative care services or a resident's treatment goal is also not a direct measurement of the quality of that care. The reasons for and actual effects of life-prolonging treatments are also not explored in depth.

At first sight it seems reassuring that a large majority (83.1%) of nursing home residents dying with dementia receive some form of palliative care and that the treatment goal in the last week of life is mostly aimed at palliation (89.2%). This indicates that in most cases care providers recognize that residents with dementia are eligible for palliative care. The WHO and a recent EAPC white paper also promote palliative care as the preferred approach for older people with age-related and cognitive problems, not only in the terminal phase but integrated early into disease management[11, 31].

When studying the type of palliative care provided, our results show that palliative care was delivered as part of regular care by the family physician in 84.5% of cases, but palliative care reference nurses and physicians who are appointed to set out a general palliative care culture in nursing homes also appear to be involved frequently (81.9%), not only in terms of consultation of regular caregivers but also in terms of bedside consultation (by the reference nurse in 60.7% and by the physician in 22.1% of cases). This suggests that the legal framework for palliative care in Belgium might be having an effect on how daily care is organised in nursing homes. However, external specialist multidisciplinary palliative care services are seldom consulted. Since our previous results show that several residents with dementia suffer from burdensome symptoms and clinical complications at the end of life, regardless of their stage[6] , we can question whether these external specialists could be used more extensively and further research is needed to study current and optimal referral criteria for such specialist services. Additionally, the quality of palliative care provided by in-house palliative care staff might also need to be improved to tackle the problems specific to dementia, especially considering their education is not yet well developed in Belgium.

Noticeably, we found a significant minority (almost two in ten) of residents with dementia not receiving any form of palliative care at any point before death. Of those with advanced dementia one in ten did not receive palliative care, either from the family physician or from in-house or external specialist palliative care services; these residents might have benefited from palliative care since people with dementia have high palliative care needs[6, 14].

Additionally, three out of ten nursing home residents dying with dementia receive potentially life-prolonging treatments such as antibiotics or artificial food/fluids in the last week of life, with no large differences between the different stages of dementia. A significant proportion of residents with dementia were also transferred to a hospital in the last month of life (19.5%), especially those with moderate/severe as opposed to advanced dementia. However, these treatments might not be optimal in promoting comfort in the final phase of life. Previous research has shown for example that the presence of a catheter or the administration of artificial food or fluids is often associated with pain and discomfort[14, 32] and that these treatments are not always beneficial and are in some cases unwanted[4, 33, 34]. Our Belgian results also correspond with studies from the US showing similarly high frequencies of potentially burdensome treatments at the end of life in selected samples of nursing home residents with advanced dementia[4, 14, 35].

As expected, residents with a palliative treatment goal were less likely to receive potentially life-prolonging treatments in the last week of life or to be transferred to the hospital in the last month of life than those without. This seems to indicate that the recognition of palliative care needs is an important factor when making treatment decisions that might prolong life, a finding that illustrates and confirms the contemporary palliative care model of Lynn et al[15, 36] suggesting that chronically ill elderly people such as those with dementia may need both disease modifying/potentially life-prolonging treatments and palliative care early in the disease course, gradually shifting to more palliative care and fewer life-prolonging treatments when the disease progresses and palliative care needs increase.

However, a significant minority of residents treated with a palliative intent still received possibly burdensome and futile life-prolonging treatments such as artificial food or fluids (7.8%) or hospital admission (16.2%) at the very end of life. The usefulness of this combination is questionable especially for residents with advanced dementia[11]. This might be explained by the limited use of specialist palliative care in this setting although the potential effect of consulting specialist palliative care services in this population is still to be confirmed.

Interestingly, the use of antibiotics for residents receiving palliative care did not differ significantly from those not receiving it. The use of antibiotics at the end of life in people with dementia is controversial; some argue that antibiotics are useful in palliative care while other argue that their use only prolongs survival time while it does not improve comfort[37]. This illustrates the complexity of the treatment decisions involved at the end of life of people with dementia. Making treatment decisions for residents with dementia with a palliative treatment goal is difficult and is often influenced by the overall level of frailty, long periods of illness or disability, exacerbation of symptoms, ethics, evidence and policy[27-29].

In conclusion, most but not all nursing homes residents dying with dementia in Belgium received some form of palliative care, most from in-house staff members and a small number from specialist multidisciplinary palliative care services. Although palliative care involves fewer life-prolonging treatments, some possibly burdensome and futile life-prolonging treatments co-existed with a palliative care approach in a minority of cases, which might be questionable especially for people with advanced dementia.

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CHAPTER 5:

HOSPITALIZATIONS OF NURSING HOME RESIDENTS WITH DEMENTIA IN THE LAST PHASE OF LIFE: RESULTS FROM A NATION WIDE STUDY

Dirk Houttekier, An Vandervoort, Lieve Van den Block, Jenny T van der Steen, Robert Vander Stichele, Luc Deliens.

In revision

ABSTRACT

BACKGROUND

Hospitalizations of nursing home residents with dementia may not be uncommon, though evidence from epidemiological studies outside the US is lacking.

AIM

To examine the proportion of nursing home residents with dementia hospitalized in the last month of life and factors associated with hospitalization, the reasons of such hospitalizations, who is involved in hospitalization decisions and whether information was transferred with the resident.

DESIGN

The design is cluster-randomized sampling survey. Nurses registered retrospectively demographic and dementia-related information. This included information about residents' hospitalizations, reasons for hospitalizations, persons involved in hospitalization decisions and type and content of information transferred when hospitalized.

SETTING/ PARTICIPANTS

Nursing home residents dying with dementia in Belgium (Flanders) in 2010.

RESULTS

In the final month of life 19.5% of nursing home residents dying with dementia (N=198) were hospitalized, including 4.6% admitted to an intensive care unit. For 11.3% of residents a do-not-hospitalize advance directive was present, for 54.4% a do-not-hospitalize GP-order. Residents without a do-not-hospitalize GP-order were more likely of being hospitalized. None of the hospitalizations occurred at the request of the resident; 37% were at the request of relatives; curative or life-prolonging treatments were the most frequent reasons given. Information about the resident's nursing care or medical treatment was transferred in almost all hospitalizations, information about wishes and preferences for future care in 19%.

CONCLUSIONS

Hospitalization in Belgian nursing home residents with dementia in the last month of life was substantial. Documentation of do-not-hospitalize physician-orders in the resident's medical files may prevent hospitalizations.

INTRODUCTION

Dementia has become a public health priority, given its growing prevalence both in developed countries and globally [1]. Dementia is a major risk factor for nursing home admission [2]. In 2005, 43% of all admitted nursing home residents in Belgium had dementia [3]. In the UK, 34% of people with dementia live in nursing homes, and the prevalence of dementia in nursing homes is 62% [4]. In the US and Europe, on average two-thirds of deaths of people with Alzheimer's or other dementia-related diseases occur in nursing homes [5,6].

Burdensome hospital transitions of nursing home residents with dementia and stays in intensive care units are not unusual [7-12]. Infection and pneumonia are found to be the most common reasons for hospital admission in the US, although treatment outcomes are no better for those hospitalized with pneumonia than for those cared for in the nursing home [12,13]. Transferred residents are at higher risk of functional decline and mortality and many are at higher risk of delirium, anorexia, incontinence and falls [14-16]. High rates of burdensome transitions are also related to other indicators of poor end-of-life care, such as tube feeding which may result in aspiration pneumonia, intensive care unit admissions, decubitus ulcer and late hospice enrolment [17,10,11]. Hospice enrolment may reduce the risk of hospitalization [15]. In Belgian nursing homes generalist palliative care can be provided by the resident's GP or the nurses of the nursing home, who may be assisted by a specialist palliative home care team. Residents, their relatives and their professional caregivers may also be supported by an in-house palliative care consultant.

The majority of research on end-of-life care for people with dementia, particularly on hospitalizations, has been conducted in the US [7], and epidemiological studies in Europe are rare [18], hence it would be highly informative to examine the hospitalization and factors associated with hospitalizations in a European health care system. In addition, little attention has been paid to the reasons for hospitalizations, those involved in the decision to hospitalize and whether information about the resident was passed to hospital staff.

The aim of this study is to examine hospitalizations of nursing home residents with dementia in the last month of life in Flanders, Belgium. The research questions are:

- What was the proportion of nursing home residents dying with dementia hospitalized in the last month of life and what was the length of hospital stay?
- Which factors were associated with hospitalization?
- Who requested the hospitalization and was curative, life-prolonging or palliative treatment needed? Who was involved in the hospitalization decision?
- Was information about the resident transferred to the hospital staff?

METHODS

We performed a retrospective cross-sectional study using a stratified random cluster-sampling procedure in Belgium (Flanders) in 2010. The National Institute for Health and Disability Insurance provided a list of all Flemish nursing homes (N=637). To be representative of all Flemish nursing homes, homes were stratified by region (five provinces) and subsequently by bed capacity (up to, or more than 90 residents) and ownership (public, private/non-profit, private/profit) and then randomly sampled. Bed capacity and ownership status are factors known to be related to quality of end-of-life care [19,20]. When an institution declined to participate, another nursing home was randomly selected until the targeted number of nursing homes per stratum was reached.

In sampled nursing homes that agreed to participate, all residents with dementia who had died in the previous three months were identified. The three-month registration period differed between nursing homes. Depending on the nursing home, residents who had died between February and October 2010 were included. For each case that met the inclusion criteria, a structured questionnaire was completed by the nurse most involved in the resident’s care. The questionnaire included questions about the socio-demographic background of the resident, dementia related issues, health status in the last month of life, transfers and hospitalizations in the last month of life, communication and advance care planning and care received in the last month of life, including palliative care. All nurses had access to the resident’s file when completing the questionnaire.
As a first step in the inclusion procedure, deceased nursing home residents were included if they met one of two criteria: (a) being completely care-dependent for bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space (the criterion used by the Belgian health insurance system) or (b) having almost daily a problem with disorientation in time and space (KATZ scale score ≥3) [21]. As a second step, eligibility criteria required that the resident’s GP (general physician) or nurse indicated that the resident ‘had dementia’ or ‘was diagnosed with dementia’.

According to their score on the Cognitive Performance Scale (CPS) and Global Deterioration Scale (GDS) as measured by the nurse, residents were classified into three groups: those with

moderate or mild dementia (CPS <5 and GDS <7), severe dementia [(CPS ≥ 5 and GDS <7) or (CPS <5 and GDS = 7)] or very severe or advanced dementia (CPS ≥ 5 and GDS = 7) [22,23].
The study protocol was approved by the Medical Ethical Committee of UZ Brussel (University Hospital of Brussels).

We used Chi^2 tests to test the age and sex distribution of the sample of deceased nursing home residents against the age and sex distribution of the population of deceased nursing home residents insured by the two largest insurance companies in Flanders insuring more than 70% of the Flemish population. Associations between the residents' personal (age, sex, stage of dementia at the time of death, capacity for medical decision making) environmental (persons involved in the residents' situation) and care (provision of palliative care, presence of a do-not-hospitalize written advance directive or do-not-hospitalize GP-order) characteristics and hospitalization were examined using Pearson Chi^2-tests. Variables for which the p-value of bivariable association with hospitalization was <0.2 were introduced in the multivariable model. Factors associated with hospitalization were examined using a binary logistic regression model with forward stepwise (likelihood ratio) selection of variables. Analyses were performed using IBM SPSS Statistics, version 19
(IBM Corporation, Somers, NY).

RESULTS

We contacted 134 nursing homes (21% of all Flemish nursing homes) of which 14 reported no deaths in the study period. Sixty-nine out of 120 nursing homes (58%), reporting at least one deceased resident in the previous three months decided to participate. By design (proportionate sampling), the sample was representative of all nursing homes in Flanders in terms of size, region and ownership. We identified 205 deceased residents with dementia. The response rate of nurses was 95% (N=198). The median time between death of the resident and completion of the questionnaire was 65 days (interquartile range [IQR]:37-91days). The sample of deceased residents was representative for the population of nursing home residents dying with dementia for age (p-value:0.55); men were overrepresented (p-value:0.02).

Thirty-eight residents (19.5%) were hospitalized in the last month of life, including nine (4.6% of total) who were admitted to an intensive care unit (Table 1). Median hospital stay was 10 days (IQR:4.75-14.0 days). Of the residents in our sample, 30.6% were older than ninety and 61.4% were female. More than half (53.3%) were very severely demented at the time of death and 76.8% had lost capacity for medical decision-making in the last month of life, as judged by the responding nurse. In 73.3% the friend or relative most involved in the resident's care was their child and in 17.9% their partner. Palliative care was provided in 83.3% of cases. One in ten subjects (11.3%) had a written do-not-hospitalize advance directive and 54.4% had a do-not-hospitalize GP-order in their medical file.

The proportion of residents hospitalized in the last month of life differed between those who received and did not receive palliative care and between those who had and had not a do-not-hospitalize GP-order in their medical files ($p<0.01$), though not between those with differing stages of dementia at the time of death ($p=0.1$). Results from binary logistic regression show that a do-not-hospitalize GP-order on the file was the only factor that was independently associated with a lower chance of being hospitalized in the final month of life (Data not shown in table). Residents without such an order were more likely to be hospitalized (adjusted odds ratio:4.9; 95% confidence interval: 2.1-11.1, Nagelkerke R^2:0.13). Stage of dementia at time of death, capacity for medical decision making in the last month of life and the provision of palliative care were found not to be associated with the risk of being hospitalized.

Table **1** Sample characteristics, hospitalization rate and factors bivariately associated with hospitalization in the last month of life of nursing home residents dying with dementia (N=198)

		Hospitalization in the last month	
	n[*] (%)	% of residents hospitalized	p-value[†]
All residents dying with dementia			
Hospitalized: general hospital ward	29	14.9	
Hospitalized: intensive care unit	9	4.6	
Not hospitalized	157	80.5	
Age			0.69
<85y	58 (31.7)	22.4	
85-90y	69 (37.7)	18.8	
>90y	56 (30.6)	16.1	
Sex			0.73
Female	113 (61.4)	20.4	
Male	71 (38.6)	18.3	
Stage of dementia at time of death (GDS/CPS)[‡]			0.10
Moderate or mild	36 (18.5)	30.6	
Severe dementia	55 (28.2)	21.8	
Advanced/ very severe	104 (53.3)	14.4	
Capacity for medical decision making in last month of life			0.07
Yes or partly	45 (23.2)	28.9	
No	149 (76.8)	16.8	
Person involved in the resident's situation[§]			
Partner			0.58
Yes	35 (17.9)	22.9	
No	160 (82.1)	18.8	
Child			0.45
Yes	143 (73.3)	18.2	
No	52 (26.7)	23.1	
Other family member			0.93
Yes	35 (17.9)	20.0	
No	160 (82.1)	19.4	
Friend or neighbour			0.61
Yes	14 (7.2)	14.3	
No	181 (92.8)	19.9	
No one			0.62
Yes	12 (6.2)	25.0	
No	183 (93.8)	19.1	
Provision of palliative care			<0.01
Yes	160 (83.3)	15.0	
No	32 (16.7)	37.5	
Do-not-hospitalize written advance directive			0.33
Yes	22 (11.3)	27.3	
No	173 (88.7)	18.5	
Do-not-hospitalize GP-order in resident's medical file			<0.01
Yes	106 (54.4)	8.5	
No	89 (45.6)	32.6	

[*] Numbers of categories of variables may not add up to N (198) because of missing values

[†] P-value of Chi^2 test of independence

[‡] CPS: Cognitive Performance Scale, GDS: Global Deterioration Scale

[§] Multiple answers were possible

According to the nurses answering the questionnaires, none of the hospitalizations had occurred at the request of the resident or for palliative treatment (Table 2); 14 were at the request of the relative and 11 were for curative or life-prolonging treatment. Three patients were hospitalized because they needed treatment after a fall. In four cases residents were involved in the decision to hospitalize. The resident's GP was involved in 30 of cases and a health care proxy or relative in 25. In none of the hospitalizations was an in-house palliative care consultant involved. A GP on duty was involved in four hospitalization decisions and a hospital hemodialysis centre in two. According to the nurse, the hospital palliative support team was involved in the care of three of the residents when in hospital, though in the majority of cases (22 of 38) the nurse did not know.

Table 2 Characteristics of hospitalizations in the last month of life of nursing home residents with dementia (N=38)

	n (%)
REASONS FOR HOSPITALIZATION*	
Requested by the resident	0 (0)
Requested by relatives	14 (37)
Requested by GP†	2 (5)
The resident needed curative or life-prolonging treatment	11 (29)
The resident needed palliative treatment	0 (0)
The resident needed treatment after a fall	3 (8)
Other	9 (24)
PERSON INVOLVED OR CONSULTED IN THE DECISION TO HOSPITALIZE*	
Resident	4 (11)
Health care proxy or relative	25 (66)
GP	30 (79)
Coordinating and advising physician of the nursing home	1 (3)
Nurse involved in care	19 (50)
Head nurse	14 (37)
Palliative care consultant	0 (0)
GP on duty	4 (11)
Hospital hemodialysis unit	2 (5)
Other	1 (3)
INVOLVEMENT OF THE HOSPITAL PALLIATIVE CARE TEAM IN RESIDENT'S HOSPITAL CARE	
Yes	3 (8)
No	11 (31)
Unknown	22 (61)

* Multiple answers were possible

† GP: General practitioner

In 36 of the 38 cases, information about the resident was transferred to the hospital at the time of hospitalization: in 24 of cases this was written information, in two cases it was verbal; in ten cases communication was both written and verbal (Table 3). Information provided with transfer was most frequently about nursing care or medical treatment (92%) and the reason for hospitalization (86%) and least frequently about activities of daily living (53%) or the resident's wishes and preferences about future care (19%). In two out of eight hospitalized residents who had personal written advance directives, these directives were transferred at the time of admission (Data not shown in table).

Of the 28 residents admitted to a general hospital ward, 18 eventually died in the nursing home of residence, nine in a general hospital ward, and one in a hospital palliative care unit. Of eight residents admitted to an intensive care unit, two died in the nursing home of residence, four in a general hospital ward, one in a palliative care unit and one in an
intensive care unit (Data not shown in table).

Table 3 Characteristics of information transferred from the nursing home to the hospital with nursing home residents with dementia hospitalized in the last month of life (N=38)

	n (%)
RESIDENTS FOR WHOM INFORMATION WAS TRANSFERRED	36 (95)
TYPE OF COMMUNICATION	
Written communication	24 (67)
Verbal communication	2 (6)
Written and oral communication	10 (28)
CONTENT OF TRANSFERRED INFORMATION*	
Information about nursing care or medical treatment	33 (92)
Reason for hospitalization	31 (86)
Name of a contact person	26 (72)
Case history	20 (56)
Activities of daily living	19 (53)
Resident's wishes and preferences about future care (eg do-not-resuscitate advance directive)	8 (19)

* Multiple answers were possible

DISCUSSION

Nearly a fifth (19.5%) of nursing home residents with dementia were hospitalized in the last month of life; almost a quarter (4.6% of total) of these were admitted to an intensive care unit. None of the hospitalizations were made at the request of the resident and few were made after consultation with them; most hospitalizations occurred at the request of or in consultation with the relative. Usually the GP was involved in the decision but no hospitalizations were done in consultation with a palliative care consultant or because the resident needed palliative treatment in hospital. In almost all cases information relating to the resident was transferred to the hospital. Hospitalization was less likely if a do-not-hospitalize GP-order was documented in the file.

This nationwide study provides a valid estimate of the hospitalization of dying nursing home residents with dementia in Belgium (Flanders) and provides an insight into the reasons for hospitalizations, those involved in the decision to hospitalize and whether information about the resident was transferred to the hospital. Many of these issues had not previously been examined on a national scale. Factors associated with the risk of hospitalization were also examined. Using a retrospective design allowed us to study a population-based sample of deaths on a nationwide level and identify a study population of residents with dementia [24]. The realized sample was representative for age compared with the Flemish population of nursing home residents with dementia but not for sex, though sex was not associated with hospitalization risk in our findings. Hospitalizations may be underestimated because of recall bias, since the median time between the resident's death and the completion of the questionnaire was more than two months. However, the questionnaire related only to the last month of life and nurses had access to the resident's file when completing the questionnaire. Furthermore, since the average number of deceased residents with dementia per nursing home was less than three, providing care to these residents is not an every-day experience for responding nurses. Due to the cross-sectional design of the study, a causal relationship between the presence of a do-not-hospitalize GP-order and being hospitalized cannot be concluded with certainty. Our findings may not apply to other European countries with different health care systems.

Although the hospital death risk for Belgian nursing home residents has declined significantly in the previous decade [8], this study shows that the hospitalization in the last month of life among nursing home residents with dementia is still considerable. Hospitalizations of nursing home residents with advanced dementia, mostly for suspected infection or pneumonia, are often avoidable and appropriate care can be offered in the nursing home [12, 25]. A possible exception is the treatment of a fracture, where it is often assumed that hospitalization is needed. Nevertheless, some residents may prefer to be hospitalized at the end of life.

No hospitalization took place at the request of residents and residents were rarely involved in the decision to hospitalize. This can be partially explained by the cognitive impairment of the deceased residents, although not all hospitalized residents were completely lacking capacity at the time of hospitalization and more could possibly have been involved in the hospitalization decision. Timely communication with the resident about preferences for future care, including hospitalization, may enhance the residents' involvement. Patient-written do-not-hospitalize advance directives may be less suitable to involve nursing home residents in decision making, previous research shows that the prevalence of such orders in Belgian nursing homes is low, as was the case in our sample [26].

Worryingly, none of decisions to hospitalize involved the in-house palliative care consultants of the nursing homes although a large majority of residents were receiving palliative care; no hospitalizations took place because the resident needed palliative treatment. This may indicate that many hospitalizations were unplanned and uncoordinated and perhaps took place in the context of an acute medical crisis. Unplanned hospitalizations may happen out of hours or during weekends or when care is temporarily provided outside the nursing home. We found that in four of the hospitalizations a GP on call was involved, replacing the resident's GP out of hours or during weekends, and in two hospitalizations an external hospital hemodialysis centre took the hospitalization decision.

In almost all cases information about the resident was transferred to the hospital, and almost always this was done in writing. Unfortunately, information on activities of daily living or the resident's wishes or preferences for future care were transferred to a much lesser extent than the reasons for hospitalization or information about nursing care or medical treatment. In only two of the eight cases of hospitalized residents with personal written advance directives were these transferred at the time of admission. This may indicate that written advanced directives were inaccessible at the time of hospitalization [27, 28].

The presence of a do-not-hospitalize GP-order in the resident's file was the only factor that was independently related to a lower risk of being hospitalized. In a cohort study in nursing home residents with advanced dementia in the US it was also shown that lack of such an order was associated with hospital transfer [12]. These orders are usually established in consultation between the resident's GP, the relatives and other professional caregivers; it is unusual that the resident is involved [26]. Our results show that these GP-orders, rather than personal written advance directives, shape the resident's care, in particular in relation to hospitalization at the end of life [26]. However, having an advance directive was associated with decreased risk of burdensome transitions in a nationwide US study in nursing home residents with cognitive impairment [11]. In Flemish nursing homes, advance directives of demented residents may not have been adhered to because they were overruled by the medical judgment of the general physician or the influence of relatives [29].

In US studies in nursing home residents with dementia hospitalization was common, with hospitalizations or burdensome transitions in the last months of life ranging between 16% and 25% [9-11]. This indicates that even in very different health care systems the continuation of care in the nursing home of residence until the end of life is hampered. Several US studies on the risk factors for hospitalization of nursing home residents with and without dementia show that the staffing of nursing homes is an important factor. Higher availability of qualified nurses and training programmes for care assistants has been shown to reduce the risk of hospitalization [25,30,31] as has the availability of a dementia special care unit [9]. Overburdening of nursing staff or high turnover were found to be risk factors for hospitalization [32,33].

A priority issue for health care professionals is timely communication with residents and their family caregivers about the circumstances and conditions surrounding future hospitalizations. The conclusions should be documented in the resident's medical file and made easily accessible to all caregivers, especially those who are only occasionally involved in their care. Health care systems will need to provide funding for a sufficiently large, well trained and motivated workforce in nursing homes.

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PART III

ADVANCE CARE PLANNING AMONG NURSING HOME RESIDENTS WITH DEMENTIA

CHAPTER 6:

ADVANCE CARE PLANNING AND PHYSICIAN ORDERS IN NURSING HOME RESIDENTS WITH DEMENTIA: A NATIONWIDE RETROSPECTIVE STUDY AMONG PROFESSIONAL CAREGIVERS AND RELATIVES

An Vandervoort, Dirk Houttekier, Lieve Van den Block, Jenny T. van der Steen, Robert Vander Stichele, Luc Deliens

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ABSTRACT

CONTEXT/OBJECTIVE

Advance care planning (ACP) is key to good palliative care for nursing home residents with dementia. We examined the extent to which family physicians (FP's), nurses and the relative most involved in the resident's care are informed about ACP, written advance directives (AD) and family physician treatment orders (FP-orders) of nursing home residents dying with dementia. We also examined the congruence between FP, nurse and relative about the content of ACP.

METHODS

Representative nationwide post-mortem study (2010) using random cluster-sampling, Flanders Belgium. In selected nursing homes, all deaths of residents with dementia in a three month period were reported. A structured questionnaire was completed by the nurse, FP and the relative.

RESULTS

We identified 205 deceased residents with dementia in 69 nursing homes. Residents expressed their wishes regarding end-of-life care in 11.8% of cases according to the FP. The FP and nurse spoke with the resident in 22.0% and 9.7% respectively and with the relative in 70.6% and 59.5%. An AD was present in 9.0% of cases according to the FP, in 13.6% according to the nurse and in 18.4% according to the relative. FP-orders were present in 77.3% according to the FP, discussed with the resident in 13.0% and with the relative in 79.3%. Congruence was fair (nurse-FP) on the documentation of FP-orders (k=0.26), poor to slight on the presence of an AD (FP-relative k=0.03, nurse-relative k=-0.05, FP-nurse k=0.12).

CONCLUSION

Communication regarding care is rarely patient-driven and more often professional caregiver- or family-driven. The level of congruence between professional caregivers and relatives is low.

INTRODUCTION

Patient-centered advance care planning (ACP) is a communication process between the resident and his/her care providers, which may involve family or friends, about the goals and desired direction of care at the end of life in the event that the resident loses the capacity to make decisions[1, 2]. ACP is one of the key ingredients of the quality of palliative care for nursing home residents, in particular for those with dementia who are often not able to express their preferences at the end of life[3].

Research to date has tended to focus on written outcomes of ACP, such as written advance directives, living wills and the appointment of a durable power of attorney[4-8]. However, communication about future care does not always result in a written record but may just as well involve conversations with residents, or residents expressing their wishes to professional caregivers. Verbal communication has received little attention so far although it may be more common than written ACP communication.

Due to the progressive nature of the disease, residents with dementia face a threshold in their ability to engage meaningfully in the advance planning of their own care[9]. Ideally the resident, their family and professional caregivers will have discussed the desired direction of care and/or have made written plans about future care in the last phase of life but this is not always the case. On the contrary, family physician treatment orders (FP-orders) are very common in such cases[10]. FP-orders are usually documented in the resident's medical file and may be discussed with other professional caregivers, relatives or with the resident but only when they have been discussed with the resident themselves can they be considered as patient-centered ACP. Their prevalence and content has not been studied extensively before.

Decision-making about care of people with dementia residing in nursing homes is complex and involves the residents, who may have expressed or documented their wishes, their FPs, the nursing home nurses and their relatives/friend. Ideally there would be consensus about what has been discussed with the resident and about the future direction of care. Therefore it is relevant to examine the level of congruence among those involved in care about the existence of verbal ACP communication and the decisions documented in ADs and FP-orders. So far, however, research has focused on the level of congruence between patients and health care proxies[11, 12]. To describe the final phase of life in a representative sample of deaths, it has been recommended to use a retrospective study design[13, 14].

The purpose of this study was to examine, using data from a representative nationwide survey:

- the extent to which FPs, nurses and relatives are involved in ACP communication, and informed about the existence and content of written advance directives and FP-orders for the care
- the level of congruence between FPs and nurses about the content of FP-orders for end-of-life care placed in the resident's medical record
- the level of congruence between FPs, nurses and relatives about the content of the resident's written advance directives

METHODS

STUDY DESIGN

Data were obtained from the Dying Well with Dementia study (2010), a post-mortem study of nursing home residents dying with dementia in Flemish nursing homes. Different questionnaires were completed by the nurse most involved in the resident's care; the family physician (FP) and the relative who is a family member or friend closely involved in the resident's care. In Belgian nursing homes, care for residents is mainly managed by their own FP. Additionally, each nursing home has a coordinating and advisory physician responsible for overall policy but, in principle, not for the care of individual patients. Nursing care is provided by skilled nurses, available 24-hours a day. Specialist palliative care in the form of consultations is provided mainly by in-house qualified palliative care reference nurses.

A detailed description of the study design is provided elsewhere. The study protocol was approved by the Medical Ethical Committee of UZ Brussel (University Hospital Brussels).

STUDY FACILITIES/SELECTION OF STUDY SUBJECTS

All deaths from a random sample of Flemish nursing homes were recorded in 2010, stratifying homes by region (five provinces) and subsequently by bed capacity (up to 90 or more than 90) and ownership (public, private/nonprofit, private/profit).

Nursing home residents with dementia who had died in the last three months were retrospectively identified from all nursing home deaths using a two-stage screening protocol:

1) the nursing home administrator identified residents who met the category Cdementia ie 'being completely care dependent for bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space' OR disorientation in time and space (KATZ≥3) ie 'having a problem almost daily with orientation in time and space'. These criteria are used by the Belgian health care insurance system to allocate financial resources[15].
2) NH residents were also required to 'have dementia' or to have been 'diagnosed with dementia' as indicated by the nurse or FP.

DATA COLLECTION

A letter introducing the research project and asking for participation was sent to the board of directors and the "coordinating and advisory physician" of each selected nursing home. In cases of no reply, the researcher contacted the nursing home after two weeks. In each participating home, the board of directors appointed one contact person for the study (ie nursing home administrator or head nurse). The researcher visited each nursing home and assisted the contact person in identifying eligible residents, the nurse who was most closely involved in resident's care, the resident's FP and the relative most closely involved in the resident's care.

The nurse, FP and nursing home administrator were sent a structured standardized questionnaire no later than three months after the death. If the identified nurse was not willing to cooperate, the head nurse was asked to fill in the questionnaire. Non-responders received a reminder after three weeks, with the administrator as a mediator to guarantee anonymity. The relatives received the questionnaire not earlier than two weeks after the resident's death. It has been shown that there is no difference in distress or response rate for the family at two weeks in comparison with a period of six weeks[16].

QUESTIONNAIRES

The FP, nurse and relative questionnaires included the following types of ACP communication (verbal/writing) about a resident's future care:

Verbal:

Resident had expressed views to the FP, nurse, the relative about his/her preferences for medical treatment at the end of life

- FP, nurse or relative had spoken with the resident about his/her preferences for medical treatment or the goals of care at the end of life
- FP or nurse had spoken with the relative about the resident's preferences for medical treatment or the goals of care at the end of life
- In writing:
- Resident had one or more written advance directives

- Resident had authorized a proxy to take decisions about treatment in the case of loss of capacity
- FP had added orders to the resident's medical file about future medical treatment. These orders may have been discussed with the resident, relative or another professional caregiver.

The written advance directives or FP-orders considered were:

- Do-not-hospitalize
- Do-not-resuscitate
- Do-not-intubate
- The withholding/withdrawing of artificial food and/or fluids
- Withholding/withdrawing other treatments
- Withholding/withdrawing antibiotics
- Euthanasia (ie administration of a lethal drug at the explicit request of the resident)
- Terminal sedation (ie using medication to keep the resident unconscious until death)
- Trying all life-prolonging treatments
- Other

STATISTICAL ANALYSES

Descriptive results are presented in frequency tables and contingency tables. Bivariate associations were tested using chi²-tests. Levels of congruence about a resident's written advance directives and FP-orders in their medical file were examined using Cohen's Kappa (rule of thumb <0 poor congruence,0.0–0.20 slight congruence,0.21–0.40 fair congruence,0.41–0.60 moderate congruence,0.61–0.80 substantial congruence,0.81–1.00 almost perfect congruence[17]).

To assess representativity we compared our sample with the population of nursing home residents dying with dementia insured by the two largest insurance companies in Flanders insuring more than 70% of the population (other data were not available).

Since we obtained high response rates for the nurses' and nursing home administrators' questionnaires, we were able to perform a thorough non-response analysis to assess a possible non-response bias. We compared responding with non-responding FPs and responding with non-responding family carers on several important characteristics assessed in the nurses' and nursing home administrators' questionnaires.

RESULTS

SAMPLE DESCRIPTION

Sixty nine nursing homes (58% response rate) participated, representative of all nursing homes in Flanders. Participating nursing homes had on average 101 beds, had on average 1 palliative care reference nurse in their staff and 72.9% had a special care unit for dementia residents. Almost half or 47.5% had institutional ACP guidelines and 93.2% had individual patient-specific planning forms (eg do-not-resuscitate). Of all identified deceased nursing home residents, 205 had dementia at time of death.

Thirty four percent (34.8%) of all residents with dementia were aged 90 or older and 61.1% were women. According to the nurse, 26.0% of all residents were capable and 34.7% partly capable of medical decision-making at the time of admission. At the time of death, 106 (52.2%) had very severe or advanced dementia, 61 (30.0%) had severe dementia and 36 (17.7%) had moderate or mild dementia (data not shown in table).

FP’s mean age (±SD) was 52.9 ±9.5, 15.0% were women. Nurses mean age was 41.5 ±9.1, 82.7% were women. Relatives mean age was 60.6 ±11.0, 64.6% were women.

Response rates to the questionnaires for FPs were 52.9%, nurses 88.4% and relatives 53.2%. For 15 residents, no relative was known or available, they were excluded from analyses. The median time between death of the resident and reception of the questionnaire was for nurses 65days (interquartile range 37-91days), for the FP 82days (IQR 48-137days) and for relatives 134days (IQR 45-104days).

Age distribution was representative (p-value=0.55) for the population of nursing home residents dying with dementia insured by the two largest insurance companies in Flanders insuring more than 70% of the population (analysis not in table). Male nursing home residents were overrepresented in our sample (p=.02).Non-response analysis showed no differences for important resident (age, gender, length of stay, place of death, cognitive status, disease severity) and care characteristics (end-of-life treatments, nursing care) between participating and non-participating relatives and between FP’s (analysis not in table).

ACP AND FP-ORDERS ACCORDING TO THE FP

When considering medical treatment and the desired direction of care in the last phase of life, residents who died with dementia had expressed their wishes to the FP in 11.8% of cases (n=120, table1). The FP spoke with the resident in 22.0% of cases, more than once in 18.6% and with the relative in 70.6%.

According to the FP, residents had a written advance directive in 9.0% of cases. The most frequent directives were do-not-resuscitate (9.0%), do-not-intubate (8.1%) and do-not-hospitalize (7.2%). A proxy for end-of-life decision-making in case of loss of capacity was appointed in 6.0% of cases.
FP-orders were documented in 77.3% according to the FP. The most frequent orders were do-not-hospitalize (65.5%), do-not-resuscitate (59.7%) and do-not-intubate (48.7%). The FP order was discussed with the resident in 13.0% of cases, with a nurse or the head nurse in 84.8% and with an authorized proxy or relative in 79.3%.

Table 1 Advance care planning and family physician's orders (FP-orders) of deceased nursing home residents with dementia in Flanders, Belgium according to the family physician (FP) (N=120).

	n (%)
Resident expressed wishes to FP concerning medical treatments at end-of-life	
Yes	14 (11.8)
No	99 (83.2)
Don't know	6 (5.0)
FP spoke with resident concerning medical treatments and the desired direction of care in the last phase of life	
Yes, once	4 (3.4)
Yes, more than once	22 (18.6)
No	92 (78.0)
FP spoke with family member or friend concerning medical treatments and the desired direction of care in the last phase of life	
Yes	84 (70.6)
No	35 (29.4)
Resident had a written advance directive according to FP †	
Yes	10 (9.0)
Advance directive concerned	
Do-not-hospitalize	8 (7.2)
Do-not-resuscitate	10 (9.0)
Do-not-intubate	9 (8.1)
Withholding or withdrawing administration of artificial food and/or fluids	7 (6.3)
Withholding or withdrawing other treatments	2 (1.8)
Withholding or withdrawing antibiotics	1 (0.9)
Euthanasia	1 (0.9)
Terminal sedation	1 (0.9)
Try all life-prolonging treatments	0 (0.0)
Resident authorized a proxy for end-of-life decision-making in case of incompetence according to FP	
Yes	5 (4.3)
Yes and FP informed the proxy about issues about the process of dying	2 (1.7)
No	110 (94.0)
FP-orders documented in resident's medical record	
Yes	92 (77.3)
FP-orders concerned†	
Do-not-hospitalize	78 (65.5)
Do-not-resuscitate	71 (59.7)
Do-not-intubate	58 (48.7)
Withholding or withdrawing administration of artificial food and/or fluids	55 (46.2)
Withholding or withdrawing other treatments	23 (19.3)
Withholding or withdrawing antibiotics	23 (19.5)
Euthanasia	2 (1.7)
Terminal sedation	12 (10.1)
Try all life-prolonging treatments	2 (1.7)
According to FP, FP-orders were discussed with †	
Resident	12 (13.0)
Authorized proxy, family member or friend or family member or friend	73 (79.3)
Nurse or head nursing	78 (84.8)
Coordinating and advisory physician (CRA)	21 (22.8)
Palliative expert	3 (3.3)
Other	1 (1.1)

* Missing values are for: resident expressed wishes to FP n=1, FP spoke with resident n=2, FP-orders were discussed with family member or friend n=28, advance directive according to FP n=9, authorized a proxy according to FP n=3, FP spoke with family member or friend n=1, FP-orders documented n=1.

† Multiple answers possible

ACP AND FP-ORDERS ACCORDING TO THE NURSE

Residents expressed their wishes regarding medical treatment and the desired direction of care in the last phase of life to a nurse in 8.2% of cases (n=198,table2). The nurse spoke with the resident in 9.7%, more than once in 5.6% and with a relative in 59.5% of cases.

A written advance directive was present in 13.6% of cases. The most frequent were do-not-resuscitate (11.6%), do-not-hospitalize (11.1%) and the withholding or withdrawing of artificial food and/or fluids (7.1%). A proxy was appointed in 5.4% of cases.

FP-orders were documented in 58.1% of cases according to the nurse. The most frequent orders were do-not-hospitalize (54.0%), do-not-resuscitate (47.0%) and do-not-intubate (35.4%). The FP order was discussed with the resident in 4.0% of cases, with a nurse or the head nurse in 84.8% and with an authorized proxy or relative in 80.8%.

Table 2 Advance care planning and family physician's orders (FP-orders) of deceased nursing home residents with dementia in Flanders, Belgium according to the nurses (N=198) *

	n (%)
Resident expressed wishes to nurse concerning medical treatments at end-of-life	
Yes	16 (8.2)
No	145 (74.0)
Don't know	35 (17.9)
Nurse spoke with resident concerning medical treatments and the desired direction of care in the last phase of life	
Yes, once	8 (4.1)
Yes, more than once	11 (5.6)
No	176 (90.3)
Nurse spoke with family member or friend concerning medical treatments and the desired direction of care in the last phase of life	
Yes	116 (59.5)
No	79 (40.5)
Resident had a written advance directive, according to nurse	
Yes	27 (13.6)
No	171 (86.4)
Advance directive concerned†	
Do-not-hospitalize	22 (11.1)
Do-not-resuscitate	23 (11.6)
Do-not-intubate	13 (6.6)
Withholding or withdrawing administration of artificial food and/or fluids	14 (7.1)
Withholding or withdrawing other treatments	5 (2.5)
Withholding or withdrawing antibiotics	8 (4.0)
Euthanasia	0 .(0.0)
Terminal sedation	0 .(0.0)
Try all life-prolonging treatments	0 .(0.0)
Resident authorized a proxy for end-of-life decision-making in case of incompetence according to nurse	
Yes	7 (3.8)
Yes and nurse informed the proxy about issues about the process of dying	3 (1.6)
No	176 (94.6)
FP-orders documented in resident's medical record, according to the nurse	
Yes	115 (58.1)
FP-orders concerned†	
Do-not-hospitalize	107 (54.0)
Do-not-resuscitate	93 (47.0)
Do-not-intubate	70 (35.4)
Withholding or withdrawing administration of artificial food and/or fluids	67 (33.8)
Withholding or withdrawing other treatments	40 (20.2)
Withholding or withdrawing antibiotics	40 (20.2)
Euthanasia	0 (0.0)
Terminal sedation	6 (3.0)
Try all life-prolonging treatments	5 (2.5)
According to nurse, FP-orders were discussed with†	
Resident	5 (4.0)
Authorized proxy, family member or friend or family member or friend	101 (80.8)
Nurse or head nursing	106 (84.8)
Coordinating and advisory physician (CRA)	35 (28.0)
Palliative expert	39 (31.2)
Other	13 (10.4)

* Missing values are for: resident expressed wishes to nurse n=2, nurse spoke with resident n=3, according to nurse FP-orders were discussed with family member or friend =73, written advance directive according to nurse n=0, authorized a proxy according to nurse n=12, nurse spoke with family member or friend n=3, FP-orders documented according to the nurse n=0.

† Multiple answers possible

ACP AND FP-ORDERS ACCORDING TO THE RELATIVE OR FRIEND

According to the relative the FP or nurse spoke with the resident in 35.6% of cases (n=101, table3) and with a family member or friend in 61.4%.

The relative was aware of a written advance directive being present in 18.4% of cases. Most frequent directives were do-not-resuscitate (9.2%), do-not-hospitalize (12.2%) and the withholding or withdrawing of artificial food and/or fluids (4.1%). A proxy for end-of-life decision-making was appointed in 10.0% of cases.

Table 3 Advance care planning and family physician's orders (FP-orders) of deceased nursing home residents with dementia in Flanders according to the relative or friend (N=101)

	n (%)
FP or nurse spoke with family member or friend concerning medical treatments at end-of-life	
Yes	62 (61.4)
Resident spoke with family member or friend or someone else concerning medical treatments and the desired direction of care in the last phase of life	
Yes	12 (11.9)
No	84 (83.2)
Don't know	5 (5.0)
FP or nurse spoke with resident, according to family member or friend concerning medical treatments and the desired direction of care in the last phase of life	
Yes	36 (35.6)
No	40 (39.6)
Don't know	25 (24.8)
Resident had a written advance directive, according to family member or friend †	
Yes	18 (18.4)
No	79 (80.6)
Advance directive concerned	
Do-not-hospitalize	12 (12.2)
Do-not-resuscitate	9 (9.2)
Do-not-intubate	2 (2.0)
Withholding or withdrawing administration of artificial food and/or fluids	4 (4.1)
Withholding or withdrawing other treatments	2 (2.0)
Withholding or withdrawing antibiotics	1 (1.0)
Terminal sedation	0 (0.0)
Try all life-prolonging treatments	3 (3.1)
Resident had an written advance directive regarding euthanasia, according to family member or friend	
Yes	1 (1.0)
Written advance directive regarding euthanasia was applicable in case of †	
Incurable condition	1 (100.0)
Persistent and unbearable physical or psychological suffering that cannot be alleviated	1 (100.0)
When death was imminent	1 (100.0)
Coma	0 (0.0)
Advanced dementia	0 (0.0)
Euthanasia under no circumstances	0 (0.0)
Resident authorized a proxy for end-of-life decision-making in case of incompetence, according to family member or friend	
Yes	10 (10.0)

* Missing values are for: FP or nurse spoke with family member or friend n=0, resident spoke with family member or friend n=0, FP or nurse spoke with resident n=0, resident had a written advance directive n=3, written advance directive regarding euthanasia n=0, advance directive regarding euthanasia was applicable in case of n=0, resident authorized a proxy n=1.

† Multiple answers possible

FP AND NURSE CONGRUENCE ABOUT ACP AND THE CONTENT OF FP-ORDERS

Cases were included in analysis when all data from the FP and the nurse was available (n=113, table 4). There was fair congruence on the documentation of FP-orders in the resident's medical record, (k=0.26). Regarding the content of FP-orders congruence was poor to slight, congruence was highest on do-not-hospitalize orders (k=0.22) and withholding or withdrawing artificial food and/or fluids (k=0.20). Congruence on who had been involved in the decision-making leading to the FP-orders was poor to moderate, congruence was highest on the involvement of an authorized proxy and relative (k=0.48) and lowest on the involvement of the resident (k=-0.03).

Table 4 Level of congruence between family physician (FP) and nurse about advance care planning and the content of family physician's orders (FP-orders) documented in the resident file of deceased nursing home residents with dementia in Flanders, Belgium (N=113)*

	According to FP n (%)	According to Nurse n (%)	Cohen's Kappa ‡
FP documented orders in resident's medical record			
Yes	85 (75.9)	65 (58.0)	0.26
No	27 (24.1)	47 (42.0)	
Content of FP-orders in resident's medical record			
Do-not-hospitalize	71 (63.4)	60 (53.6)	0.22
Do-not-resuscitate	65 (58.0)	52 (46.4)	0.14
Do-not-intubate	52 (46.4)	36 (32.1)	0.08
Withholding or withdrawing administration of artificial food and/or fluids	49 (43.8)	40 (35.7)	0.20
Withholding or withdrawing other treatments	19 (17.0)	20 (17.9)	0.04
Withholding or withdrawing antibiotics	19 (17.1)	17 (15.3)	-0.060
Euthanasia	2 (1.8)	-	-
Terminal sedation	10 (8.9)	5 (4.5)	0.08
Try all life-prolonging treatments	2 (1.8)	2 (1.8)	-0.02
FP-orders discussed with			
Resident	6 (9.7)	1 (1.6)	*-0.03*
Authorized proxy, family member or friend or family member or friend	52 (83.9)	51 (82.3)	0.48
Nurse or head nursing	54 (87.1)	52 (83.9)	-0.17
Coordinating and advisory physician (CRA)	14 (22.6)	18 (29.0)	0.50
Palliative expert	2 (3.2)	18 (29.0)	0.05
Other	-	6 (9.7)	-

* Missing values are for FP-orders n=1, for FP-orders were discussed with n=51.

† Cases that were answered as "don't know" were recoded as missing values (for nurse n=35, for FP n=6).

‡ Cohen's Kappa (rule of thumb < 0 poor congruence, 0.0 – 0.20 slight congruence, 0.21 – 0.40 fair congruence, 0.41 – 0.60 moderate congruence, 0.61 – 0.80 substantial congruence, 0.81 – 1.00 almost perfect congruence [17])

FP, NURSE AND RELATIVE CONGRUENCE ABOUT ACP AND THE CONTENT OF FP-ORDERS

Cases were included in analysis when all data from the FP, nurse and relative was available (n=66, table5). The level of congruence on the presence of a written advance directive was slight for the FP-family pair (k=0.03) and FP-nurse pair (k=0.12) and poor for the nurse-family pair (k=-0.05). Regarding the content of written advance directives the congruence was slight to fair for the FP-family pair and the FP-nurse pair (respectively do-not-hospitalize k=0.03 and k=0.23, do-not-resuscitate k=0.07 and k=0.16, do-not-intubate k=0.21 and k=0.17, withholding or withdrawing administration of artificial food and/or fluids k=0.25 and k=0.13). Congruence on the content of written advance directives for the nurse-family pair was slight to poor (do-not-hospitalize k=0.04, do-not-resuscitate k=-0.10, do-not-intubate k=-0.02, withholding or withdrawing administration of artificial food and/or fluids k=-0.05).

The level of congruence on the authorization of a proxy by the resident was moderate for the FP-family pair (k=0.40), poor for the FP-nurse pair (k=-0.09) and slight for the nurse-family pair (k=0.13).

Table 5 Level of congruence between family physician (FP), nurse and the relative or friend regarding written advance directives and the authorization of a proxy of deceased nursing home residents with dementia in Flanders, Belgium (N=66)*

	Congruence FP – Family member or friend			Congruence Nurse – family member or friend			Congruence FP - nurse		
	FP n (%)	Family member or friend n (%)	Cohen’s Kappa †	Nurse N (%)	Family member or friend n (%)	Cohen’s Kappa †	FP n (%)	Nurse N (%)	Cohen’s Kappa †
Resident had a written advance directive									
Yes	10 (17.2)	7 (12.1)	0.03	9 (14.3%)	10 (15.9)	-0.05	7 (11.5)	10 (16.4)	0.12
No	48 (82.8)	51 (87.9)		54 (85.7%)	53 (84.1%)		54 (88.5)	51 (83.6)	
Written advance directive concerned									
Do-not-hospitalize	6 (10.3)	8 (13.8)	0.03	6 (9.5)	8 (12.7)	0.04	6 (9.8)	7 (11.5)	0.23
Do-not-resuscitate	7 (12.1)	5 (8.6)	0.07	7 (11.1)	5 (7.9)	-0.10	7 (11.5)	8 (13.1)	0.16
Do-not-intubate	6 (10.3)	2 (3.4)	0.21	2 (3.2)	2 (1.6)	-0.02	6 (9.8)	3 (4.9)	0.17
Withholding or withdrawing administration of artificial food and/or fluids	5 (8.6)	2 (3.4)	0.25	5 (7.9)	2 (3.2)	-0.05	5 (8.2)	5 (8.2)	0.13
Withholding or withdrawing other treatments	-	-	-	1 (1.6)	-	-	-	2 (3.3)	-
Withholding or withdrawing antibiotics	1 (1.7)	1 (1.7)	1.00	2 (3.2)	1 (1.6)	-0.02	1 (1.6)	2 (3.3)	-0.02
Euthanasia	1 (1.6)	1 (1.6)	1.00	-	1 (1.5)	-	1 (1.6)	-	-
Terminal sedation	-	-	-	-	-	-	-	-	-
Try all life-prolonging treatments	-	-	-	-	-	-	-	-	-
Resident authorized a proxy									
Yes	6 (9.2)	7 (10.8)	0.40	4 (6.8)	6 (10.2)	-0.09	6 (10.3)	4 (6.9)	0.13
No	59 (90.8)	58 (89.2)		55 (93.2)	53 (89.8)		52 (89.7)	54 (93.1)	

* Missing values are for: written advance directive FP and family member or friend n=5, authorized a proxy between FP and family member or friend n=1, written advance directive nurse and family member or friend n=0,
authorized a proxy between nurse and family member or friend n=7, written advance directive nurse and family member or friend n=5, authorized a proxy between nurse and family member or friend n=8.

† Cohen’s Kappa (rule of thumb < 0 poor congruence, 0.0 – 0.20 slight congruence, 0.21 – 0.40 fair congruence, 0.41 – 0.60 moderate congruence, 0.61 – 0.80 substantial congruence, 0.81 – 1.00 almost perfect congruence [17])

DISCUSSION

The results of this study suggest that nursing home residents with dementia in Flanders, Belgium have rarely expressed their wishes regarding medical treatment and the direction of their care in the last phase of life (11.8% according to the FP, 8.2% according to nurse). Communication regarding end-of-life care between professional caregivers and nursing home residents is uncommon (22.0% according to the FP, 9.7% according to the nurse), whereas communication between professional caregivers and relatives appears to be more frequent (70.6% according to the FP, 59.5% according to nurse). The level of congruence found between the nurse, FP and relative about the existence and content of ACP and FP-orders is rather low (eg congruence on the presence of an advance directive was poor to slight).

For the first time, this study described in detail the levels of verbal and written communication about future care for nursing home residents dying with dementia, using data from a representative nationwide survey. By performing non-response analyses we were able to compare the characteristics of deceased nursing home residents between responding with non-responding FPs, and relatives. No significant differences were found in demographics, cognition, decision-making capacity, treatment and care.

Residents in the response group were representative for the age distribution of the population of the nursing home residents dying with dementia insured by the two largest insurance companies in Flanders who insure more than 70.0% of the Flemish population. Using the perspective of the nurse, FP and relative we gained a privileged insight into communication at the end of life for nursing home residents dying with dementia. In contrast with other research, our study considered all deceased nursing home residents with dementia regardless of stage.

However, this study also has some limitations. It was retrospective; therefore, memory bias cannot be ruled out, though this was limited by minimizing the time between death and the completion of the questionnaires. Some of our results may be biased because only residents with relatives were included, and those without relatives were excluded from analysis.

Male nursing home residents were overrepresented in our sample (p-value=0.02). Also, in spite of the satisfying response rates, a non-response bias cannot be ruled out. The response rates were acceptable, given that the lowest response rates are higher than the average response rates of physician postal surveys and the response rate of most medical surveys in Belgium[18, 19]. Our findings may not be generalizable to other healthcare systems, where the main professional healthcare professional for nursing home residents with dementia is not the resident's FP, but an in-house nursing home physician as is the case in the Netherlands. Finally, we had to rely on the perspective of the nurse, the FP and the relative/friend, which may have differed from the perspective of the resident.

According to all three groups of respondents, patient-driven ACP is reported less frequently than are FP-orders. Written advance directives (present in one out of ten cases according to the FP and nurse) were reported far less often than FP-orders (present in seven out of ten cases according to the FP and in six out of ten cases according to the nurse). Compared with the US where advance directive completion is highest in nursing homes, completion in Flemish nursing homes is particularly low[20, 21]. Our findings confirm that there is a need for care planning; findings also suggest that it is mainly done at the very end of life through the use of FP-orders[22]. FP-orders have been shown to influence place of death; where an FP-order is documented residents were less often transferred to hospital at the very end of life[22]. The current study found that FP-orders were discussed with the relative (in eight out of ten cases according to the FP and nurse) rather than the resident (in one or less than one out of ten cases according to the FP and nurse). In general, therefore, it seems that FP-orders are rarely generated with the resident's involvement. A possible explanation for the low resident involvement might be that the resident was lacking in capacity and no longer able to express his/her wishes. However our data shows that at the time of nursing home admission 63.7% were capable or partly capable of medical decision-making whereas results suggest that care planning is not done until the very end of life.

Regarding medical treatment and the desired direction of care in the last phase of life, professional caregivers more often communicated with the relative than with the resident (respectively 70.6% vs. 22.0% for the FP and 59.5% vs. 9.7% for the nurse). Passive and active barriers to ACP for people with dementia have been described, such as not realizing the importance of planning until it is too late or avoiding the topic[23]; however, the known trajectory of the condition means that many residents with dementia will progress to an advanced stage where they will no longer be able to communicate their preferences. Nursing home residents with advanced dementia, and also those with severe or with moderate/mild dementia, experience significant clinical complications and distressing symptoms at the end of their life[24] and early communication about these issues is of paramount importance.

Another major finding is that the level of congruence between FPs, nurses and relatives about the content of FP-orders and written advance directives is rather low. Congruence between the FP and the nurse on both the existence of a proxy authorised by the resident and the presence of an FP-order was moderate to fair, but was only slight to poor regarding the actual content of FP-orders and the presence of advance directives. Also FPs more often report the presence of an FP-order which suggests lack of communication, and therefore a possible lack of continuity in care, between professional caregivers. Being informed about the presence and content of FP-orders is important since these are associated with place of death, and the FP is not always present at the time of an acute event[22]. This study also shows that the congruence between the nurses and the relative regarding future care was low.

These results suggest that communication regarding future care is not only limited but also that both decisions and orders are not made jointly, which limits the chance of providing care in accordance with the resident’s wishes.

Given the importance of communication about the end-of-life care of residents with dementia, timely initiation of the communication process should be given priority; our results show that this is not yet the case. Discussions about care seem to take place at the very end of life when the resident has already lost the capacity to take part or is unable to express his or her wishes and relatives/friends have to be consulted. Initiation of end of life discussion could start at home by the FP or shortly after nursing home admission, while many are still (partly) competent and able to be involved. Communication regarding care is more often professional caregiver- or family-driven than patient-driven. Considering the importance of achieving a consensus about what has been discussed with the resident and about the direction that future care should take, initiatives to improve congruence between FPs, nurses and relatives about ACP and the content of FP-orders could assist the complexity of care for nursing home residents dying with dementia.

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CHAPTER 7:

ADVANCE DIRECTIVES AND PHYSICIANS’ ORDERS IN NURSING HOME RESIDENTS WITH DEMENTIA IN FLANDERS, BELGIUM: PREVALENCE AND ASSOCIATED OUTCOMES

An Vandervoort, Lieve Van den Block, Jenny T. van der Steen, Robert Vander Stichele, Johan Bilsen, Luc Deliens.

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ABSTRACT

BACKGROUND

Advance care planning is an important element of high-quality care in nursing homes, especially for residents suffering from dementia who are often incompetent for decision making towards the end of life. The aim of this study is to describe the prevalence of documented advance care planning among nursing home residents with dementia in Flanders, Belgium and associated clinical characteristics and outcomes.

METHOD

All 594 nursing homes in Flanders were asked to participate in a retrospective cross-sectional postmortem survey in 2006. Participating homes identified all residents who had died over the last two months. A structured questionnaire was mailed to the nurses closely involved in the deceased resident's care regarding the diagnosis of dementia and documented care planning ie advance patient directives, authorization of a legal representative and general practitioners' treatment orders (GP orders).

RESULTS

In 345 nursing homes (58% response rate) nurses identified 764 deceased residents with dementia of whom 62% had some type of documented care plan ie advance patient directives in 3%, a legal representative in 8% and GP orders in 59%. Multivariate logistic regression showed that presence of GP orders was positively associated with receiving specialist palliative care in the nursing home (OR 3.10; CI, 2.07 to 4.65). Chances of dying in a hospital were lower if there was a GP order (OR 0.38; CI, 0.21 to 0.70).

CONCLUSIONS

Whereas GP orders are relatively common among residents with dementia, advance patient directives and a legal representative are relatively uncommon. Nursing home residents receiving palliative care are more likely to have a GP order. GP orders may affect place of death.

INTRODUCTION

Advance care planning is an important element of end-of-life care in nursing homes, especially for residents suffering from dementia who often lack the competence to make decisions towards the end of life. Advance care planning (ACP) concerns the discussion with the resident and/or his/her representative about the goals and desired direction of care, particularly end-of-life care, in the event that the resident is or becomes incompetent to make decisions (Mesh Database, 2009). The goal of this early-initiated and ongoing process of communication is to give weight to the resident's values, attitudes and wishes in their end-of-life care (Robinson *et al.*, 2010;Teno, 2003).

Advance care planning can result in the making and documenting of advance directives (ie patient-oriented orders or living wills such as a 'Do Not Attempt Cardiopulmonary Resuscitation' order) or the authorization of a legal representative (ie a surrogate decision-maker who can make decisions for the resident in case of loss of competence) (Dobalian 2006;Martin *et al.*, 1999;Silveira *et al.*, 2010). In addition to these patient-driven directives, a resident's end of life can also be determined by physicians' treatment orders such as GP orders, which are instructions from the general practitioner placed in in the resident's medical file governing the use of specific treatments towards the end of life. These GP orders can be seen as part of the general care planning process in nursing homes, providing a plan for current and continuing health care. They can be written in discussion with the individual or can be completed for an individual who lacks capacity in their best interest. (The National End of Life Care Programme, 2007;The National End of Life Care Programme, 2010). In Belgium, they are not legally binding, and advisory only. (Belgisch Staatsblad 22 juni 2002 [Belgian official collection of the laws June 22], 2002).

Previous studies on advance care planning in the nursing home have not distinguished between these three forms of care planning and have reported mostly on the nursing home population as a whole (Allen *et al.*, 2003;Brown 2002;Cantor *et al.*, 2004;Daaleman *et al.*, 2009;De Gendt *et al.*, 2010b) rather than specifically on nursing home residents living with dementia. However, advance care planning is of particular importance for residents with dementia because of the progressive nature of the illness. Most individuals with dementia will decline into a state in which they can no longer communicate their treatment wishes (Triplett *et al.*, 2008). Further, earlier research mainly concerned US studies focusing on patient oriented orders such as the completion of living wills

(Bradley *et al.,* 1998;DeLaGarza *et al.,* 2001;Janofsky *et al.,* 1993;Jones *et al.,* 2011;McAuley *et al.,* 2006;Monturo *et al.,* 2007). Furthermore, where existing research does focus on individuals with dementia, it is mostly restricted to the study of do-not-hospitalize and do-not-resuscitate orders (Dautzenberg *et al.,* 1996;Dobalian 2006;Lamberg *et al.,* 2005a;Lambourne *et al.,* 2001;Levy *et al.,* 2005;Maust D.T. *et al.,* 2008;Messinger-Rapport *et al.,* 2005;Mitchell *et al.,* 2007;Sulmasy *et al.,* 2004), whereas wishes about other important medical decisions such as intensifying pain and symptom management, palliative sedation, forgoing food and fluids, antibiotics or other treatments, have been addressed in only a studied limited to a few studies (Triplett *et al,* 2008). Finally, we identified only one study that addressed the association between advanced directives and quality of care where the completion of an AD was associated with greater use of hospice and fewer concerns with communication. However this study was not dementia specific and limited to the US (Teno *et al.,* 2007).

Therefore this study addresses the prevalence and some associated outcomes of these advance directives, authorization of a legal representative and GP treatment orders among deceased nursing home residents with dementia in Flanders, Belgium. Our research questions are:

- what is the prevalence and content of advance directives, authorization of a legal representative and general practitioner treatment orders among deceased nursing home residents with dementia in Flanders, Belgium?
- are patient characteristics and the provision of palliative care associated with the presence of advance directives or GP orders?
- is place of death and quality of dying associated with the presence of an advance directive or GP order?

METHODS

DESIGN AND RESEARCH PROCEDURE

A retrospective cross-sectional postmortem survey was conducted in nursing homes in Flanders, the Dutch-speaking part of Belgium where about 60% of the Belgian population lives (approximately six million people). All nursing homes for elderly people recognized as high care nursing homes (N=594) were approached using contact information from the Flemish Ministry of Health. The treating physician in these homes is the resident's general practitioner.

The administrator of each nursing home received a questionnaire asking them to report the number of residents who had died during September and October 2006 (recall period of maximum 2 months). (De Gendt *et al*, 2010b) and to pass a structured questionnaire for each of these deceased residents to the nurse mostly involved in that resident's care, or to the head nurse if no nurse could be identified. The questionnaires were accompanied by a letter of recommendation, signed by six nursing home umbrella organizations. Non-responders received a follow-up letter one month later. If there was still no response after three weeks, a telephone call was made. The Medical Ethical Commission of the UZ Brussel (University Hospital of Brussels) approved of the study (De Gendt *et al*, 2010b). Anonymity was guaranteed for residents and respondents.

As was described in a previous publication (De Gendt *et al.*, 2010a) nurses reported 1,240 deaths of residents in 345 Flemish nursing homes (58% response rate). To identify residents with dementia, we asked the nurse whether this resident was diagnosed with dementia and if so its severity, with the response options 'moderate' and 'severe'. Where this question was unanswered (N=68) the case was not included in this study. The total number of deceased residents with dementia was 764. Sex and age characteristics of our sample were compared with sex and age characteristics of nursing home deaths in a representative death certificate study in 2001 in Flanders. There were no significant differences (data not shown in tables).

The nurse most closely involved in the deceased resident's care filled in a structured questionnaire surveying:

- the resident's characteristics at time of death e.g. age, gender, level of dependency, having an involved friend or family caregiver, activities of daily living based on a modified version of the Katz ADL scale (Katz 1983), the Belgian Evaluation Scale for Activities of Daily Living (BESADL) a federally mandated and validated instrument used by Belgian health insurance institutions to allocate finances to each nursing home. Resident dependency is based on bathing, dressing, transfer, toileting, continence, eating and disorientation in time and space. In contrast to the original scale, each function has four instead of three possible scores and, capitals O (lowest dependency), A, B, and C (highest dependency) are assigned on the basis of a combination of scores. (Aerneart *et al.,* 1999;Paquay *et al.,* 2004)

- documentation of the resident's wishes in an advance patient directive (i.e. advance treatment directive or authorization of a legal representative in a written living will in case the resident loses competence)
- documentation in the resident's file of GP treatment orders regulating the use of specific treatments at the end of life
- whether death was expected or not
- provision of palliative care by the GP, nursing home caregivers, a palliative home care team and/or by a hospital
- symptom presence in the last week of life, as measured by the Edmonton Symptom Assessment Scale (0, absence of symptoms; 10, worst possible symptom presence) (Chang *et al.,* 2000). Results concern patients with a score > 4 on each symptom. A cut of 4 is generally presumed to indicate a clinically relevant symptom score (Parker *et al.,* 2004).
- estimated quality of life during the last week of life assessed on a 7-point Likert scale (1, very poor; 7, excellent) and mildness of death assessed on a 7-point Likert scale (1, not mild death; 7, mild death) (Van den Block L. *et al.,* 2007b).
- place of death

STATISTICAL ANALYSIS

All analyses were performed with PASW statistical software, version 17.0 (SPSS Inc., Chicago, IL). Shown cut-off scores are >4 for the ESAS, the estimated quality of life and mildness of death. Differences in distribution were calculated using Chi Square Tests. We used multivariate logistic regression (stepwise conditional) analysis to calculate odds-ratios correcting for resident characteristics, palliative care and other variables significant in the bivariate analysis. For table 3, we examined associations between a documented care plan (dependent variable) and resident characteristics, palliative care and other outcomes (independent variables). For table 4, we examined associations between a documented care plan (independent variable) and resident outcomes (dependent variables).

RESULTS

Of all 764 residents dying with dementia, 285 (37.3%) had moderate and 479 (62.7%) severe dementia.

RESIDENT CHARACTERISTICS

Of all residents dying with dementia, 59.8% were 85 years or older at time of death, 72.4% were female, 93.8% had an involved friend or family caregiver while in the nursing home (Table 1). Of all residents dying with dementia, 83.9% (74.6% for moderate dementia; 89.4% for severe dementia) died in the nursing home as opposed to the hospital or palliative care unit (16.1%). Compared with residents with moderate dementia, those with severe dementia were more likely to have died in the nursing home.

Table 1. Characteristics of Decaesed Residents with Moderate and Severe Dementia in Flemish Nursing Homes

Resident Characteristics*	N (%) Residents with Moderate Dementia (n=285)	Residents with Severe Dementia (n=479)	Total (n=764)	P Value †
Age (years)				0.645
<80	45 (16.1)	85 (18.0)	130 (17.3)	
80-84	59 (21.1)	113 (23.9)	172 (22.9)	
85-89	66 (23.7)	116 (24.5)	182 (24.2)	
90-94	67 (24.0)	100 (21.1)	167 (22.2)	
≥ 95	42 (15.1)	59 (12.5)	101 (13.4)	
mean	86.7	86.0	86.3	
Gender				0.370
Male	84 (29.5)	126 (26.5)	210 (27.6)	
Female	201 (70.5)	350 (73.5)	551 (72.4)	
Having an involved friend or family caregiver				0.042
Yes	272 (96.1)	440 (92.4)	712 (93.8)	
No	11 (3.9)	36 (7.6)	47 (6.2)	
Activities of Daily Living (KATZ)				<0.001
Independent (O)	5 (1.9)	2 (0.4)	7 (1.0)	
Little dependent (A)	16 (6.1)	1 (0.2)	17 (2.4)	
Dependent (B)	43 (16.3)	28 (6.1)	71 (9.9)	
Severely dependent (C)	68 (25.8)	30 (6.6)	98 (13.6)	
Severly dependent and mostly demented (Cd)	132 (50.0)	395 (86.6)	527 (73.2)	
Treating GP was treating physician before nursing home admission				0.400
Yes	214 (75.6)	371 (78.3)	585 (77.3)	
No	69 (24.4)	103 (21.7)	172 (22.7)	
Treating GP is the coordinating and advisory physician of the nursing home				0.890
Yes	50 (17.7)	86 (18.1)	136 (17.9)	
No	233 (82.3)	390 (81.9)	623 (82.1)	
Place of death II				<0.001
Nursing home	212 (74.6)	428 (89.4)	640 (83.9)	
Hospital or palliative care unit	72 (25.4)	51 (10.6)	123 (16.1)	

* Missing values for age n=12, for gender n=3, for involved friend or family caregiver n=5, for KATZ-scale n=44, for GP n=7, for CRA is treating GP n= 5, place of death n=1.

† Differences are tested using Chi-Square, significance level at 0.05

PREVALENCE AND CONTENT OF DOCUMENTED CARE PLANNING

Table 2 shows that 61.7% of the deceased nursing home residents with dementia had some type of documented care plan.

An advance patient directive was present in 10.3% of cases . A legal representative was appointed in 8.1% of cases and an advance treatment directive in 3.2% of cases. The most frequent treatment directives were do-not-hospitalize (2.5%) and do-not-resuscitate orders (2.1%).

GP orders were reported in 59.2% of which the most frequent were do-not-hospitalize orders (46.3%), do-not-resuscitate orders (36.1%) and forgoing artificial flood (30.6%) or fluids (29.5%) orders. For five residents (0.7%) a documented agreement concerning euthanasia was available in the resident’s file.

Advance patient directives were more common among residents with moderate dementia than among those with severe dementia (13.4% vs 8.4%) whereas GP orders were more common among residents with severe dementia than among those with moderate dementia (61.9% vs 54.6%).

Table 2. Prevalence and Content of Documented Care Planning among Deceased Nursing Home Residents with Dementia.

	Residents with Moderate Dementia (N=285)	Residents with Severe Dementia (N=479)	Bivariate P value ‡	Total (N=764)
Documented care planning (total)	158 (58.7)	290 (63.5)	0.298	448 (61.7)
Advance patient directives*	38 (13.4)	40 (8.4)	0.029	78 (10.3)
Advance treatment directives	14 (4.9)	10 (2.1)	0.031	24 (3.2)
Do-not-hospitalise	11 (3.9)	8 (1.7)	0.142	19 (2.5)
Do-not-resuscitate	10 (3.6)	6 (1.3)	0.099	16 (2.1)
Withholding or withdrawing administration of artificial food and/or fluids	9 (3.2)	3 (0.6)	0.024	12 (1.6)
Withholding or withdrawing other treatments	6 (2.1)	1 (0.2)	0.024	7 (0.9)
Withholding or withdrawing antibiotics	3 (1.1)	2 (0.4)	0.146	5 (0.7)
Euthanasia (administration of a lethal drug with the explicit request of the resident)	2 (0.7)	2 (0.4)	0.142	4 (0.5)
Terminal sedation (using medication to keep the resident unconscious until death)	0 (0.0)	1 (0.2)	0.072	1 (0.1)
Authorization of a legal representative	28 (9.8)	34 (7.1)	0.096	62 (8.1)
General practitioner’s orders †	147 (54.6)	283 (61.9)	0.054	430 (59.2)
Do-not-hospitalize	110 (42.1)	220 (48.7)	0.092	330 (46.3)
Do-not-resuscitate	79 (30.6)	177 (39.2)	0.021	256 (36.1)
Forgoing artificial food	65 (25.0)	153 (33.8)	0.014	218 (30.6)
Forgoing artificial fluids	60 (23.1)	150 (33.1)	0.005	210 (29.5)
Forgoing antibiotics	50 (19.5)	99 (22.0)	0.425	149 (21.1)
Forgoing chemotherapy	55 (21.3)	87 (19.4)	0.535	142 (20.1)
Forgoing blood transfusion	41 (15.8)	76 (16.9)	0.715	117 (16.5)
Forgoing haemodialysis	42 (16.2)	65 (14.5)	0.534	107 (15.1)
Alleviation of pain and symptoms knowing that this might shorten the resident’s life	74 (28.5)	155 (35.0)	0.075	229 (32.6)
Terminal sedation (using medication to keep the resident unconscious until death)				
- without artificial food or fluids	39 (15.5)	74 (16.9)	0.634	113 (16.4)
- with artificial food or-fluids	20 (8.1)	27 (6.3)	0.391	47 (7.0)
Euthanasia (administration of a lethal drug with the explicit request of the resident)	3 (1.2)	2 (0.5)	0.266	5 (0.7)

* Missing values for advance patient directives n=2

† Missing values for GP orders n=4.

‡ Chi-square test

CLINICAL CHARACTERISTICS AND PALLIATIVE CARE

Multivariate logistic regression analysis (Table 3) indicates that residents who died unexpectedly were half as likely to have a GP order than those who died expectedly (OR 0.41; CI, 0.23 to 0.73). Residents receiving palliative care from nursing home caregivers or from their GP were respectively three times (OR 3.10; CI, 2.07 to 4.65) and twice (2.06; CI, 1.37 to 3.09) as likely to have a GP order as those not receiving this palliative care. The multivariate logistic regression model comparing residents with and without a patient directive showed no significant results.

Table 3. Patient Characteristics and Palliative Care Provision Associated with the Prevalence of Documented Care Planning among Deceased Nursing Home Residents with Dementia (n=764).

Characteristics *	Residents with dementia (N=764)	Patient Directive			GP Order		
		Patient Directives N (row %)	Bivariate P value¶	Multivariate OR (95% CI) #	GP Order N (row %)	Bivariate P value¶	Multivariate OR (95% CI) #
Age (years)							
<80	130 (17.3)	16 (12.3)	0.835	1.85 0.70-4.93)	78 (62.9)	0.511	1.62 (0.81-3.26)
80-84	172 (22.9)	17 (10.0)		1.41 (0.54-3.72)	89 (54.9)		0.95 (0.50-1.82)
85-89	182 (24.2)	20 (11.0)		1.35 (0.53-3.41)	107 (60.5)		1.03 (0.55-1.92)
90-94	167 (22.2)	14 (8.5)		0.68 (0.23-1.98)	88 (56.1)		0.96 (0.51-1.82)
≥ 95	101 (13.4)	9 (9.0)		1.00 (1.00-1.00)	60 (63.2)		1.00 (1.00-1.00)
Gender							
Male	210 (27.6)	20 (9.6)	0.665	1.00 (1.00-1.00)	110 (56.1)	0.327	1.00 (1.00-1.00)
Female	551 (72.4)	58 (10.6)		1.16 (0.63-2.15)	317 (60.2)		1.20 (0.79-1.82)
Having an involved friend or family caregiver							
Yes	712 (93.8)	78 (11.0)	0.017	**	407 (60.0)	0.077	1.82 (0.89-3.71)
No	47 (6.2)	0 (0.0)			21 (46.7)		1.00 (1.00-1.00)
Stage of dementia							
Moderate	285(37.3)	38 (13.4)	0.029	1.50 (0.83-2.71)	147 (54.6)	0.054	1.27 (0.84-1.94)
Severe	479 (62.7)	40 (8.4)		1.00 (1.00-1.00)	283 (61.9)		1.00 (1.00-1.00)
Activities of Daily Living (KATZ)							
Independent (O)	7 (1.0)	2 (28.6)	0.366	5.08 (0.80-32.18)	5 (71.4)	0.004	4.40 (0.40-49.01)
Little dependent (A)	17 (2.4)	2 (11.8)		1.42 (0.28-7.23)	5 (38.5)		0.67 (0.18-2.56)
Dependent (B)	71 (9.9)	5 (7.0)		0.92 (0.33-2.56)	28 (43.1)		0.84 (0.44-1.59)
Severely dependent (C)	98 (13.6)	11 (11.7)		1.31 (0.59-2.89)	46 (49.5)		0.66 (0.37-1.15)
Severly dependent and mostly demented (Cd)	527 (73.2)	47 (9.0)		1.00 (1.00-1.00)	316 (62.5)		1.00 (1.00-1.00)
Type of death							
Expected death	642 (84.5)	71 (11.2)	0.091	1.00 (1.00-1.00)	401 (65.3)	0.001	1.00 (1.00-1.00)
Unexpected death	118 (15.5)	7 (6.0)		0.57 (0.21-1.54)	26 (24.1)		0.41 (0.23-0.73)
Palliative care provision †							
By the general practitioner	371 (50.7)	44 (11.9)	0.123	1.30 (0.70-2.41)	273 (75.2)	0.001	2.06 (1.37-3.09)
Not by the GP	361 (49.3)	30 (8.4)		1.00 (1.00-1.00)	149 (44.5)		1.00 (1.00-1.00)
By nursing home caregivers ‡	441 (60.2)	51 (11.7)	0.106	1.18 (0.61-2.27)	320 (75.1)	0.001	3.10 (2.07-4.65)
Not by nursing home caregivers	291 (39.8)	23 (8.0)		1.00 (1.00-1.00)	102 (37.5)		1.00 (1.00-1.00)
By palliative home care team	21 (2.9)	2 (9.5)	0.918	0.51 (0.06-4.02)	16 (76.2)	0.134	1.77 (0.47-6.65)
Not by the home care team	711 (97.1)	72 (10.2)		1.00 (1.00-1.00)	406 (60.0)		1.00 (1.00-1.00)
In hospital §	28 (3.8)	2 (7.1)	0.586	0.71 (0.16-3.19)	14 (53.8)	0.482	0.66 (0.26-1.60)
Not in the hospital	704 (96.2)	72 (10.3)		1.00 (1.00-1.00)	408 (60.7)		1.00 (1.00-1.00)

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* Missing values for age n=12, for gender n=3, for involved friend or family caregiver n=5, for stage of dementia n=0, for KATZ-scale n=44, for type of death n=4, for palliative care n=32.

† Multiple responses possible.

‡ Palliative care provided by nursing home caregivers can be a patient discussion performed by a palliative task group, the involvement of a palliative care reference nurse, or the involvement of a coordinating and advisory physician.

§ Palliative care provided in hospital can be the involvement of a mobile palliative care support team of the hospital or being admitted to an inpatient palliative care unit.

¶ Chi-square test

Odds ratios based on logistic regression analysis with the presence of a documented care plan as dependent variable (ref=no documented care plan).

** Involved friend or family caregiver not included in multivariate model. In the GP order model we excluded 18 cases in the reference category (no GP order) because these cases had a patient directive.

PLACE OF DEATH AND QUALITY OF DYING

Bivariate analysis in Table 4 indicates that residents who had a patient directive had significantly more depressive symptoms and shortness of breath (more than 4 on the ESAS scale from 0 to 10) than those without a patient directive. These differences did not remain in the multivariate analyses.

Residents with a GP order were 1.7 times more likely to have a mild death (more than 4 on the ESAS scale from 0 to 10, OR 1.75; CI, 1.09-2.81) than those without a GP order. The odds of dying in a hospital were three times lower if there was a GP order (OR 0.38; CI, 0.21 to 0.70) present.

Separate analyses for advance treatment directives and legal representative showed similar results (not in tables).

Table 4. Association Between Documented Care Planning and Patient Outcomes among Deceased Nursing Home Residents with Dementia

		Patient Directive				GP Order			
Patient Outcomes *	Residents with dementia (N=764)	Patient Directive N (%) #	No Patient directive N (%) #	Bivariate P-Value **	Multivariate OR (95% CI) ††	GP Order N (%) #	No GP order N (%) #	Bivariate P-Value **	Multivariate OR (95% CI) ††
Symptom presence evaluated in last week of life by nurse scored >4 †									
Pain	199 (33.8)	19 (32.2)	178 (33.8)	0.801	0.72 (0.37-1.40)	123 (35.1)	67 (31.3)	0.350	0.88 (0.57-1.36)
Tiredness	388 (66.2)	43 (72.9)	342 (65.3)	0.242	1.08 (0.54-2.15)	245 (70.2)	127 (59.6)	0.010	1.07 (0.69-1.66)
Nausea	86 (14.7)	9 (15.3)	76 (14.5)	0.877	0.55 (0.20-1.51)	57 (16.4)	24 (11.2)	0.091	1.22 (0.65-2.27)
Depression	153 (26.7)	23 (38.8)	130 (25.5)	0.034	1.42 (0.73-2.77)	93 (27.5)	52 (24.6)	0.458	1.06 (0.66-1.72)
Anxiety	213 (36.5)	27 (45.0)	183 (35.1)	0.132	1.38 (0.73-2.58)	138 (39.5)	63 (29.9)	0.021	1.12 (0.72-1.73)
Drowsiness	355 (60.8)	37 (61.7)	315 (60.5)	0.856	0.78 (0.40-1.51)	232 (66.5)	110 (52.1)	0.001	1.13 (0.72-1.76)
Appetite	410 (69.6)	46 (75.4)	361 (68.8)	0.286	1.14 (0.55-2.40)	258 (73.3)	136 (63.8)	0.018	1.10 (0.69-1.75)
Shortness of breath	241 (41.1)	32 (54.2)	206 (39.3)	0.027	1.19 (0.63-2.23)	154 (43.9)	73 (34.6)	0.030	1.49 (0.96-2.32)
Average symptom presence scored >4	285 (49.2)	32 (55.2)	250 (48.3)	0.913	0.97 (0.51-1.86)	188 (54.3)	85 (40.7)	0.002	1.11 (0.66-1.84)
Estimated quality of life during last week by nurse scored >4 ‡	204 (34.1)	20 (32.8)	184 (34.5)	0.787	1.14 (0.58-2.24)	112 (31.5)	84 (38.5)	0.083	1.03 (0.66-1.60)
Mildness of death as estimated by nurse scored >4 §	558 (84.2)	62 (88.6)	495 (84.0)	0.322	1.70 (0.70-4.12)	357 (88.1)	183 (79.2)	0.002	1.75 (1.09-2.81)
Place of death ¶									
Nursing home	640 (83.9)	62 (79.5)	571 (84.2)	0.284	1.00 (1.00-1.00)	406 (94.4)	211 (71.5)	0.001	1.00 (1.00-1.00)
Hospital or palliative care unit	123 (16.1)	16 (20.5)	107 (15.8)		2.09 (0.92-4.72)	24 (5.6)	84 (28.5)		0.38 (0.21-0.70)

* Missing values for place of death n=1, for estimated quality of life n=166, for estimated quality of dying n=101, for pain n=176, for tiredness n= 178, for nausea n= 178, for depression n=191, for anxiety n=180, for drowsiness n=180, for appetite n=175, for shortness of breath n=178, for average symptom presence n=185.

† Edmonton Symptom Assessment Scale , ESAS (0,absence of symptom; 10, worst possible symptom presence) Results concern patients with a score > 4 on each symptom.

‡ Scores were assessed on a 7-point Likert scale (1, very poor; 7, excellent). Results shown concern patients with a score >4.

§ Scores were assessed on a 7-point Likert scale (1, not mild death; 7, mild death). Results concern patients with a score >4.

¶ 7 residents died in a palliative care unit. None of them had a patient directive; two had a GP order.

Column percentages.

** Chi-square test

†† Logistic regression analysis using patient outcomes as dependent variables (reference scores are >4 for all symptoms, mildness of death and quality of life). The presence of a documented care plan is the independent variable (ref=no documented care plan). We controlled for patient characteristics, palliative care and other outcome variables. In the GP order model we excluded 18 cases in the reference category (no GP order) because these cases had a patient directive.

DISCUSSION

The results of this study show that GP orders were relatively common, whereas advance patient directives and the authorization of a legal representative were quite uncommon among deceased nursing home residents with dementia in Flanders, Belgium. In contrast with advance patient directives, GP orders appear to be more frequent among residents with severe dementia than among those with moderate dementia. Receiving palliative care from nursing home caregivers was associated with having a GP order, as was receiving palliative care from the GP; GP orders also appear relevant in affecting place and mildness of death.

A first key finding is the rather low prevalence of documented advance treatment directives among deceased residents with dementia, both moderate (4.9%) and severe (2.1%). Especially when comparing residents with severe dementia with the prevalence found among all deceased nursing home residents in Flanders (5%) (De Gendt *et al.*, 2010a), this result is remarkable, considering that many of these nursing home residents with dementia will lose the ability to make decisions at the end of life. The results correspond with earlier research from the US showing that residents with dementia are less likely to have directives limiting care than cancer residents (Mitchell *et al.*, 2004). Further, the authorization of a legal representative is not common in Belgium (8.1%) despite the fact that almost all deceased nursing home residents with dementia had a support person while in the nursing home. Because persons suffering from dementia are likely to lack the capacity for decision-making at the end of life, planning should start in the earlier stages of dementia while people are competent and able to express values and preferences (Malcomson *et al.*, 2009;Sampson 2010).

This study has some limitations. Firstly, we studied the prevalence of documented care planning only, whereas the quality of the advance care planning process was not investigated, nor was the involvement of the deceased nursing home residents with dementia with their families, or the presence of verbal non-documented agreements. Secondly, since a retrospective research design was used, recall bias cannot be ruled out. However, this was limited by minimizing the time between the resident's death and the completion of the questionnaire. Additionally, we needed to rely on the nurse's judgement of the diagnosis of dementia, assessment of mildness of death and symptom burden, but given that the nurse has a gate-keeping position in the care of nursing home residents and a as main caregiver a privileged insight into the development of the residents' health status, the possibility of misclassifications in dementia severity is probably low. Further previous studies have shown that congruence concerning symptoms or other subjective assessments is not always high between respondents. Finally, we did not survey background information regarding the respondents.

This is the first nationwide study to describe such a diverse range of end-of-life decisions ie non-treatment decisions, intensified alleviation of pain and/or symptom management knowing that this might shorten the resident's life, the use of life-ending drugs with the explicit intention of ending life and terminal sedation, in this population (Daaleman *et al,* 2009). This study is also representative for the whole of Flanders. Also to our knowledge, this study is the first in Belgium to look at the prevalence and associated outcomes regarding documented advance patient directives and GP orders with a focus on nursing home residents with dementia.

Our results further show that patient-driven directives (present in one out of ten cases) are reported far less often than physician-driven orders (six out of ten). The high prevalence of GP orders confirms that some type of care planning regulating end-of-life decision-making seems necessary at the end of life of residents suffering from dementia, but at the same time might indicate that these advance decisions may not always be made in consultation with the resident themselves. It can therefore be assumed that such GP orders are in place only when death of the resident is near or when the resident with dementia is no longer able to participate in the decision-making. Further research should study in more detail how GP orders are established and how often patients are involved in the decision-making process.

Several reasons might explain the low prevalence of patient-driven directives. Dementia is not always formally diagnosed by clinicians (Chodosh *et al.,* 2004;De Lepeleire *et al.,* 1994;Lliffe *et al.,* 2005;Lopponen *et al.,* 2003), disclosed , or recognized as a possibly terminal illness (Chang *et al.,* 2010;Jordan 2010;Wolf-Klein *et al.,* 2007), estimation of life expectancy is difficult (Banerjee 2010;Di Giulio P *et al.,* 2008;Mitchell *et al,* 2004;Sachs *et al.,* 2004) and physicians often hesitate to discuss end-of-life care issues with residents (Brown 2002;Curtis *et al.,* 2000;Deschepper *et al.,* 2006;Eliasson *et al.,* 1999;Meeussen *et al.,* 2011;Tierney *et al.,* 2001). Not only might clinicians be hesitant to start advance care planning conversations but the residents themselves might also wait too long; whether, when and how residents express their wishes seems to be influenced by several intrinsic factors (eg the desire to spare surrogates the burden of difficult decisions) as well as extrinsic factors (eg the resident's declining health) (Black *et al.,* 2009;Deschepper *et al.,* 2008;Fried *et al.,* 2010). On a nursing home level, completion of advance directives can also be influenced by the nursing home culture (Caplan *et al.,* 2006;Levy *et al,* 2005;Mezey *et al.,* 1997;Molloy *et al.,* 2000;Morrison *et al.,* 2005).

The results of our study can also be explained by the rather late implementation of ACP policy in Flemish nursing homes. Attention increased mainly after 2000 resulting in an ACP policy in the majority (95,1%) of nursing homes in Flanders Belgium in 2006 (De Gendt *et al,* 2010b) but apparently leading to more GP orders than patient-driven directives. Our results therefore suggest that advance care planning is not yet a basic part of end-of-life care for residents with dementia in Flemish nursing homes.

Where patient directives or GP orders were present, they mainly concerned the same treatments ie do-not-hospitalize and do-not-resuscitate orders. Prevalence figures for these treatments correspond to figures found in other international studies (Dautzenberg *et al,* 1996;Dobalian 2006;Lamberg *et al.,* 2005b;Maust D.T. *et al,* 2008;Mitchell *et al,* 2007). Other important end–of-life care issues which are prevalent in the treatment of residents with dementia ie use of antibiotics or administration of artificial food and fluids, were only regulated in 1 in 5 cases (Koopmans *et al.,* 2007;Mitchell *et al.,* 2009;van der Steen *et al.,* 2002;van der Steen 2010).

Another main finding is the association between GP orders and the provision of palliative care by the nursing home caregiver and by the GP. Since causality cannot be inferred with certainty from this study, this could either imply that the provision of palliative care leads to more care planning or that the presence of GP orders triggers palliative care provision.

Finally, the association we found between the presence of a care plan and several important resident outcomes is an important result of this study and further strengthens the case for documented care plans. In particular the presence of documented GP orders in a resident's file appears to influence where they will die. When a GP order was present, residents were less often transferred to hospital at the very end of life; this life indicating that residents died in their substitute home ie the nursing home (Mezey *et al.,* 2002;Van den Block L. *et al.,* 2007a). Since most GP orders are do-not-hospitalize orders, the results underline the positive effect of such orders on place of death. We might assume that the decision to forgo hospitalization is based on this order and therefore aides the nursing home staff in their decision-making, since the GP is often not present in the nursing home at the time of an acute event requiring a hospitalization decision. A recent study also showed that terminal hospitalizations decreased when increasing the rate of DNR orders in nursing homes (Teno *et al.*, 2011). The association between patient directives and place of death showed the same tendency but were not significant, probably due to a lack of power.

Also, after controlling for other differences in a multivariate regression analysis, including for the provision of palliative care by the GP and/or nursing home caregivers, deceased nursing home residents with dementia who had a GP order were judged by the nurse to have had a milder death. However, this might be a highly subjective judgment; we found no direct association between GP orders and the more objective assessments of symptom management.

In conclusion, whereas GP orders are relatively common among residents with dementia in Belgium, advance patient directives and the authorization of a legal representative are quite uncommon. Nursing home residents receiving palliative care are more likely to have a GP order. GP orders appear very relevant in affecting place of death.

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CHAPTER 8:

QUALITY OF DYING IN NURSING HOME RESIDENTS DYING WITH DEMENTIA: DOES ADVANCED CARE PLANNING MATTER? A NATIONWIDE POSTMORTEM STUDY

An Vandervoort, Dirk Houttekier, Robert Vander Stichele, Jenny T van der Steen, Lieve Van den Block.

PLoS One (in press)

ABSTRACT

BACKGROUND

Advance care planning is considered a central component of good quality palliative care and especially relevant for people who lose the capacity to make decisions at the end of life, which is the case for many nursing home residents with dementia. We set out to investigate to what extent (1) advance care planning in the form of written advance patient directives and verbal communication with patient and/or relatives about future care and (2) the existence of written advance general practitioner orders are related to the quality of dying of nursing home residents with dementia.

METHODS

Cross-sectional study of deaths (2010) using random cluster-sampling. Representative sample of nursing homes in Flanders, Belgium. Deaths of residents with dementia in a three-month period were reported; for each the nurse most involved in care, GP and closest relative completed structured questionnaires.

FINDINGS

We identified 101 deaths of residents with dementia in 69 nursing homes (58% response rate). A written advance patient directive was present for 17.5%, GP-orders for 56.7%. Controlling for socio-demographic/clinical characteristics in multivariate regression analyses, chances of having a higher mean rating of emotional well-being (less fear and anxiety) on the Comfort Assessment in Dying with Dementia scale were three times higher with a written advance patient directive and more specifically when having a do-not-resuscitate order (AOR 3.45;CI,1.1-11) than for those without either (AOR 2.99;CI,1.1–8.3). We found no association between verbal communication or having a GP order and quality of dying.

CONCLUSION

For nursing home residents with dementia there is a strong association between having a written advance directive and quality of dying. Where wishes are written, relatives report lower levels of emotional distress at the end of life. These results underpin the importance of advance care planning for people with dementia and beginning this process as early as possible.

INTRODUCTION

Advance care planning (ACP) is considered a central component of good quality palliative care and is especially relevant for people who lose the capacity to make decisions at the end of life, which is the case for many nursing home residents with dementia[1–3]. ACP is a communication process between the patient and his/her care providers, which may involve family or friends, about the goals and desired direction of care at the end of life in the event of loss of capacity to make decisions[4,5]. The process of ACP can result in the making of advance directives in writing, often in the form of life-limiting treatment decisions[6,7]. When planning for current and future care, general practitioner (GP) orders are also very common among nursing home residents dying with dementia. In a recent study in Belgium, we found that GP orders consisting of instructions from the GP placed in the resident's medical file governing the use of specific treatments toward the end of life were present in 59% of cases[6].

The advance planning of care can be of particular importance for nursing home residents with dementia considering the loss of decision-making capacity inherent to the disease[2,8–14]. However the beneficial impact on outcomes of ACP – verbal ie spoken or in writing – and of GP orders on the quality of dying is unclear, especially for this disease population. Earlier studies concerning ACP are mostly limited to other patient populations[15] or to studying written advance patient directives only and suggest that advance directives have a low potential for improving patient care[16–19]. Some recent studies do suggest that ACP is associated with the greater use of hospices, less use of life-sustaining treatments such as feeding tubes, lower likelihood of terminal hospitalization, fewer concerns with physician communication and the resident being better informed about the dying process. However, these studies did not focus on residents with dementia[1,9,20–22]. One previous study in Belgium did study nursing home residents with dementia and found that they were less likely to die in hospital if a GP order was present[6]. However, existing research mainly focused on care processes or care utilization and its association with ACP rather than relating different forms of ACP to patient outcomes and quality of dying.

In this study, we investigate to what extent ACP in the form of written advance directives, verbal ie spoken advance communication with patient and/or relatives and the existence of GP orders relate to the quality of dying in nursing home residents with dementia.

METHOD

ETHICS STATEMENT

The research procedures respected privacy/confidentiality of patients and respondents. The study protocol was approved by the Medical Ethics Committee of UZ Brussel (University Hospital of Brussels).

DESIGN

We performed a cross-sectional study of deaths to describe the end of life of nursing home residents dying with dementia, representative for Flanders, Belgium (Dying Well with Dementia study)[2]. All deaths from a random sample of Flemish nursing homes were recorded in 2010, stratifying homes by region (five provinces) and subsequently by bed capacity (up to 90 or more than 90) and ownership (public, private/nonprofit, private/profit).

Questionnaires were completed by the nurse most involved in the resident’s care, the resident’s general practitioner (GP), a family member or friend closely involved in the resident's care, and the nursing home administrator in the case of nursing home residents.

SETTING AND SELECTION OF RESIDENTS

Nursing home residents with dementia who had died in the last three months were identified from all nursing home deaths using a two-stage screening protocol:

3. In the first step residents were included if they met the criteria for (1) ‘category C dementia’ ie ‘being completely care dependent or needing help for bathing, dressing, eating, toileting, continence and transferring plus being disoriented in time and space’, OR (2) disorientation in time and space (KATZ scale ≥3 or having ‘almost daily a problem with disorientation in time and space’)[23].
4. In the second step additional eligibility criteria required that the family physician or nurse indicated that the resident ‘had dementia’ or ‘was diagnosed with dementia’.

MEASUREMENTS

The after-death questionnaires sent to nurses surveyed the socio-demographic characteristics of the person: their health status, care planning and advance care planning communication. Those sent to the relatives used the Comfort Assessment in Dying with Dementia (CAD-EOLD) to measure the quality of dying (see box1 for all measurements).

Box1: Content of after-death questionnaires

DEMOGRAPHICS AND CHARACTERISTICS OF RESIDENTS (by nursing home administrator)

- age, gender
- length of nursing home stay
- whether the residents lived in a special care unit for dementia (ie a closed unit within the nursing home where care is adjusted to the special needs of residents with dementia, sometimes with staff trained in dementia care)
- place of death

HEALTH STATUS

- median survival time after onset of dementia (by the nurse)
- Bedford Alzheimer Nursing Severity-Scale (BANS-S)[24] (by the nurse)
- co-existing conditions (by the GP)
- level of dementia (by nurse and/or GP)

DOCUMENTED CARE PLANNING (by the nurse)

- presence of written advance patient directives
- existence of proxy authorized in writing to take decisions about treatment in the case of loss of capacity
- presence of GP orders (documentation in the resident’s file of GP orders limiting the use of specific treatments at the end of life).

These documents considered the following treatment decisions: do-not-hospitalize, do-not-resuscitate, do-not-intubate, the withholding/withdrawing of artificial food and/or fluids, withholding/withdrawing other treatments, withholding/withdrawing antibiotics, euthanasia (ie administration of a lethal drug at the explicit request of the resident), terminal sedation (ie using medication to keep the resident unconscious until death), trying all life-prolonging treatments, other.

ACP COMMUNICATION about a resident's future care (by the nurse)

- resident expressed wishes to nurse concerning medical treatment at end of life
- nurse spoke with resident concerning medical treatment and the desired goals of care in the last phase of life
- nurse spoke with family member or friend in advance concerning medical treatment and the goals of care in the last phase of life

COMFORT ASSESSMENT IN DYING WITH DEMENTIA (CAD-EOLD, by the relative)[25]

Evaluates the comfort around dying of cognitively impaired persons (three response options 1-3). The total score ranges from 14 to 42 with higher scores indicating better comfort. The four subscales and 14 individual items are:

- Physical Distress: discomfort, pain, restlessness, and shortness of breath
- Dying Symptoms: shortness of breath, choking, gurgling, and difficulty swallowing
- Emotional Distress: fear, anxiety, crying, and moaning
- Well Being: serenity, peace, and calm

For Physical Distress, Dying Symptoms and Emotional Distress the range is from 4 (worst) to 12 (best); for Well-Being from 3 (worst) to 9 (best).

ANALYSES

Analyses were performed with PASW statistical software, 17.0 (SPSS Inc., Chicago, IL). The CAD-EOLD total score is calculated by summing the value of each item. Missing CAD-EOLD items were imputed with the overall residents' mean for that item in cases where there were four or fewer missing scores on the scale. Coding was reversed when applicable such that higher scores represent more comfort.

Descriptive results are presented in frequency tables. Bivariate associations were tested using Mann-Whitney U test (because of the ordinal measurements of the CAD-EOLD items, significance level $p < .05$,). We performed a multivariate ordinal regression (because of non-normal distribution of the residuals) to explore characteristics ie care planning and advance care planning communication (from the nurse) associated with the outcome measure ie Comfort Assessment in Dying with Dementia (CAD-EOLD, from the relative). For the multivariate ordinal regression analyses the CAD-EOLD total score (dependent variable at ordinal level) was categorized into five categories and the subscales scores into four categories based on distribution (reference=highest scores/category or better comfort) and ACP as independent variable (dichotomous, yes or no, reference=no) controlled for age, gender, level of dementia and sentinel events.

RESULTS

SAMPLE DESCRIPTION

Sixtynine nursing homes (58% response rate) participated, representative of all nursing homes in Flanders. Of the 477 deceased nursing home residents, 205 had dementia at the time of death; 15 cases were excluded because there was no relative available[2]. Response rates for questionnaires were nurses 88.4%, GPs 52.9%, nursing home administrators 95.0% and relatives 53.2%[2]. Cases were selected for analysis when both the nurse and the relative questionnaires were completed (n=101). The median time between death of the resident and receipt of the questionnaire was 65 days for nurses (interquartile range 37-91days), 82 days for GPs (IQR 48-137days) and 134 days for relatives (IQR 45-104 days). The realized sample of nursing home residents was representative for age (p-value=0.55) for the population of nursing home residents dying with dementia insured by the two largest insurance companies in Flanders covering more than 70% of the population (analysis not in table). Men were overrepresented in our sample (p=.02). Non-response analysis showed no differences for important resident (age, gender, length of stay, place of death, cognitive status, disease severity) and care (end-of-life treatments, nursing care) characteristics between residents of participating and non-participating GP[2].

At time of death, 51% had very severe or advanced dementia, 25% severe dementia and 24% moderate or mild dementia. Sixty three percent of all residents with dementia were aged 85 or older and 42% were male (Table 1). The median length of stay was 2.1 years. The mean BANS-S score was 20.7. (range from 7 to 28; higher scores indicate greater functional and cognitive disability). The most common co-existing conditions were cardiovascular (41%) and neurological (19%). Place of death was the nursing home in 92%.

The mean CAD-EOLD total score was 29.6 (Table 1). CAD-EOLD subscales scores (mean) for Physical Distress were 8.3, Dying Symptoms 8.1, Emotional Distress 9.2 and Well-Being 6.0.

Table 1. Deceased Nursing Home Residents with Dementia in Flanders, Belgium: Description of the Sample (N=101) *

RESIDENT CHARACTERISTICS	N (%)
Age – yr	
<80	16 (16)
80-84	20 (20)
85-89	26 (27)
90-94	21 (21)
≥95	15 (15)
Gender, male	40 (42)
Median (quartiles) length of nursing home stay (years)	2.1 (1.0-3.7)
Living in special care unit for dementia	50 (53)
Place of death	
Nursing home	88 (92)
General hospital ward or intensive care unit	6 (6)
Palliative care unit	2 (2)
HEALTH STATUS	
BANS-S one month before death (mean ± SD) †	20.7 ±3.7
Co-existing conditions ‡	
Malignant tumour	7 (10)
Cardiovascular	28 (41)
Respiratory	9 (13)
Neurological	13 (19)
Kidney disease	7 (10)
Other	12 (17)
None of the above	13 (19)
Level of dementia	
Moderate or mild dementia	24 (24)
Severe dementia	25 (25)
Very severe or advanced dementia	52 (51)
QUALITY OF DYING ACCORDING TO THE RELATIVE §	mean ± SD
CAD-EOLD total scores ‖	29.6 ±6.4
CAD-EOLD subscales	
Physical Distress	8.3 ±2.3
Dying Symptoms	8.1 ±2.6
Emotional Distress	9.2 ±2.3
Well-Being	6.0 ±1.8
CAD-EOLD individual items	
Discomfort	2.2 ±0.7
Pain	2.0 ±0.8
Restlessness	1.9 ±0.8
Shortness of breath	2.2 ±0.9
Choking	2.1 ±0.8
Gurgling	2.1 ±0.8
Difficulty swallowing	1.8 ±0.8
Fear	2.2 ±0.8
Anxiety	2.1 ±0.8
Crying	2.6 ±0.6
Moaning	2.3 ±0.8
Serenity	2.0 ±0.7
Peace	2.0 ±0.6
Calm	1.9 ±0.7

*Missing values are for age n=3, for gender n=6, LOS n= 5, living in care unit for dementia n=6, BANS-S n=4, co-existing conditions n=32 (of which 31 because no questionnaire was received from the GP), CAD-EOLD n=9.

† Scores on the BANS-S (Bedford Alzheimer Nursing Severity Scale) range from 7 to 28; higher scores indicate greater functional and cognitive disability.

‡ Multiple answers possible

§ CAD-EOLD. All items were (re)coded so that higher scores means better symptoms management.

‖ The CAD-EOLD total score is constructed by summing the value of each item. It ranges from 14 to 42 with higher scores indicating better symptom control.

FREQUENCY OF ACP

A written advance patient directive was present in 17.5% of cases (Table 2). GP orders were reported in 56.7% and they were discussed with the resident in 3.2%. The nurse spoke with the residents concerning medical treatments and the desired goals of care in the last phase of life in 13.7% of cases (Table 3).

ASSOCIATION BETWEEN CARE PLANNING AND QUALITY OF DYING

In tables 2 and 3 the results of multivariate ordinal regression analyses are reported, showing associations between various forms of care planning and quality of dying in the last week of life (using the CAD-EOLD) as reported by the resident's relative. The chances of having a higher ie better rating on the Emotional Distress subscale were three times greater for residents with a written advance patient directive than for those without such a directive (Table 2, Adjusted OR 2.99; CI, 1.1–8.3). A do-not-resuscitate order decreased the chance of experiencing Emotional Distress in the last week of life compared with not having a do-not-resuscitate order (Adjusted OR 3.45; CI, 1.1-11). Bivariate analyses showed that having a do-not-hospitalize order was associated significantly with experiencing less emotional distress (p-value=0.038; analysis not shown in table), however this did not remain significant in multivariate analyses (Adjusted OR 2.54; CI, 0.8-7.7).

Studying the individual items of the Emotional Distress subscale of the CAD-EOLD (analysis not shown in table) showed that having a written advance directive decreased the chance of experiencing fear in the last week of life compared with not having a written advance directive (AOR 3.72; CI, 1.2-11.8) and that having a do-not-resuscitate order decreased the chance of experiencing fear (AOR 3.85; CI, 1.1-13.4) and anxiety (AOR 3.57; CI, 1.0-12.3).

The quality of dying was not significantly associated with the existence of a GP order (Table 2).

No association was found between the quality of dying as judged by the relative and verbal communication such as the resident expressing their wishes to the nurse or the nurse speaking with the resident concerning medical treatments at the end of life or the desired direction of care (Table 3).

Residents about whom the nurse had spoken with a family member or friend in advance concerning the desired direction of care were more likely to have a lower rating on Physical Distress subscale (Adjusted OR 0.28; CI, 0.08-0.98) and Dying Symptoms subscale of the CAD-EOLD (Adjusted OR 0.26: CI, 0.1-0.6) (Table 3).

Studying the relationships between the individual item scores of the CAD-EOLD scale and care planning (not shown in tables) shows that residents about whom the nurse had spoken with a family member or friend in advance were also more likely to have lower ratings of discomfort (Physical Distress subscale, AOR 0.23; CI, 0.09-0.60), restlessness (Physical Distress subscale, AOR 0.41; CI, 0.17-0.98), gurgling (Dying Symptoms subscale, OAR 0.32; CI, 0.1-0.8) and difficulty swallowing (Dying Symptoms subscale, AOR 0.24; CI, 0.1-0.6).

Table 2. Association between documented care planning and quality of dying (CAD-EOLD total score and subscales) among nursing home residents dying with dementia in Flanders, Belgium (n=101)

	N (%)*	Comfort Assessment in Dying with Dementia (CAD-EOLD) measured by the resident's relative									
				SUBSCALES SCORES							
		TOTAL SCORE		Physical Distress		Dying Symptoms		Emotional Distress		Well-Being	
		Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡
RESIDENT'S ADVANCE CARE PLANNING											
Written advance patient directive, Yes	17 (17.5)	31.9 (7.1)	ns	8.8 (2.9)	ns	8.6 (2.4)	ns	10.2 (2.3)	2.99 [1.1-8.3]	6.2 (1.9)	ns
No	80 (82.5)	29.1 (6.3)		8.2 (2.2)		8.0 (2.6)		9.0 (2.3)		5.9 (1.9)	
Do-not-hospitalise, Yes	14 (14.4)	32.8 (6.4)	ns	8.8 (2.9)	ns	9.1 (2.2)	ns	10.4 (1.8)	2.54 [0.8-7.7]	6.4 (2.0)	ns
No	83 (85.6)	29.1 (6.4)		8.2 (2.2)		8.0 (2.6)		9.0 (2.4)		5.9 (1.9)	
Do-not resuscitate, Yes	13 (13.4)	32.9 (5.6)	ns	9.3 (2.7)	ns	8.6 (2.3)	ns	10.6 (1.7)	3.45 [1.1-11]	6.5 (1.6)	ns
No	84 (86.6)	29.1 (6.5)		8.1 (2.2)		8.1 (2.7)		9.0 (2.4)		5.9 (1.9)	
Proxy decision-maker assigned, Yes	5 (5.7)	29.1 (7.6)	ns	8.2 (2.6)	ns	7.8 (3.0)	ns	9.4 (3.3)	ns	5.6 (0.9)	ns
No	82 (94.3)	29.4 (6.3)		8.1 (2.3)		8.0 (2.6)		9.1 (2.3)		5.9 (1.9)	
GENERAL PRACTITIONER'S ORDERS (GP ORDERS)											
GP orders, Yes	55 (56.7)	29.0 (6.1)	ns	8.3 (2.2)	ns	7.9 (2.6)	ns	9.0 (2.4)	ns	5.9 (1.9)	ns
No	42 (43.3)	30.6 (7.1)		8.3 (2.4)		8.5 (2.6)		9.4 (2.3)		6.1 (1.9)	
GP-orders were discussed with Resident, Yes	2 (3.2)	35.2 (4.0)	ns	10.5 (0.7)	ns	10.0 (2.8)	ns	11.0 (1.4)	ns	6.0 (0.0)	ns
No	61 (96.8)	29.2 (6.3)		8.2 (2.3)		8.0 (2.6)		9.1 (2.4)		6.0 (1.9)	

* Numbers of categories of variables may not add up to 101 because of missing values.

† The CAD-EOLD total score ranges from 14 to 42 with higher scores indicating better symptom control. The CAD-EOLD subscales range for Physical Distress, Dying Symptoms and Emotional Distress from 4 (worst) to 12 (best). For Well-Being it ranges from 3 (worst) to 9 (best).

‡ Adjusted odds ratio using a multivariate ordinal regression model

Table 3. Association between ACP communication and quality of dying (CAD-EOLD total score and subscales) among nursing home residents dying with dementia in Flanders, Belgium (n=101)

	N (%)*	Comfort Assessment in Dying with Dementia (CAD-EOLD) measured by the resident's relative									
				SUBSCALES SCORES							
		TOTAL SCORE		Physical Distress		Dying Symptoms		Emotional Distress		Well-Being	
		Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡	Mean (SD) †	AOR ‡
RESIDENT'S ADVANCE CARE PLANNING, VERBALLY											
Resident expressed wishes to nurse concerning medical treatments at end-of-life, Yes	13 (17.1)	32.1 (8.0)	ns	8.0 (2.9)	ns	8.4 (3.1)	ns	9.3 (3.1)	ns	7.0 (2.0)	ns
No	63 (82.9)	29.1 (6.4)		8.2 (2.2)		8.1 (2.7)		9.0 (2.2)		5.8 (1.8)	
Nurse spoke with resident concerning medical treatments and the desired direction of care in the last phase of life, Yes	13 (13.7)	32.8 (5.1)	ns	8.6 (2.8)	ns	8.6 (2.5)	ns	9.7 (2.6)	ns	6.9 (1.4)	ns
No	82 (86.3)	29.3 (6.7)		8.2 (2.3)		8.1 (2.6)		9.2 (2.3)		5.9 (1.9)	
COMMUNICATION WITH RELATIVES											
Nurse spoke with family member or friend in advance concerning medical treatments and the desired direction of care in the last phase of life, Yes	57 (60.6)	28.5 (6.8)	1.21 [0.3-5.6]	7.8 (2.3)	0.28 [0.08-0.98]	7.5 (2.6)	0.26 [0.1-0.6]	8.9 (2.5)	ns	6.0 (1.9)	ns
No	37 (39.4)	31.4 (6.0)		9.0 (2.2)		9.0 (2.5)		9.6 (2.1)		5.9 (1.9)	

* Numbers of categories of variables may not add up to 101 because of missing values.

† The CAD-EOLD total score ranges from 14 to 42 with higher scores indicating better symptom control. The CAD-EOLD subscales range for Physical Distress, Dying Symptoms and Emotional Distress from 4 (worst) to 12 (best). For Well-Being it ranges from 3 (worst) to 9 (best).

‡ Adjusted odds ratio using a multivariate ordinal regression model

DISCUSSION

In this study among nursing home residents dying with dementia we found a strong association between the existence of a written advance directive and the quality of dying, in particular with lower levels of emotional distress ie fear and anxiety. No association was found between there having been spoken communication between the care staff and resident or the existence of a GP order and the quality of dying, while spoken communication between a nurse and a relative appears to have a negative association with the quality of dying.

This is the first study to relate ACP to the quality of dying of nursing home residents with dementia in Flanders. A strength of the study is the use of data from a large representative nationwide population-based study and the identification of a clear study population (deceased nursing home residents with dementia). Other strengths contributing to the quality of the data are the high response rates (the lowest were from GPs (52.9%) and relatives (53.2%), although these are still higher than average for physician postal surveys and for most medical surveys in Belgium[26,27]), the use of a two-step screening protocol to identify the study population and the use of a validated scale (CAD-EOLD) to measure the quality of dying [28]. A non-response analysis showed no differences between residents whose family physicians did or did not respond on important characteristics such as demographics, cognition, decision-making capacity, treatment and care[2]. Finally, we were able to measure residents' outcomes from the perspective of the relative while care processes were reported by nurses.

Nevertheless, the study has several limitations. It was retrospective, therefore memory bias cannot be ruled out, although this was limited by focusing on the final week of life. Also, when interpreting the results, we acknowledge that were relying on relatives' and nurses' reports and perception of care planning and quality of dying, which may differ from what residents themselves would have reported[7,15]. Also, by using a cross-sectional design we can only establish associations and not causal relationships.

A major finding is that nursing home residents with dementia who had a written advance directive were judged by relatives to have had higher ratings of emotional wellbeing while dying than those who had no written advance directive; specifically, they were judged to have shown less fear and anxiety while dying. This is a striking finding considering that previous studies mainly show the association between advance care planning and the use of end-of-life care (eg more hospice enrolment, less aggressive treatment), place of death or relatives' satisfaction with care[1,20,21]

While this study relates the existence of written advance directives to a better quality of dying, the fact that advance directives may affect emotional rather than physical distress or dying symptoms (eg pain or shortness of breath) is intriguing. Although we cannot disentangle the particular mechanisms responsible for this association, a number of hypotheses related to the resident him/herself, the relative, nurse or the nursing home may be formulated. Firstly, advance directives might be the result of a psychological process by the resident, induced by a thorough process of communication concerning their preferred care at the end of life, ultimately resulting in dying with less fear and anxiety. Considering that half of residents dying with dementia are not in an advanced stage a month before dying[2], this seems a possible explanation. Secondly, the scores of the relatives might reflect their own emotional state of mind more than the actual situation of the resident. On the one hand, this might suggest that in cases where an advance directive was present, relatives interpret the condition of the resident as emotionally better. However, a previous report on prevalence of ACP in this population shows that relatives are not always aware of the existence of advance directives reported by the nurses[7]. On the other hand, nurses might have communicated with relatives about the dying process of the resident, positively interpreting their emotional state where an advance directive is present, reassuring the relatives about how the resident is dying. However, if this hypothesis were true, it is surprising that the items measuring well-being such as serenity or peace were not associated. Thirdly, some nursing homes might have an established palliative care culture where advance care planning is performed extensively which might be associated with more patients dying well. This seems less likely however considering that we found no analogous association between advance directives and physical distress or dying symptoms.

Regardless of the precise reasons or cause-effect hypotheses, the results do show the strong relationship between patient-centered planning and quality of dying which should be unravelled in more detail in further research. Considering the relatively low prevalence of advance care planning and advance directives, the results advocate the need to increase early communication about end-of-life issues for people with dementia in nursing homes, enabling them to reflect on their options and facilitating a psychological process oriented towards the final period of life.

One relationship found in our study is difficult to explain ie that verbal communication between the nurse and a relative showed a negative association with the quality of dying (discomfort, restlessness, gurgling, difficulty swallowing). One possible explanation is that these conversations take place reactively or ad hoc – when residents are experiencing clinical complications at the end of life[2] – ie too late in the illness trajectory. Ideally, advance care planning starts in the earlier stages of the disease, especially for nursing home residents with dementia, and focuses on both current and future care. This would imply the benefits of a proactive attitude among nursing home staff in developing advance care plans and facilitating end of life discussion with all involved in care[29].

It is interesting to note that neither discussion between residents and nurses nor the presence of GP orders regulating end-of-life treatment decisions – which both occurred considerably more often than written advance directives – were strongly related to the quality of dying (ie the differences were not large enough to reach significance). One possible explanation is that the conversations between resident and nurses were limited in frequency, not repeated over time or not intense or thorough enough, and that the GP orders were made without involving the resident him/herself which our previous study in Belgium has shown is often the case. Hence, for this specific patient population of nursing home residents with dementia, our results seem to suggest that having a conversation about future care might not be associated with a better quality of dying if not resulting in a clear formulation of wishes in writing. This of course does not suggest that merely presenting people with paper forms in which they need to state their preferences for end-of-life treatments, without careful or regular conversations about future options, will achieve better results; other studies have shown that focusing on the completion of advance directives alone does not improve medical end-of-life care[1,19].

In conclusion, our study shows a clear relationship between having expressed end-of-life care treatment preferences in a written patient advance directive and dying with less emotional distress. Regardless of the specific mechanisms behind this relationship and the respective roles of relatives, residents and caregivers, these results underline the importance of beginning the process of ACP for people with dementia as early as possible, and the need to increase this practice.

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PART IV:

GENERAL DISCUSSION

CHAPTER 9:

GENERAL DISCUSSION

INTRODUCTION

In this part IV, the main study findings will be discussed. First, we will provide an overview of the most important results, followed by an overall discussion of these findings. We will conclude part IV by formulating challenges for practice and policy and further directions for research.

Methodological considerations on the study on Advance Care Planning in Nursing homes are outlined in the discussion of chapter 7, on the Dying Well with Dementia study in the study protocol in chapter 2 and the research articles in chapter 3-7 and 8.

SUMMARY OF THE MAIN FINDINGS

In the following paragraphs, the results of the previous chapters are summarised in four themes regarding nursing home residents with dementia, namely i.e. (1) the quality of dying; (2) palliative care; (3) potentially life-prolonging treatments in the last week of life and end-of-life hospitalizations and (4) advance care planning and general practitioners' treatment orders.

Theme 1 - Quality of dying in nursing home residents with dementia

In chapter 3, nurses and general practitioners reported the clinical characteristics and quality of dying of 198 nursing home residents with dementia in Flanders, Belgium (Dying Well with Dementia study). Of all identified deaths 46.7% had dementia at the time of death. Using the Cognitive Performance Scale (CPS) and the Global Deterioration Scale (GDS) residents with dementia were classified in three groups: 106 (53.5%) cases with very severe or advanced dementia: 56 (28.3%) with severe dementia and 36 (18.2%) with moderate or mild dementia. In the last month of life, 95.5% had one or more sentinel events ie eating/drinking problems (65.7%), febrile episodes (42.9%) and pneumonia (32.3%). The only significant difference between groups (mild/moderate dementia, severe dementia, very severe/advanced dementia) was that the prevalence of eating/drinking problems in the last month of life increased with severity of dementia (p=0.03). In the last month of life most frequently reported symptoms were pain, fear, anxiety, agitation and resistance to care (using the Symptom Management End-of–Life in Dementia or SM-EOLD). Presence of symptoms did not differ significantly in stages of dementia. In the last week, difficulty swallowing and pain were reported most frequently (using the Comfort Assessment in Dying End-of-Life in Dementia or CAD-EOLD). The mean quality of life during the last week (Quality of life in late stage dementia or QUALID, range 11 best to 55 worst) was 28.9, and was similar in all three groups. Pressure sores were present in 26.9%, incontinence in 89.2% and cachexia in 45.8%. Physical upper body or limb restraints were used in 21.4%. Place of death was hospital in 8.9% of cases. Comparing stages of dementia revealed few differences between groups regarding clinical complications, symptoms or quality of dying.

Theme 2 - Palliative care for nursing home residents with dementia

In chapter 4, the Dying Well with Dementia study (2010) provided an overview of how often palliative care was provided to the 205 deceased residents with dementia (of whom 106 with advanced dementia) in 69 nursing homes. Palliative care was studied in a number of different ways. A palliative treatment goal was present in 89.2% and did not differ significantly between dementia stages (p=0.12). Palliative care was provided by the general practitioner in 84.5% of the cases - varying between 74.1% (moderate dementia) and 90.7% (very severe/advanced dementia) depending on dementia severity (p=0.049) - and by in-house palliative care reference staff (nursing home staff with minimal palliative care training) in 81.9% of cases - varying between 70.8% (severe dementia) and 89.0% (very severe/advanced dementia) (p=0.02). In-house palliative care reference staff consisted of the involvement of a palliative care reference nurse (66.3%), discussion by a palliative care task group (48.8%) or the involvement of the coordinating and advisory physician (26.5%). External specialist palliative care services (a palliative multidisciplinary home care team coming into the nursing home or an admission to a palliative care unit in the last three months of life) were involved in 11.2% of cases. Taking in-house or external palliative care together, palliative care was more often provided to residents with advanced (90.1%) compared with severe (72.9%) or moderate dementia (77.8%) (p=0.02). Six in ten residents dying with dementia (61.7%) had a formal palliative care record in the nursing home.

In chapter 7, the study on Advance Care Planning in Nursing Homes (2006) investigated the association between palliative care and the provision of advance directives or GP orders (documentation in the resident’s file of GP treatment orders regulating the use of specific treatment at the end of life) of 764 residents dying with dementia in 345 nursing homes in Flanders Belgium. Palliative care was provided by the general practitioner in 50.7%, by nursing home caregivers in 60.2%, by a palliative reference person from the care home (eg a patient discussion performed by a palliative task group, the involvement of a palliative reference nurse or the involvement of a coordinating and advisory physician) or in a hospital (eg the involvement of a mobile palliative care support team of the hospital or being admitted to an inpatient palliative care unit) in 3.8% of cases. Residents receiving palliative care from nursing home caregivers or from their GP were respectively, three times (OR 3.10; CI, 2.07-4.65) and two times (2.06; CI, 1.37-3.09) as likely to have a GP orders as those not receiving such palliative care. The relationship between palliative care and patient advance directives was not found to be significant.

Theme 3 – Potentially life prolonging treatments in the last week of life and end-of-life hospitalizations

In chapter 4 we reported that in the last week of life, 30.8% of residents with dementia received one or more potentially life-prolonging treatment, of which 19.5% consisted of antibiotics and 20.6% of administration of artificial food/fluids. Although residents with a palliative treatment goal were less likely to receive potentially life-prolonging treatments overall than those without this treatment goal (adjusted OR 0.16; CI, 0.03-0.78), 7.8% received artificial food/fluid in the last week of life and 16.2% were hospitalized in the last month of life.

In chapter 7, we examined hospitalizations of nursing home residents with dementia in the last month of their life. In the last month of life, 19.5% were hospitalized, of whom 4.6% were admitted to an intensive care unit. Nursing home residents with severe or very severe/advanced dementia were no less likely to be hospitalized than those with moderate or mild dementia. According to the nurse, none of these hospitalizations occurred at the request of the resident, 37% were at the request of relatives and 29% were for curative or life-prolonging treatments. In almost all cases information about nursing care or medical treatments (92%) was transferred, information about the resident's wishes and preferences about future care (eg do-not-resuscitate orders) in 19%.

Residents without a GP order were more likely to be hospitalized (Adjusted odds ratio:4.9; 95% confidence interval: 2.1-11.1).

Using the Dying Well with Dementia data, we reported several results relating to the place of death. In chapter 3 and chapter 4 the nurse reported the place of death of 205 (n=198 for chapter 3, n=205 for chapter 4) nursing home residents with dementia. Place of death was the nursing home in 90.3% of cases, a general hospital ward or intensive care unit in 8.7% and a palliative care unit in 1.0%. Overall, 19.5% of nursing home residents with dementia were transferred to a hospital in the last month of life, varying from 14.4% in very severe/advanced dementia to 30.6% in moderate dementia (p=0.09). Those with a palliative treatment goal were less likely to be transferred to a hospital (16.2%) than those without (50%). Residents with a palliative treatment goal being transferred to hospital had advanced dementia in 43.8% of cases.

Theme 4 - Advance care planning and general practitioners' treatment orders

In chapter 6; nurses, GPs and relatives reported the prevalence and content of advance care plans in various forms, hence we were able to study the level of congruence between these respondents concerning the presence and content of GP orders and written advance directives for 205 nursing home residents with dementia (Dying Well with Dementia study).

Concerning medical treatment and the desired direction of care in the last phase of life, GPs reported that residents with dementia expressed their wishes in 11.8% of cases and to the nurse in 8.2%. The GP and nurse spoke with the resident in 22.0% and 9.7% respectively and with the relative in 70.6% and 59.5%. A written advance directive was present in 9.0% according to the FP, in 13.6% according to the nurse and in 18.4% according to the relative. Congruence was poor to slight on the presence of an advance directive (GP-relative, k=0.03; nurse-relative, k=-0.05; GP-nurse, k=0.12). According to all respondents the most frequent directives were do-not-resuscitate, do-not-intubate, do-not-hospitalize and withholding or withdrawing of artificial food and/or fluids. A proxy was appointed in 6% according to the GP, in 5.4% according to the nurse and in 10.0% according to the relative. The level of congruence on the authorization of a proxy by the resident was moderate for the GP-relative pair (k=0.40), poor for the GP-nurse pair (k=-0.09) and slight for the nurse-relative pair (k=0.13).

GP orders were present in 77.3% according to the GP (according to the nurse in 58.1%), discussed with the resident in 13.0% and with the relative in 79.3% (according to the nurse in respectively 4.0% and 80.8%).

Congruence was fair (nurse-FP) on the documentation of GP-orders (k=0.26).

In chapter 7, the study on Advance Care Planning in Nursing Homes (2006) investigated the prevalence and content of documented care planning for 764 residents dying with dementia in 345 nursing homes, as reported by the nurses. The study showed that 61.7% of the deceased nursing home residents with dementia had some type of documented care plan. An advance patient directive was present in 10.3% of cases; a legal representative (authorization of a legal representative in a written living will in case the resident loses competence) was appointed in 8.1% of cases and an advance treatment directive in 3.2% of cases. The most frequent treatment directives were do-not-hospitalize (2.5%) and do not-resuscitate orders (2.1%). A GP order (documentation in the resident's file of GP orders limiting the use of specific treatments at the end of life) was reported in 59.2% of which the most frequent were do-not-hospitalize orders (46.3%), do-not-resuscitate orders (36.1%), and forgoing artificial food (30.6%) or fluids (29.5%) orders. The odds of dying in the hospital were three times lower if there was a GP order (i.e. documentation in the resident's file of GP treatment orders regulating the use of specific treatment at the end of life, OR 0.38; CI, 0.21-0.70) present.

In chapter 8, we investigated how advance care planning related to the quality of dying using the perspective of nurses, GPs and relatives (Dying Well with Dementia study) for 101 nursing home residents with dementia. A written advance patient directive was present in 17.5% of cases. GP orders (documentation in the resident's file of GP orders limiting the use of specific treatments at the end of life) were reported in 56.7% and they were discussed with the resident in 3.2%. The nurse spoke with the resident concerning medical treatments and the desired goals of care in the last phase of life in 13.7% of cases. We studied the association between various forms of care planning and the quality of dying in the last week of life (using the Comfort Assessment in Dying End-of-Life in Dementia or CAD-EOLD) as reported by the resident's relative. Controlling for socio-demographic/clinical characteristics in multivariate regression analyses, chances of having a higher mean rating of emotional well-being (less fear and anxiety) on the CAD-EOLD scale were three times higher (Adjusted OR 2.99; CI, 1.1–8.3) with a written advance patient directive. More specifically a do-not-resuscitate order decreased the chance of experiencing Emotional Distress (less fear and anxiety) in the last week of life compared with not having a do-not-resuscitate order (Adjusted OR 3.45; CI, 1.1-11). We found no association between having a GP order or verbal communication and the quality of dying.

In chapter 7, the study on Advance Care Planning in Nursing Homes (2006) investigated the association between advance directives or GP orders (documentation in the resident’s file of GP treatment orders regulating the use of specific treatment at the end of life) and some aspects of the quality of dying of 764 residents dying with dementia (as judged by nurses) in 345 nursing homes. Residents who had a patient directive had significantly more depressive symptoms and shortness of breath (score of more than 4 on the Edmonton Symptom Assessment System or ESAS) in the last week of life than those without a patient directive. These differences did not remain in the multivariate analyses. Similarly the nurse reported that residents with GP orders experienced more tiredness, anxiety, drowsiness, appetite and shortness of breath. These differences did not remain in the multivariate analyses. Residents with a GP order were 1.7 times more likely to have a mild death (more than 4 on the ESAS scale from 0 to 10, OR 1.75; CI, 1.09–2.81, as estimated by the nurse) than those without a GP order.

GENERAL DISCUSSION

For the first time in Flanders, Belgium, our study shows that nearly half of all nursing home residents die with dementia and half of these have very severe or advanced dementia at the time of death. From a public health point of view, this provides important data concerning the magnitude of the problem of dying with dementia in nursing homes. Considering the future increase in people developing dementia[1], our results confirm that dying well with dementia in nursing homes is one of the most important public health challenges faced by society.

The following paragraphs provide some reflections on the main results of this study, organized following the four themes structuring this dissertation ie (1) the quality of dying; (2) palliative care; (3) potentially life-prolonging treatments in the last week of life and end-of-life hospitalizations and (4) advance care planning and general practitioners’ treatment orders. Finally, for some discussion points specific recommendations and challenges for practice are given.

Theme 1 - Quality of dying in nursing home residents with dementia

Our data (Dying Well with Dementia study), using a combination of different observers, provided us with a unique insight into the quality of dying of nursing home residents with dementia. Studying the quality of dying for nursing home residents with dementia is challenging given that we had to rely on the perspectives of proxies (nurse, general practitioner, relative) which may have differed from the perspective of the resident. However, proxies are an important source of information given that for the majority of this patient population self-reporting is not possible, research has shown that proxies can provide useful information particularly on the more concrete, observable aspects of the quality of life[2, 3]. Grief is another issue concerning validity of proxy reports; in our study relatives received the questionnaire no earlier than two weeks after the resident's death. It has been shown that there is no difference in distress or response rate for the family at two weeks in comparison with a period of six weeks[4].

Our data shows that regardless of the stage of dementia, many residents develop serious clinical complications and symptoms in the terminal phase of life. The most common clinical complications in the last month of life were eating or drinking problems (65.7%), febrile episodes (42.9%) and pneumonia (32.2%). Across all dementia stages, the most commonly reported symptoms in the last month of life were pain, fear and anxiety. Overall, the most common clinical characteristics in the last week of life were incontinence for urine or faeces, pressure sores and cachexia/dehydration. Comparing our data with other studies is difficult due to differences in population and research procedures. However in US and Italian studies, which are limited to advanced dementia, similar complications and symptoms are cited[5-7]. Importantly, we additionally found that the prevalence of clinical complications in the last month of life (eg pneumonia or other infections), levels of comfort and quality of life in the last week did not differ significantly between groups, nor did the presence of distressing symptoms in the last month. Therefore, research addressing the challenge of providing high quality end-of-life care for residents with dementia should not only focus on residents with advanced dementia. Moreover, end of life care practices in nursing homes might benefit from a regular and systematic assessment of symptoms and problems among residents with dementia, and from preparing caregivers, residents and their families for the clinical complications that might occur at the end of life and the accompanying end of life decisions, regardless of the stage. The recently published white paper emphasised this by stating that an exclusive focus on advanced dementia only is not helpful[8]. Shaping end of life care in dementia across dementia stages needs further study, for example recommendations need to be refined between needs that are more likely to occur after diagnosis versus the dying phase[8].

Our Belgian cross-sectional retrospective study Dying Well with Dementia was also compared with a similar study from the Netherlands which combined prospective and retrospective measurements (publication not included in this dissertation), showing the potential room for improvement in quality of dying for Belgian residents. We compared Flemish and Dutch residents who died with dementia on quality of dying and the quality of end-of-life care (as judged by relatives)[9]. Results showed that – after controlling for important differences between countries in population characteristics of nursing home residents (such as functional status) – symptom frequencies in the last month of life and satisfaction with care in the last week were rated similarly in the two countries[9]. Strikingly, significant differences were found between Belgian and Dutch nursing home residents with dementia in comfort and symptoms experienced while dying (using the Comfort Assessment in Dying End-of-Life in Dementia or CAD-EOLD) indicating a higher quality of dying in the Netherlands[9]. More specifically, Dutch residents were judged by relatives to experience less discomfort while dying; Belgian residents experienced more problems with swallowing, restlessness, anxiety, pain and other burdensome symptoms[9], findings that could not be attributed to differences in nursing home populations, length of stay or disease severity[9]. The continuous (24 hours a day) presence of an Elderly Care Physician in the Netherlands compared with our regularly visiting general practitioner was hypothesised to be a possible explanation for the found differences[9]. Dutch elderly physicians might be better trained in caring for the complex problems that can occur in the final phase of dementia or might be within reach at the time of an acute event[9]. Another explanation might also be that there is a difference in how Dutch and Belgian care staff communicate with relatives; Dutch relatives might be better prepared for what to expect in the dying phase. These findings might have implications for optimizing care structures and procedures aimed at enhancing the quality of dying in nursing homes[9]. On the other hand, implementing new interventions in another country is challenging, given differences between health care settings, cultures, policy etc. A recent example is the implementation of the Liverpool Care Pathway (LCP) in an Italian care setting; the LCP is a programme developed in the UK for dying patients aimed to transfer UK hospice practice to end-of-life care to hospitals. A recent multicenter cluster randomized trial comprising of patients with cancer and their families showed no significant difference between patients who died in wards in which LCP had been implemented compared with those in which it had not [10, 11]. A possible explanation is the substantial difference between the Italian health system and that in the UK[11]. Interventions need to be critically assessed in rigorous trials of health services since good evidence is not easily translated into policy[10, 11].

Theme 2 - Palliative care for nursing home residents with dementia

The nationwide representative post-mortem Dying Well with Dementia study in nursing homes in Flanders, Belgium, demonstrates that a large majority of residents with dementia (83.1%) receive “palliative care” at any point of time and that the treatment goal in the last week is mostly (89.2%) aimed at palliative care. In 2006 the study on Advance Care Planning in Nursing Homes found that 50.7% of nursing home residents received palliative care from their general practitioner, in the 2010 (Dying Well with Dementia study) this was the case for 84.5% of nursing home residents with dementia. These numbers confirm the tendency that palliative care is starting to become more generally acknowledged for non-cancer patients, such as people with dementia, over the last decade. For most cases, health care providers in Flemish nursing homes seem to recognize that residents with dementia are eligible for a palliative care approach. The WHO and a recent EAPC white paper also promote palliative care as the preferred approach for older people with age-related and cognitive problems, not only in the terminal phase but integrated into disease management[8, 42]. An important limitation of our quantitative study is that we cannot provide in depth insights into the way care was delivered and what palliative care for these residents entailed. Additionally, while in-house palliative care might have been provided, the quality of the actually delivered care is not measured and the data on quality of dying shows that there is still substantial room for improvement in outcomes for people with dementia. Hence, while awareness of the importance of a palliative care approach can be an important first step in improving quality of dying, the quality of palliative care processes can still be improved.

It is noteworthy that we found a significant minority (almost two in ten) of residents with dementia - of whom one in ten had advanced dementia – who were not receiving any form of palliative care at any point of time before dying. Nevertheless, could a palliative care approach have benefitted these patients? Nursing home residents with dementia – and with advanced dementia - have high palliative care needs in which case palliative care may improve the quality of life, decrease the number of unnecessary treatments and potentially reduce costs[6, 8, 18, 21]. Residents being treated with a palliative intent were less likely to receive potentially life–prolonging treatments although possibly burdensome treatments co-existed with a palliative care approach in a minority of people (further discussed in theme 3).

A recent white paper of the European Association for Palliative Care drafted the core domains of palliative care for older people with dementia of which one is the applicability of palliative care[8]. It stated that dementia can be regarded as a “terminal condition and a geriatric problem, and that recognizing its terminal nature is the basis for anticipating future problems and an impulse for the provision of palliative care”[8]. Improving quality of life, maintaining function and maximizing comfort can be considered appropriate in dementia throughout the disease trajectory, with the emphasis on particular goals changing over time[8]. Traditionally palliative care is considered relevant only in the very last phase of life[43]; however a nursing home culture that encourages comfort care (a general palliative care approach with eg assessment and treatment of pain and other symptoms, patient-centred communication and decision-making, multi-professional cooperation, better communication on all levels and more inclusion of relatives into a patients care) from the early stages of the disease could enhance quality of end-of-life care for nursing home residents with dementia. Specialist palliative care service might then be consulted according to the needs of the residents.

Studying the type of palliative care provision we found that palliative care was mainly provided by in-house nursing (assistance) staff, but in very few cases by specialized multidisciplinary palliative care services. Palliative care was delivered as part of regular care by the general practitioner and by in-house nursing staff (nursing home staff with minimal palliative care training, eg palliative care reference nurse, coordinating and advisory physician) in the majority of cases. The palliative care reference nurse and physicians appear to be frequently involved in terms of consultation of regular caregivers but also in terms of bedside consultation (by the reference nurse in 60.7% and by the physician in 22.1% of cases). Compared to other countries Belgium has a unique system of in-house palliative care provision, required by the Belgian Law on Palliative Care (2002) and the Decree on Residential Care (2009). Each nursing home is required to have palliative caregivers supporting the regular caregivers by giving advice and if requested by taking over some aspects of care eg a coordinating and advisory physician of the nursing home (eg a general practitioner who is among other things responsible for the development of a strategy regarding end-of-life care ie the coordinating and advisory physician), or an in-house reference nurse for palliative care, or a palliative care task group). The in-house caregivers are appointed to set out a general palliative care culture in nursing homes and our results suggest that our legal framework might be having an effect on how daily care is organised in nursing homes. Based on our study we cannot however describe their intervention and the quality of their care. The coordinating and advisory physician has many tasks of which development of a strategy regarding end-of-life care is only one; besides they are not required to follow any formal training. Another possible issue of the coordinating and advisory physician is that the number of hours that they are present in the nursing home is variable (and depending on the size of the home), possibly providing difficulties in developing a strategy for end of life care. Notwithstanding that our results suggest that the in-house palliative care initiatives have an active role, their function and impact could be further developed and help to tackle the problems specific for dementia.

We found that external specialist multidisciplinary palliative care services are seldom consulted. Given that residents with dementia suffer from burdensome symptoms and clinical complications at the end of life, we can question whether these external specialists could be used more extensively and further research is needed to study current and optimal referral criteria for such specialist services, as well as their collaboration with the coordinating and advisory physician and/or reference nurses. Networks for palliative care in Flanders might also be more involved in the formal and continuous training of the CRA/reference nurses.

Theme 3 - Potentially life prolonging treatments in the last week of life and end-of-life hospitalisations

The Dying Well with Dementia study showed that three out of ten nursing home residents dying with dementia received potentially life-prolonging treatments such as antibiotics or artificial food/fluids in the last week of life and nearly a fifth were hospitalized in the last month of life (of whom almost a quarter to an intensive care unit). None of the hospitalizations were made at the request of the resident (few after consultation with them), 37% were at the request of relatives and curative or life-prolonging treatments were the most frequent reasons given. These treatments might not be optimal in promoting comfort in the last phase of life, are not always beneficial, are in some cases unwanted and some are associated with markers of poor quality in end-of-life care[6, 12, 13]. For example the presence of a catheter or the administration of artificial food or fluids is often associated with pain and discomfort[6, 13]. Our results also correspond with studies from the US showing similarly high frequencies of potentially burdensome treatments at the end of life in selected samples of nursing home residents with advanced dementia[6, 7, 14]. Pneumonia and other infections are common end-of-life issues for residents with dementia and recurrent hospitalizations are potentially avoidable; a randomized controlled trial of pneumonia treatment among nursing home resident with dementia showed that the majority of residents with pneumonia can be treated in the nursing home without a significant effect on mortality, level of functioning and quality of life[12, 15-18]. In the contemporary palliative care model of Lynn et al [19]it is suggested that chronically ill elderly people - such as people with dementia - may need both disease modifying/potentially life-prolonging treatments and palliative care early in the disease course, gradually shifting to more palliative care and fewer life-prolonging treatments when the disease progresses and palliative care needs increase. Palliative care is then considered as supportive care rather than terminal care, based on the needs of the resident.

When having a palliative treatment goal, residents were less likely to receive potentially life-prolonging treatments in the last week of life or to be transferred to the hospital in the last month of life than those without. However, a significant minority of residents treated with a palliative intent still received possibly burdensome and futile life-prolonging treatments such as artificial food or fluids (7.8%) or hospital admission (16.2%) at the very end of life. Earlier research also found that although the primary goal of care was comfort, care for nursing home residents with cognitive issues (eg residents with dementia) is often inconsistent with that goal[12]. The usefulness of this combination is questionable especially for residents with advanced dementia[8]. Earlier research also showed that end of life care for people with dementia consisted of too many interventions with little benefit (eg laboratory tests, the use of restraints, intravenous medication) or too little pain control, emotional and social neglect and the absence of spiritual/existential care[20, 21]. In our study, the use of antibiotics for residents receiving palliative care did not differ significantly from those not receiving it. Since some argue that the use of antibiotics is useful in palliative care and others that it prolongs survival time, this illustrates the complexity of end of life treatment decisions for people with dementia[22].

Theme 4 - Advance care planning and general practitioners' treatment orders

Prevalence and characteristics of advance care planning and general care planning

Patient-centered advance care planning (ACP) is a communication process between a patient and his/her care providers, which may involve family or friends, about the goals and desired direction of care at the end of life in the event that the patient loses the capacity to make decisions[23, 24]. Additionally, general practitioners' treatment orders (GP orders) are used to guide end of life care; these are instructions from the general practitioner governing the use of specific treatments toward the end of life[25, 26]. GP orders are usually documented in the resident's medical file and may be discussed with other professional caregivers, relatives, or with the resident, but only when they have been discussed with the residents themselves can they be considered as patient-centred ACP[25, 26].

Despite the importance of advance care planning (ACP) for people with dementia, the findings presented in chapter 6 and 7 show that the prevalence of advance care planning for nursing home residents with dementia is rather low.

We found these rather low numbers for documented advance care planning (advance directives, authorization of proxy for end-of-life decision making) and communication regarding end-of-life care (between professional caregivers and residents with dementia). Patient-driven ACP (eg advance directives, authorization of proxy for end-of-life decision making) was reported far less often than GP-orders (documentation in the resident's file of GP treatment orders regulating the use of specific treatment at the end of life) which are predominantly used when planning care in advance. Importantly these GP-orders were discussed with the relative in one or less than one cases out of 10 and more often discussed with other professional caregivers or relatives. Also, communication regarding end-of-life care between professional caregivers and relatives appears more frequent than professional caregiver-patient communication. GP orders can be seen as part of the general care planning process in nursing homes. General care planning is described by The National End of Life Care Programme (UK) and distinguished from the process of ACP. Both involve an on-going, continuing and effective dialogue between the patient, carers, partners and relatives; where general care planning aims at current and continuing healthcare and can be completed for an individual who lacks capacity to act in their own best interests, ACP requires patient involvement and aims at directing future care[27]. Other reasons for the low prevalence of patient-driven directives might be that dementia is not always formally diagnosed by clinicians, disclosed or recognized as a terminal illness[28-30]. Residents might be unfamiliar with the possibility of completing an advance directive. Medical care for nursing home residents in Flanders is mainly managed by their own general practitioner, with whom a long-lasting relationship is often developed; residents might therefore have more faith in their physician to make decisions in their best interest. Research however has shown that general practitioners are not always aware of the resident's preferences[27, 31]. Another plausible explanation is that physicians might be hesitant to start ACP conversations and residents might not realize the importance of planning until it is too late, or either party might avoid the topic[32]. Our data showed that at time of nursing home admission 63.7% were capable or partly capable of medical decision making, suggesting that care planning is often performed when the resident is no longer able to participate in decisions making, late in the illness trajectory when death is near or ad hoc when complications occur. Advance care planning is considered as one of the key ingredients of good quality end-of-life care, in particular for nursing home residents with dementia who face a threshold in their ability to engage meaningfully in the advance planning of their own care[23, 24, 33, 34]. Given that nursing home residents with dementia experience significant clinical complications, early communication about the resident's preferences is crucial if they want to meaningfully engage in the planning of their own care. For example, eating or drinking problems (65.7%) are one of the most common clinical complications in the last month of life. It might be therefore one of the most common end points for which residents with dementia and family members need to be prepared, and one of the issues that can be discussed – among more general issues such as the resident's quality of life and general care goal preferences - early in the disease trajectory as part of an advance care planning process. Several models of ACP propose a stepwise approach that can be integrated flexibly into routine clinical encounters by the practitioner or other health care providers[24, 35-37]. It could be helpful to think of ACP as a process in its broadest sense (ie a process of continuous communication between caregivers, patients and/or their representatives about the goals and desired direction of care, particularly end-of-life care, in the event that the patient is or becomes incompetent to make decisions)[35]. The three step model by Teno and colleagues includes (1) actively listening to the resident, (2) creating goals of care based on mutual understanding and (3) formulating contingency plans to honour these goals[24, 37]. Based on our data there are few indications that ACP for nursing home residents with dementia is currently practiced in a broad sense or is integrated early in the disease trajectory.

Most advance care plans (advance directives and GP orders) concerned anticipatory decisions such as do-not-hospitalize, do-not-hospitalize, withholding or withdrawing administration of artificial food or fluids and do-not-intubate orders. Euthanasia, which is performed in 0.2% of all nursing home deaths, was rarely documented in advance care plans (between 0.1% and 0.7%)[38]. Terminal sedation, a practice that is becoming more prevalent in nursing homes (2.9% in 2001 to 9.4% in 2007) was even less often documented (0.2%)[39]. The concordance between advance care plans and the delivered end-of-life care was not studied.

Level of congruence between the nurse, GP and relative regarding advance care planning and GP orders

Strikingly, the level of congruence between professional caregivers (nurse, GP) and relatives regarding the content of ACP is low. Making decisions about the care of people with dementia involves the resident, GP, nurse and their relatives and ideally there would be consensus about what had been discussed with the resident and the future direction of care. Congruence could ensure continuity in care and could enhance provision of care in accordance with the resident's wishes. A recent study showed that concordance between expressed preferences for care and the documentation of those preferences in the medical record was low (30.2%)**[40]**. The study discloses several gaps in communication and documentation (in a hospital setting, elderly patients who were at high risk of dying in the next 6 months)**[40]**. It found that although patients and relatives considered their end-of-life wishes, there was little communication about these wishes and inadequate documentation (no documentation at all or documented incorrectly) in the medical record and this could be viewed as a "failure of communication" or a medical error**[40]**. They stated that investing in ACP is one of the most important issues in improving the quality of care from the perspectives of patients and family members **[40]**. Being informed about the presence of advance care plans is important since these are associated with quality of dying or place of death, particularly in our setting where the GP is not always present at the time of an acute event. Our data suggest that communication regarding future care is not only limited but also that both decisions are not made jointly, which limits the chance of providing care in accordance with the resident's wishes. Initiatives to improve congruence between FPs, nurses and relatives about ACP and the content of FP-orders could assist the complexity of care for nursing home residents dying with dementia.

Association between place of death and advance care planning and GP orders

Chapters 7 and 8 show that for nursing home residents dying with dementia hospitalization was less likely if a do-not hospitalize GP-order was documented in their medical file. When a GP order was present (most GP orders are do-not-hospitalise order) residents were less often transferred to hospital at the very end of life, indicating that residents died outside their regular place of care. The fact that the presence of documented GP orders in the resident's file appear to be associated with their place of death underlines the importance of such orders on place of death. They might aid the nursing home staff at the time of an acute event when a hospitalization decision is required and the GP is often not present at the nursing home. The association between patient directives and place of death showed the same tendency but was not significant (probably due to a lack of power); GP-orders rather than patient-driven written advance directives seem to shape the resident's care.

Association between quality of dying and advance care planning and GP orders

When studying the relation between quality of dying and advance care planning we found some interesting results (chapters 7 and 8).

We studied how various forms of advance care planning (written advance patient directives, authorization of proxy decision-maker, verbal communication with resident/relative) and general practitioners orders related to the quality of dying as judged by the relative (Comfort Assessment in Dying with Dementia or CAD-EOLD scale). Our data showed that for nursing home residents with dementia there is a strong association between having a written advance directive and quality of dying. Nursing home residents with dementia who had a written advance directive were judged by relatives to have had higher ratings of emotional wellbeing while dying than those who had no written advance directive; specifically, they were judged to have shown less fear and anxiety while dying. Our quantitative research design cannot unravel the mechanisms responsible for this association, however a number of hypotheses can be formulated (chapter 8). Advance directives might be the result of a psychological process by the resident resulting in dying with less fear and anxiety, relatives might reflect their own emotional states rather than the actual experience of the resident or an established palliative care culture in some nursing homes where advance care planning is performed extensively might be associated with more patients dying well. This seems less likely however considering that we found no analogous association between advance directives and physical distress or dying symptoms. The strong relationship between patient-centred planning and the quality of dying should be unravelled in further research.

Additionally, our data showed that neither the discussion between residents and nurses nor the presence of GP orders regulating end-of-life treatment decisions were strongly related to the quality of dying. No association was found between spoken communication between the care staff and resident or the existence of a GP order and the quality of dying, while spoken communication between a nurse and a relative appears to have a negative association with the quality of dying. Our results advocate the need to increase early communication about end-of-life issues for people with dementia in nursing homes and the need to increase this practice, enabling them to talk about such sensitive issues and reflect on their options and facilitating a psychological process oriented towards the final period of life.

Care planning (ie GP orders) seems to affect mildness of death; nursing home residents with dementia who had a GP-order were judged by the nurse to have a milder death. A plausible explanation is that nurses experienced the death as more mild because they had an explicit understanding of the treatment plan since decisions were made in advance while we cannot know whether the resident actually died more mildly based on these data[41]. This may be a subjective judgement from the nurse since we found no association between GP orders and symptoms assessment, which may be more objective.

Association between palliative care and advance care planning and GP orders

Finally, the study on Advance Care Planning in Nursing Homes found that the presence of a GP order (documentation in the resident’s file of GP treatment orders regulating the use of specific treatment at the end of life) was positively associated with receiving specialist palliative care from nursing home caregivers and from the GP in the nursing home. Although causality cannot be inferred from this study, this could either imply that the provision of palliative care leads to more care planning or that the presence of GP orders triggers palliative care provision. Since discussion of goals is inherent in palliative care, it is plausible that palliative care leads to discussing preferences for the end-of-life. The fact that we found no association between palliative care and patient driven ACP such as advance directives might be explained by the fact that the onset of palliative care often occurs late in the disease trajectory, even later for people with dementia than for people with cancer, when the resident with dementia is no longer able to complete an advance directive but professional caregivers and family member can still complete a GP order.

CHALLENGES FOR PRACTICE AND POLICY AND RECOMMENDATIONS FOR FUTURE RESEARCH

PRACTICE AND POLICY

Invest in a palliative care culture in the nursing home

Our results suggest that the need for palliative care is increasingly being recognized in practice. However, while palliative care has been promoted as the preferred approach for people with dementia, introduction of a palliative care approach into nursing homes remains challenging. Nursing home residents with dementia (regardless of the stage) still receive potentially life-prolonging treatments, experience serious clinical complications and symptoms in the last phase of life and, compared with Dutch residents with dementia, experience more discomfort while dying. Palliative care might still be perceived as ‘terminal care’, care for people in the final days/weeks of life or relevant only in the final stage of dementia. However, as the WHO definition indicates, palliative care is applicable early in the disease course. Even though residents are not all terminally ill, they can benefit from a palliative care approach or culture screening residents for palliative care needs in a systematic manner (regardless of the dementia stage). Developing, investing and implementing a palliative care strategy in nursing homes could enhance a general palliative care approach with eg assessment and treatment of pain and other symptoms, patient-centred communication and decision-making, multi-professional cooperation, better communication on all levels and more inclusion of relatives into a patient’s care from the early stages of the disease could enhance quality of end-of-life care for nursing home residents with dementia and help to tackle the problems specific to dementia. The system of in-house palliative care provision could be further developed eg developing the function and impact of the coordinating and advisory physician around palliative care. When palliative care delivered by in-house staff is insufficient or when facing the possible complex care for a resident with dementia, a choice can be made to collaborate with specialized multidisciplinary palliative care services that are currently seldom consulted.

Encourage communication regarding end-of-life care and patient-driven advance care planning

Few nursing home residents with dementia have expressed their wishes regarding medical treatment at the end-of-life or have completed advance directives or authorized a proxy for end-of-life decision making (ie patient-driving advance care planning). Given that residents with dementia face a threshold in their ability to engage meaningfully in the advance planning of their own care, discussions about end-of-life care (and of current and future aspects of health and social care) should preferably start as early as possible. Planning in advance provides opportunities to provide care in accordance with the resident's wishes when he/she is no longer able to communicate these preferences. Our data showed that this is not always the case and other studies have identified several barriers that might discourage the residents and health care providers from engaging in advance care planning. For example residents might find it difficult to understand their possible future situation and health care providers might struggle to initiate end-of-life conversations because of time-constrictions or uncertainty. In spite of all the possible barriers, it can be recommended to encourage advance care planning and sensitively and proactively explore the resident's wishes and balance all possible choices that can be made. The fact that GP orders are very common and that communication regarding end-of-life care between professional caregivers and relatives appears to be more frequent indicates that planning in advance is done, though often ad hoc or very late in the disease trajectory. The development and implementation of standardises institutional guidelines regarding advance care planning could also guide caregivers.

Invest in education and training to enhance the knowledge and communication skills of nursing home staff and general practitioners

An additional step forward could be made by enhancing health care professionals' knowledge on palliative care in the basic curriculum, in post-graduate training programs, through training courses, workshops and seminars. Ideally, training of health care staff includes sufficient time devoted to palliative medicine, geriatric medicine and geriatric nursing and professionals are supported in keeping up to date. Additionally, more financial means and manpower in nursing homes could contribute to the quality of care. For example, staffing and a higher availability of qualified nursing has been shown to reduce the risk of hospitalization[44, 45]. Also communication between health care staff in nursing homes might be subject to improvement; our data showed that the level of congruence between the nurse and the general practitioner on aspects of advance care planning is low

Recognize the need at national and international policy level

Recognizing the growing population of people with dementia and their palliative care needs as one of the biggest public health challenges, our study showed that nearly half of nursing home residents die with dementia (and half of these have very severe or advanced dementia at the time of death) and that they suffer from serious clinical complications and symptoms in the terminal phase of life. While the need for attention to the epidemic of dementia is being recognised on a global scale – as is evidenced for example by the recently organised G8 Summit on dementia (London, 2013) – the need for improving palliative and end of life care in this population has so far received too little attention on a national and international policy level. Policy makers could invest in putting palliative care for people with dementia high on national and international policy agendas and initiate or support initiatives to improve care in practice, as outlined in the previous paragraphs.

FUTURE RESEARCH

The results of this dissertation provide important quantitative insights into end-of-life care for nursing home residents with dementia. These insights can be used as a reference point for further research.

As many other European countries face similar challenges in providing high quality end-of-life care for people with dementia in long term care settings, an international collaboration combining comparable data may provide very valuable insights. In this context, collaborative research between Flanders and the Netherlands (Dutch End of life in Dementia study, DEOLD) was initiated in order to compare health systems and quality of care and dying of nursing home residents in each country. Data have been merged to make cross-country comparisons possible. The first results showed that Dutch residents experienced less discomfort while dying than Flemish residents, and suggest room for improvement in both countries and particularly in the dying phase in Belgium[9].

Additionally, some of the instruments used in this study have been developed and used in US studies – mainly among people with advanced dementia – making interesting comparisons possible between Europe and the US where health systems are organized very differently. Other countries such as Switzerland, Italy, Poland and the UK have expressed interest in studying long term care facilities using this methodology in the future and preliminary consortia have been set up coordinated by the End of Life Care Research Group in Belgium.

Also, while reporting on palliative care and quality of dying for nursing home residents in a quantitative and retrospective manner, we cannot provide in depth insights into the way care was delivered and what palliative care for these residents entailed. Future research studying specific care processes in more detail (eg barriers and facilitators that influence the onset of palliative care) or in a prospective longitudinal design could further enhance research on quality of end-of-life care for nursing home residents with dementia. Additionally, analysing and comparing residents with dementia with specific patient groups eg residents with cancer, heart diseases or other chronic conditions can provide important insight into the differences in dying trajectories in nursing homes.

Additionally, our study showed that for many nursing home residents with dementia quality of dying could be enhanced and access to palliative care improved. Palliative care might be improved via the enhancement of skills and knowledge of in-house nursing home staff or via improving access to specialist palliative care. However, research on optimal strategies to improve end of life care in nursing homes is lacking. Future studies should focus on investigating the effectiveness of interventions introducing palliative care in nursing homes, evaluating its impact on quality of dying as well as its cost-effectiveness. Several innovative approaches have been started (eg Gold Standard Framework UK) but its empirical evidence base is lacking. Such studies would need to use robust and well-powered research designs involving clinical randomized trials. So far, research involving older people and in particular people with dementia has been too scarce to be able to guide practice in an evidence-based manner.

Considering our study also found that a small but important number of residents with dementia are moved to a hospital at the end of life, future research could also particularly focus on how to identify and prevent unnecessary hospital admissions at the end of life. Accordingly, future studies might look at the use of different life-prolonging treatments at the end of life in more detail, evaluate their effectiveness in terms of quality of life, quantity of life and costs, and evaluate how unnecessary or burdensome treatments can be prevented in this population.

Finally, one of the main conclusions of this dissertation is that advance care planning and communication at the end of life could improve. There is little evidence on how advance care planning for people with dementia can be improved and who can assist in this. Additionally there is a high need for guidelines on advance care planning (how, when, with whom to engage in structured conversations on preferences for future care). An ACP intervention study including this particular patient population could measure the effect of additional training for health care professionals, in terms of patient and family outcomes – in the short and longer term – as well as on staff attitudes and skills. So far there have been no trials focusing on this population.

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NEDERLANDSTALIGE SAMENVATTING

ACHTERGROND

Onze samenleving wordt steeds ouder. Wereldwijd is er een aanhoudend groeiend aantal personen met hoge leeftijd; in Europa zal het aantal 65-plussers bijna verdubbelen van 87 miljoen in 2010 naar 153 miljoen in 2060. Met de toenemende omvang van de vergrijzing, neemt ook het aantal personen met dementie toe. Wereldwijd zijn er op dit moment 36 miljoen mensen met dementie en dit zal naar verwachting stijgen tot 115 miljoen in 2050. Een “tsunami” van dementie wordt wereldwijd voorspeld, waardoor dementie zo één van de grootste uitdagingen voor onze gezondheidszorg. Men schat dat binnen enkele tientallen jaren 1 op 4 mensen in de Westerse landen zal overlijden met dementie vormt. De meeste personen met dementie verblijven gedurende lange tijd thuis. Naarmate de ziekte vordert ziet men dat meer en meer personen met dementie opgenomen worden in een woon- en zorgcentrum. Woon- en zorgcentra spelen zodus een steeds grotere rol in de levenseindezorg voor kwetsbare ouderen zoals personen met dementie.

Ondanks het sterk groeiend aantal personen met dementie die sterven in woon-en zorgcentra is er weinig onderzoek verricht over hoe deze personen sterven. Deze studie hoopt hieraan een bijdrage te leveren door betrouwbare gegevens aan te reiken over de laatste levensfase voor rusthuisbewoners met dementie en de omstandigheden van het overlijden.

ONDERZOEKSVRAGEN

Dit proefschrift heeft twee algemene doelstellingen:

1. Beschrijven van de prevalentie van overleden bewoners met dementie in woon- en zorgcentra in een representatieve steekproef in Vlaanderen, en het beschrijven van hun kwaliteit van sterven en zorg aan het einde van het leven.
2. Beschrijven van de prevalentie en inhoud van voorafgaande of vroegtijdige zorgplanning van overleden bewoners met dementie in woon- en zorgcentra en hun nabestaanden.

Meer specifiek behandelen we volgende onderzoeksvragen:

DEEL II - Kwaliteit van sterven, gebruik van palliatieve zorg en potentieel levensverlengende behandelingen aan het levenseinde van bewoners met dementie in woon- en zorgcentra

1. Hoeveel bewoners van woon-en zorgcentra hadden dementie op moment van overlijden en welke zijn de klinische karakteristieken van deze bewoner evenals hun kwaliteit van sterven?
2. Hoe vaak en welk type van palliatieve zorg en potentieel levensverlengende behandelingen ontvangen bewoners met dementie in woon-en zorgcentra?
3. Hoe vaak worden bewoners met dementie van woon-en zorgcentra gehospitaliseerd in de laatste levensfase?

DEEL III – Voorafgaande zorgplanning voor bewoners met dementie in woon-en zorgcentra

1. Wat is prevalentie en inhoud van voorafgaande zorgplannen en voorafgaande instructies vanuit de arts en wat is de mate van congruentie tussen huisartsen, verpleegkundigen en nabestaanden voor bewoners met dementie in woon- en zorgcentra?
2. In welke mate zijn voorafgaande zorgplanning en voorafgaande instructies vanuit de arts geassocieerd met de kwaliteit van sterven van bewoners met dementie in woon-en zorgcentra?

METHODE

Twee retrospectieve studies werden gebruik om deze onderzoeksvragen te beantwoorden:

Dying Well with dementia in 2010

De Dying Well with Dementia studie (2010) is een beschrijvend retrospectief onderzoek naar het levenseinde van bewoners met dementie in Vlaamse woon-en zorgcentra via een bevraging van huisartsen, verpleegkundigen/verzorgenden en nabestaanden. Het belangrijkste doel is om een breed overzicht te geven van hoe rusthuisbewoners sterven met dementie in Vlaamse woon-en zorgcentra. De onderzoeksvragen uit hoofdstukken 3-6 en hoofdstuk 8 werden beantwoord door middel van deze studie.

Deze cross-sectionele retrospectieve studie maakt gebruik van gestructureerde vragenlijsten gericht aan de verpleegkundige/verzorgende nauw betrokken in de zorg van de bewoner, de huisarts, een nabestaande nauw betrokken bij de bewoner en de dagelijks verantwoordelijke van het woon-en zorgcentrum. Vertrekkende vanuit een lijst van alle woon- en zorgcentra in Vlaanderen in 2010 (aangeleverd door het RIZIV) werd een representatieve groep van Vlaams woon-en zorgcentra geselecteerd door middel van een cluster sampling (gebaseerd op provincie, type en grootte). De deelnemende woon- en zorgcentra bleken ook representatief voor de verschillende koepelorganisaties in Vlaanderen. In de deelnemende woon-en zorgcentra werden alle bewoners met dementie geïncludeerd die overleden waren in de laatste 3 maanden (categorie Cdementie volgens de KATZ-schaal of een desoriëntatie in tijd en ruimte én dementie volgens de arts of de verpleegkundige). Nadien werd via de vragenlijsten van de verpleegkundige en huisarts meer specifiek nagegaan wie dementie had en wie niet.

Het studieprotocol werd goedgekeurd door de Medisch Ethische Commissie van het UZ Brussel (UZ Brussel).

Voorafgaande zorgplanning in woon- en zorgcentra in 2006

De onderzoeksvragen uit hoofdstuk 7 werden beantwoord door deze studie rond voorafgaande zorgplanning in woon-en zorgcentra uit 2006.

Alle woon- en zorgcentra (rust-en verzorgingstehuizen excl ziekenhuis-RVT’s) werden gevraagd om mee te werken aan dit onderzoek (n=594) en om alle instellingsverlaters overleden gedurende september en oktober 2006 te includeren. Het onderzoek omvatte een retrospectieve bevraging via een gestructureerde vragenlijst van de (hoofd)verpleegkundige die het meest betrokken was bij de verzorging van de overleden instellingsverlater. De (hoofd)verpleegkundige werd bevraagd over de karakteristieken van de overleden bewoner, het voorkomen van ziekenhuistransfers en het verstrekken van palliatieve zorg aan het levenseinde, de aanwezigheid van voorafgaande zorgplannen en of de bewoner een vertegenwoordiger had benoemd.

In dit proefschrift (hoofdstuk 7) hebben we de gegevens van 764 verpleeghuisbewoners met dementie (secundaire analyses) bestudeerd.

Het studieprotocol werd goedgekeurd door de Medisch Ethische Commissie van het UZ Brussel (UZ Brussel).

BELANGRIJKSTE BEVINDINGEN

De resultaten van alle studies werden verwerkt in hoofstukken 2-8 van deze doctoraatsthesis.

Thema 1 – Kwaliteit van sterven voor bewoners met dementie in woon-en zorgcentra

Van alle overlijdens van de geïdentificeerde rusthuisbewoners had 46.7% dementie op het moment van overlijden (hoofdstuk 3); van wie 106 (53.5%) gevorderde dementie, 56 (28.3%) ernstige dementie en 36 (18.2%) matige dementie. In de laatste maand van het leven, had 95.5% een potentieel levensbedreigende aandoening zoals een eet/drinkprobleem (65.7%), koorts (42.9%) of een pneumonie (32.3%). Het enige significante verschil tussen drie verschillende stadia van dementie (gevorderde dementie, ernstige dementie, matige dementie) was dat de prevalentie van een eet/drinkprobleem in de laatste maand van het leven toenam met de ernst van de dementie (p=0.03). De meest voorkomende symptomen in de laatste maand van het leven waren pijn, angst, ongerustheid, opwinding en weerstand bieden tegen zorg (gemeten met de Symptom Management End-of–Life in Dementia of SM-EOLD). De aanwezigheid van symptomen verschilde niet significant voor de verschillende stadia van dementie. De meest voorkomende symptomen in de laatste week van het leven bleken moeilijkheden met slikken en pijn (gemeten met de Comfort Assessment in Dying End-of-Life in Dementia of CAD-EOLD). De kwaliteit van leven (gemeten met de Quality of Life in Late Stage Dementia or QUALID, score van 11 best tot 55 slechtst) was 28.9 en was vergelijkbaar voor de drie stadia van dementie. Decubitus was aanwezig in 26.9%, incontinentie in 89.2% en cachexie in 45.8%. Fixatie van het bovenlichaam of ledematen werd gebruik in 21.4%. De plaats van overlijden was het ziekenhuis in 8.9%. Bij het vergelijken van de drie stadia van dementie vonden we dus weinig verschillen aangaande de klinische complicaties, symptomen en kwaliteit van sterven.

Thema 2 – Palliatieve zorg voor bewoners van woon-en zorgcentra met dementie

In hoofdstuk 7, onderzochten we (vanuit de studie rond voorafgaande zorgplanning in woon- en zorgcentra, 2006) de associatie tussen palliatieve zorg en de aanwezigheid van voorafgaande instructies vanuit de bewoner (schriftelijke voorafgaande wilsverklaring of het aanwijzen van een vertegenwoordiger die beslissingen kan nemen in het geval van incompetentie) of voorafgaande instructies van de arts (in het bewonersdossier gedocumenteerde voorafgaande instructies van de huisarts betreffende specifieke behandelingen aan het einde van het leven, bv het stopzetten of niet opstarten van reanimatie) van 764 bewoners met dementie in 345 woon-en zorgcentra in Vlaanderen. Bewoners met dementie kregen palliatieve zorg van de huisarts in 50.7% van de gevallen, van zorgverleners (verzorgenden of verpleegkundigen van het woon-en zorgcentrum) in 60.2%, van “de palliatieve functie” binnen het woon- en zorgcentrum (dit kon gaan om een bewonersbespreking door de palliatieve werkgroep, de betrokkenheid van de palliatief referentieverpleegkundige of de betrokkenheid van de coördinerend en raadgevend (CRA) arts) of palliatieve zorg in het ziekenhuis (dit kon gaan om de betrokkenheid van het palliatief support team in het ziekenhuis of een opname op de palliatieve eenheid van een ziekenhuis) in 3.8%. Bewoners die palliatieve zorg ontvingen van zorgverleners in het woon-en zorgcentra of van hun huisarts hadden respectievelijk, drie keer (OR 3.10; BI, 2.07-4.65) en twee keer (2.06; BI, 1.37-3.09) meer kans om een voorafgaande instructie vanuit de huisarts te hebben dan zij die geen palliatieve zorg ontvingen. De associatie tussen palliatieve zorg en een voorafgaande instructies van de bewoner was niet significant.

In hoofdstuk 4, (the Dying Well with Dementia study, 2010) wordt een overzicht gegeven van de incidentie van palliatieve zorg en mogelijk levensverlengende behandelingen van 205 overleden bewoners met dementie (van wie 106 met gevorderde dementie) in de 69 woon-en zorgcentra. Een palliatief behandeldoel was aanwezig in 89.2% van de gevallen en verschilde niet significant tussen de stadia van dementie (p=0.12). Palliatieve zorg werd in 84.5% geboden door de huisarts en vanuit de palliatieve functie van het woon- en zorgcentrum (di een bewonersbespreking door de palliatieve werkgroep in 48.8%, de betrokkenheid van de palliatief referentieverpleegkundige in 66.3% of de betrokkenheid van de coördinerend en raadgevend arts in 26.5%) in 81.9%. Externe gespecialiseerde palliatieve services (di externe palliatieve thuiszorgequipe of een opname op een palliatieve eenheid) werden betrokken in 11.2%. Samen genomen werd palliatieve zorg verkregen door 90.1% van de bewoners met gevorderde dementie, door 72.9% van de bewoners met ernstige dementie en door 77.8% van de bewoners met matige dementie in (p=0.02).

Thema 3 – Potentieel levensverlengende behandelingen in de laatste week van het leven en ziekenhuisopnames

In hoofdstuk 4 rapporteren we dat 30.8% van bewoners met dementie in de laatste levensweek één of meerdere potentieel levensverlengende behandelingen kreeg, bijvoorbeeld antibiotica in 19.5% of de kunstmatige toediening van vocht en voeding in 20.6%. Niettegenstaande dat bewoners met een palliatief zorgdoel minder vaak levensverlengende behandelingen kregen (OR 0.16; BI, 0.03-0.78), kreeg 7.8% (van degene met een palliatief zorgdoel) kunstmatige toediening van vocht en voeding en werd 16.2 opgenomen in het ziekenhuis in de laatste maand van het leven.

In hoofdstuk 7 onderzochten we ziekenhuisopnames van rusthuisbewoners met dementie in de laatste levensmaand. In de laatste maand van het leven werd 19.5% opgenomen in het ziekenhuis, van wie 4.6% op een intensieve zorgen afdeling. Bewoners met ernstige of gevorderde dementie hadden evenveel kans om opgenomen te worden in het ziekenhuis dan bewoners met matige dementie. Volgens het oordeel van de verpleegkundige, gebeurden geen van deze ziekenhuisopnames op vraag van de bewoner, 37% op vraag van familie en 29% voor verlenen van curatieve of levensverlengende behandelingen. In bijna alle gevallen werd er informatie over de verpleegkundige zorg en medische behandelingen (92%) mee getransfereerd naar het ziekenhuis; in 19% informatie over wensen van de bewoner over toekomstige zorg (bv mbt cardiopulmonaire resuscitatie). Bewoners zonder een voorafgaande instructie vanuit de huisarts (in het bewonersdossier gedocumenteerde voorafgaande instructies van de huisarts betreffende specifieke behandelingen aan het einde van het leven, bv het stopzetten of niet opstarten van reanimatie) werden vaker gehospitaliseerd (OR 4.9; 95% BI: 2.1-11.1).

In hoofdstuk 3 en 4 rapporteren we de plaats van overlijden voor 205 rusthuisbewoners met dementie. De plaats van overlijden was het woon- en zorgcentra in 90.3% van de gevallen, een algemene ziekenhuisafdeling of een afdeling intensieve zorgen in 8.7% en een palliatieve eenheid in het ziekenhuis in 1%. In hoofdstuk 4 onderzochten we in welke mate potentieel levensverlengende behandelingen (bv een transfer naar een ziekenhuis in de laatst levensfase) mede voorkomen met een palliatief behandeldoel. In het algemeen werd 19.5 opgenomen in het ziekenhuis in de laatste maand van het leven, variërend van 14.4% voor bewoners met gevorderde dementie tot 30.6% voor bewoners met matige dementie (p=0.09). Degene met een palliatief zorgdoel werden minder vaak getransfereerd naar een ziekenhuis (16.2%) dan degene zonder palliatief zorgdoel (50%). Bewoners met een palliatief zorgdoel die werden getransfereerd naar het ziekenhuis hadden gevorderde dementie in 43.8%.

In hoofdstuk 7, (gebruikmakend van de studie rond voorafgaande zorgplanning in woon- en zorgcentra, 2006) rapporteerden we dat de plaats van overlijden het woon-en zorgcentra was in 83.9% en het ziekenhuis (inclusief een palliatieve eenheid) in 16.1%. De kans op sterfte in het ziekenhuis was drie keer kleiner als er een voorafgaande instructie vanuit de arts aanwezig was (OR 0.38; BI, 0.21-0.70).

Thema 4 – Voorafgaande zorgplanning en voorafgaande instructies vanuit de arts

In hoofdstuk 7 (gebruikmakend van de studie rond voorafgaande zorgplanning in woon- en zorgcentra, 2006) onderzochten we de prevalentie en inhoud van voorafgaande instructies in het dossier voor 764 bewoner met dementie die stierven in 345 woon-en zorgcentra. De studie toonde aan dat 61.7% van de overleden bewoners met dementie een voorafgaande instructies in het dossier had. Een voorafgaande instructie vanuit de bewoner was aanwezig in 10.3%: een vertegenwoordiger die in geval van incompetentie beslissingen kan nemen was aangesteld in 8.1% en een schriftelijke voorafgaande wilsverklaring was aanwezig in 3.2%. De meest voorkomende wilsverklaring betroffen het niet meer hospitaliseren (2.5%) en het niet meer reanimeren (2.1%). Een voorafgaande instructie vanuit de arts (in het bewonersdossier gedocumenteerde voorafgaande instructies van de huisarts betreffende specifieke behandelingen aan het einde van het leven, bv het stopzetten of niet opstarten van reanimatie) was aanwezig in 59.2% van welke een niet meer transfereer beslissing (46.3%) en een niet meer reanimeer beslissing (36.1%) de meest frequente waren.

In hoofdstuk 6, rapporteerden verpleegkundigen/verzorgenden, huisartsen en nabestaanden de prevalentie en inhoud van voorafgaande zorgplannen. Hierdoor was het mogelijk om de congruentie tussen deze respondenten te meten, dit voor 205 bewoners met dementie in woon-en zorgcentra (Dying Well with Dementia study). Aangaande medische behandelingen en de gewenste richting van zorg in de laatste levensfase rapporteerden artsen dat bewoners met dementie hun wens geuit hadden in 11.8%. De huisarts en verpleegkundige/verzorgende spraken met de bewoner in 22.0% en 9.7% over de gewenste zorg aan het einde van het leven. De congruentie over de aanwezigheid van voorafgaande instructies vanuit de bewoner of het aanstellen van een vertegenwoordiger tussen de huisarts, verpleegkundige/verzorgende en nabestaanden was laag. Een voorafgaande instructie vanuit de huisarts was aanwezig in 77.3% en besproken met de bewoner in 13.0% en met een nabestaande in 79.3%. De congruentie tussen huisartsen en verpleegkundigen/verzorgenden over de aanwezigheid van een voorafgaande instructie vanuit de huisarts was matig.

BEKNOPTE DISCUSSIE

Uit dit onderzoek blijkt dat bijna de helft van alle bewoner in woon-en zorgcentra sterven met dementie en helft hiervan sterft met gevorderde dementie. Deze studie levert zo belangrijke gegevens over de omvang van het probleem van sterven met dementie in woon- en zorgcentra. Gezien de verwachte toename van personen met dementie en personen die sterven met dementie, bevestigen onze resultaten dat sterven met dementie in woon-en zorgcentra een zeer belangrijke uitdaging vormt voor onze gezondheidszorg.

Thema 1 - Kwaliteit van sterven voor bewoners met dementie in woon-en zorgcentra

Een grote meerderheid van bewoners met dementie in woon-en zorgcentra ontwikkelt ernstige klinische complicaties en symptomen in de laatste fase van het leven, ongeacht het stadium van dementie. De meest voorkomende klinische complicaties zijn een eet-of drinkprobleem, koortsepisodes en een pneumonie. Ongeacht het stadium van dementie zijn de meest gerapporteerde symptomen in de laatste maand van het leven pijn, angst en onrust. In de laatste week van het leven zijn incontinentie, doorligwonden, cachexie en dehydratatie veel voorkomende klinische karakteristieken. Het vergelijken van onze data met andere studies is moeilijk gezien verschillen in populatie en onderzoeksmethodes. Desondanks, in studies uit de VS en Italië, welke gelimiteerd zijn tot personen met gevorderde dementie, werden gelijkaardige complicaties en symptomen beschreven. Belangrijk is dat we aanvullend kunnen stellen dat klinische complicaties in de laatste maand (bv pneumonie), comfort, kwaliteit van leven in de laatste week en symptoomlast niet verschillen tussen de stadia van dementie. Bijgevolg zou onderzoek naar de kwaliteit van levenseindezorg niet enkel moeten focussen op bewoners met gevorderde dementie. Het zou ook zinvol zijn om in woon- en zorgcentra symptomen en complicaties regelmatig en systematisch te beoordelen en om zorgverleners, bewoners en familieleden voor te bereiden op de klinische complicaties die kunnen optreden in de laatste fase van het leven, ongeacht het stadium van dementie. Een recent gepubliceerde “white paper” van de European Association for Palliative Care (EAPC) stelt mede dat een exclusieve focus op enkel personen met gevorderde dementie niet optimaal is.

Onze data werd vergeleken met een gelijkaardige studie van Nederland, meer specifiek werd de kwaliteit van sterven en levenseindezorg van Vlaamse bewoners en Nederlandse verpleeghuisbewoners vergeleken (beoordeeld door de nabestaande). De symptoomfrequentie en tevredenheid met de zorg volgens nabestaanden was gelijkaardig in de twee landen. Treffend is dat er verschillen gevonden werd in comfort en symptoomlast tijdens de stervensfase wat wijst op een hogere kwaliteit van sterven in Nederland. Meer specifiek ervaren Nederlandse verpleeghuisbewoners minder discomfort en Vlaamse rusthuisbewoners meer problemen met slikken, onrust, angst, pijn en andere symptomen, zoals beoordeeld door de nabestaande. Verschillende verklaringen werden geformuleerd: de continue (24u/24u) aanwezigheid van Nederlandse verpleeghuisartsen, de mogelijks betere training van verpleeghuisartsen in de complexe zorg van personen met dementie of een betere voorbereiding op de stervensfase van nabestaanden in Nederland. Deze bevinding kan ons helpen om de levenseindezorg voor personen met dementie te optimaliseren.

Thema 2 – Palliatieve zorg voor bewoners van woon-en zorgcentra met dementie

Onze resultaten tonen aan dat een grote meerderheid van bewoners met dementie palliatieve zorg ontvangt (83.1%) op een bepaald moment voor overlijden, en dat het behandeldoel in de laatste week van het leven in de meerderheid van de gevallen gericht is op palliatie of comfort (89.2%). De cijfers bevestigen de trend dat palliatieve zorg steeds meer erkend wordt voor ook niet-kanker patiënten zoals personen met dementie. De Wereldgezondheidsorganisatie (WGO) en recente aanbevelingen van de European Association for Palliative Care (EAPC) promoten palliatieve zorg ook als de gewenste aanpak voor oudere personen met leeftijd gerelateerde cognitieve problemen – niet enkel in de terminal fase maar ook in de eerdere stadia van de aandoening. Opmerkelijk is dat een belangrijke minderheid (bijna twee op tien) van de bewoners met dementie – van wie bewoners met gevorderde dementie (1 op 10) – geen enkele vorm van “palliatieve zorg” kreeg op enig moment in de tijd. Bewoners met dementie hebben vaak een belangrijke palliatieve zorgnoden en een palliatieve zorgvisie zou mogelijk de kwaliteit van sterven positief kunnen beïnvloeden. Verder hadden bewoners met een palliatief zorgdoel minder kans om potentieel levensverlengende behandelingen te krijgen, dit ondanks de bevinding dat voor een minderheid van de bewoners potentieel levensverlengende behandelingen samengingen met een palliatieve zorgaanpak. De vroegere visie op palliatieve zorg gaat uit van een duidelijk te onderscheiden transitie van zorg gericht op levensverlenging of genezing naar comfortzorg waarbij palliatieve zorg pas in de laatste dagen of weken van het leven relevant is. Voor personen met dementie, waarbij er vaak een hoge palliatieve zorgnood is, lijkt het gepast aan te bevelen dat ze gebaat kunnen zijn met een palliatieve zorgcultuur in het woon-en zorgcentra (als een soort van supportieve zorg/algemene zorgvisie), niet alleen tijdens de terminale fase maar eerder in het ziektetraject.

Palliatieve zorg werd in een meerderheid geboden door de huisarts en door zorgverleners van het woon- en zorgcentrum (bv de palliatief referentieverpleegkundige en de coördinerend en raadgevend arts) en in mindere mate door externe gespecialiseerde palliatieve diensten (di externe palliatieve thuiszorgequipe of een opname op een palliatieve eenheid). Vergeleken met andere landen heeft België heeft een uniek systeem van palliatieve zorgverlening in woon- en zorgcentra. Ieder woon-en zorgcentrum moet de reguliere zorgverleners ondersteunen door zorgverleners met palliatieve expertise die in het woon- en zorgcentru aanwezig zijn (nl de coördinerend raadgevend arts of een palliatief referentieverpleegkundige). Op basis van onze resultaten kunnen we stellen dat voor bewoners met dementie deze interne palliatieve zorg meer en meer aanwezig blijkt in de dagelijkse zorg in woon-en zorgcentra. Echter, we kunnen op basis van onze studie geen uitspraken doen over de de kwaliteit van de geleverde palliatieve zorg zelf. Belangrijke aandachtspunten hierbij zijn dat de coördinerend raadgevend arts soms beperkt aanwezig is in het woon-en zorgcentra en belast is met vele taken waarvan palliatieve zorg slechts één is. Ook is er tot nu toe weinig verplichte opleiding voor CRA of referentieverpleegkundigen die specifiek gericht is op palliatieve zorg. Netwerken voor palliatieve zorg in Vlaanderen zouden ook meer betrokken kunnen worden bij de formele en permanente opleiding van coördinerend en raadgevend artsen en palliatief referentieverpleegkundigen.

Thema 3 – Potentieel levensverlengende behandelingen in de laatste week van het leven en ziekenhuisopnames

Drie op de tien bewoners met dementie in woon-en zorgcentra krijgen in de laatste week van het leven potentieel levensverlengende behandelingen zoals antibiotica of kunstmatige toediening van vocht of voedsel en bijna één of vijf werd in de laatste maand van het leven opgenomen in het ziekenhuis (van wie een kwart op een afdeling intensieve zorgen). Deze behandelingen zijn mogelijk niet optimaal voor het bevorderen van comfort in de laatste levensfase, en in sommige gevallen kunnen ze ongewenst zijn en geassocieerd met een slechte kwaliteit van levenseindezorg, zoals blijkt uit andere studies. Deze resultaten komen overeen met studies uit de VS die gelijkaardige potentieel levensverlengende behandelingen aan het einde van het leven beschrijven voor personen met gevorderde dementie.

Verder hadden bewoners met een palliatief zorgdoel minder kans om potentieel levensverlengende behandelingen te ontvangen in de laatste week van het leven of om opgenomen te worden in het ziekenhuis in de laatste maand van het leven dan zij zonder palliatief zorgdoel. Echter, een belangrijke minderheid van de bewoners met een palliatief zorgdoel kregen in de laatste week potentieel levensverlengende behandelingen zoals toediening van kunstmatige voeding of vocht in de laatste week van het leven of een ziekenhuisopname in de laatste fase van het leven. Deze combinatie is betwistbaar, zeker voor bewoners met gevorderde dementie. Eerder onderzoek toonde ook aan dat levenseindezorg personen met dementie vaak bestaat uit veel interventies als labotesten, intraveneuze medicatie, weinig pijnbestrijding en weinig aandacht voor emotionele, sociale of spirituele aspecten.

Thema 4 – Voorafgaande zorgplanning en voorafgaande instructies vanuit de arts

Prevalentie en karakteristieken van voorafgaande zorgplanning en voorafgaande instructies vanuit de arts

De prevalentie van voorafgaande zorgplanning door bewoners met dementie in woon-en zorgcentra is eerder laag. Zowel de prevalentie van voorafgaande instructies in het dossier (di schriftelijke voorafgaande wilsverklaring en of aanwijzen van een vertegenwoordiger die in geval van incompetentie beslissingen kan nemen) als mondelinge communicatie rond het levenseinde (tussen zorgverleners en de bewoner met dementie) blijken eerder laag. Opmerkelijk is dat vanuit de bewoner geïnitieerde voorafgaande zorgplanning minder vaak voorkomt dan voorafgaande instructies van de arts (in het bewonersdossier gedocumenteerde voorafgaande instructies van de huisarts betreffende specifieke behandelingen aan het einde van het leven, bv het stopzetten of niet opstarten van reanimatie). Deze voorafgaande instructies van de huisarts werden echter zelden besproken met de bewoner zelf. Verschillende redenen voor de lage prevalentie van voorafgaande zorgplanning zijn beschreven; zo wordt de diagnose van dementie niet altijd formeel gesteld of besproken met de bewoner, wordt dementie niet gezien als een terminale aandoening, is de bewoner niet voldoende vertrouwd met de mogelijkheid van voorafgaande zorgplanning, artsen kunnen terughoudend zijn om zulke gesprekken te starten of het belang van voorafgaand zorgplanning wordt niet tijdig ingezien. Voorafgaande zorgplanning wordt als één van de belangrijkste aspecten van een goede levenseindezorg beschouwd, in het bijzonder voor bewoners met dementie die aan het einde van het leven vaak niet meer in staat zijn hun wensen te uiten. Bovendien ervaren bewoners met dementie aan het einde van hun leven belangrijke klinische complicaties, het is mede daarom van belang om (levenseinde)zorg vroeg in het ziekteverloop bespreekbaar te maken en zo bewoners maximaal te betrekken bij het plannen van hun (levenseinde)zorg.

Mate van congruentie tussen verpleegkundige/verzorgende, huisarts en nabestaanden aangaande voorafgaande zorgplanning en voorafgaande instructies vanuit de arts

Opvallend is dat de mate van overeenkomst tussen zorgverleners (huisarts en verpleegkundige/verzorgende) en nabestaanden aangaande de inhoud van voorafgaande zorgplanning laag is. Zowel de bewoner, huisarts, verpleegkundige en nabestaanden kunnen betrokken worden bij het nemen van beslissingen en idealiter is er consensus over wat besproken is en welke de toekomstige zorgvisie is. Deze consensus kan een positieve invloed hebben op de continuïteit van de zorg en vergroot de kans dat levenseindezorg overeenstemt met de wensen van de bewoner. Onze gegevens suggereren dat de communicatie over toekomstige zorg niet enkel beperkt is maar ook dat beslissingen niet altijd in samenspraak gemaakt worden. Initiatieven om de congruentie tussen de verpleegkundige/verzorgende, huisarts en nabestaanden aangaande voorafgaande zorgplanning te verbeteren kunnen de complexe levenseindezorg van bewoners met dementie ondersteunen.

Associatie tussen plaats van overlijden – kwaliteit van sterven – palliatieve zorg en voorafgaande zorgplanning en voorafgaande instructies vanuit de arts

Bewoners met dementie hebben minder kans op een ziekenhuisopname als er een voorafgaande instructie vanuit de arts gedocumenteerd was. Wanneer een voorafgaande instructie vanuit de arts aanwezig was in het bewonersdossier werden bewoners minder getransfereerd naar het ziekenhuis aan het einde van hun leven. Deze associatie onderstreept het belang van dergelijke orders op de plaats van overlijden. Ze kunnen zorgverleners van het woon-en zorgcentra helpen in hun besluit name op acute momenten. Verder onderzochten we de associatie tussen de kwaliteit van sterven en voorafgaande zorgplanning. Onze gegevens tonen dat er een sterke associatie is tussen schriftelijk voorafgaande instructies vanuit de bewoner en de kwaliteit van sterven. Bewoners met dementie met een voorafgaande instructie (schriftelijke voorafgaande wilsverklaring en of aanwijzen van een vertegenwoordiger die in geval van incompetentie beslissingen kan nemen) scoorden hoger inzake emotioneel welbevinden tijdens het sterven (minder angst en onrust tijdens het sterven). Deze sterke relatie moet verder onderzocht worden. Tot slot onderzochten we de associatie tussen palliatieve zorg en voorafgaande instructies vanuit de arts. De aanwezigheid van een voorafgaande instructie vanuit de arts was positief geassocieerd met het krijgen van palliatieve zorg.

CURRICULUM VITAE OF AN VANDERVOORT

CURRICULUM VITAE

An Vandervoort was born on 27 September 1982 in Bree, Belgium, as the second child of Gerard Vandervoort and Christine Proot.

She attended secondary school at the Sint-Augustinusinstituut in Bree. At the PXL university college (Hasselt), she obtained her Bachelor in Nursing in 2005 and at the Katholieke Universiteit Leuven a Master in Nursing Science in 2007.

She started working as a registered nurse at a geriatric ward in a general hospital (Ziekenhuis-Oost Limburg, Genk). In August 2008, she joined the Vrije Universiteit Brussel & Ghent University End-of-Life Care Research Group, where she worked as a junior researcher on a PhD project on nursing home residents dying with dementia in Flanders Belgium (the Dying Well with Dementia Study), supervised by Prof. Dr. Luc Deliens and co-supervised by Prof. Dr. Lieve Van den Block.

She currently works at the PXL university college (Hasselt), department Healthcare

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AN VANDERVOORT

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