

# **Hospital admissions at the end of life**

Reasons, appropriateness and avoidability

THIJS REYNIERS

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# Hospital admissions at the end of life

Reasons, appropriateness and avoidability

**THIJS REYNIERS**

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## **CHAPTERS 2-8 ARE BASED ON THE FOLLOWING PUBLICATIONS**

### **CHAPTER 2**

Reyniers T, Deliens L, Pasman R, Morin L, Addington-Hall J, Frova L, Cardenas-Turanzas M, Onwuteaka-Philipsen B, Naylor W, Ruiz-Ramos M, Wilson D, Loucka M, Csikos A, Rhee JY, Teno J, Cohen J, Houttekier D. *International variation in place of death of older persons who died from dementia in 14 European and non-European countries*. Journal of the American Medical Directors Association. 2015;16(2):165-71

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### **CHAPTER 4**

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### **CHAPTER 5**

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# VOORWOORD

Vier jaren geleden was mijn besluit vast en zeker: ik zou onderzoeker worden; en dat is ook nu niet anders. Maar tussen dan en nu is er wel het een en ander veranderd. Het schrijven, indienen en verdedigen van dit doctoraat is dan ook – als mijlpaal in zekere zin – maar een snapshot van de weg die werd afgelegd. Daarom wil ik deze kans ook benutten om even stil te staan en de mensen te bedanken die samen met mij deze weg hebben afgelegd, die mij de weg hebben getoond, de weg enorm ervaringsrijk hebben gemaakt en die mij – onderweg – hebben gesteund.

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# PART I

General Introduction



# CHAPTER 1

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## Introduction and Research Aims

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## GENERAL INTRODUCTION

The acute hospital setting consistently remains a frequent place of death in most developed countries;<sup>1</sup> in Belgium more than half of all deaths occur in the hospital setting.<sup>2</sup> To reduce the number of hospital deaths, there has been an increased interest in reducing the number of end-of-life hospital admissions.<sup>3</sup> The present dissertation aims to shed some light on the complexity of the reasons for and circumstances leading to such admissions and to provide a more thorough understanding about the appropriateness and avoidability of these admissions in order to add some value to the debate concerning place of death and to provide implications for policy and practice, to enable further improvements in end-of-life care provision.

However, before addressing the specific research aims of this study, a short introduction will be provided in order to situate this dissertation into the wider societal, demographical and scientific developments that have taken place and that have changed death and dying in contemporary society. First, a brief background explains how the hospital setting has become an important place of death and why there has been an increased interest in 'place of death'. Next, it is described how end-of-life care policy and research hitherto have been focusing on the home setting as the most desirable place of death, as well as how research shows that end-of-life care provision within the acute hospital setting is suboptimal. The more recent focus on end-of-life hospital admissions is then explained, together with some unresolved issues concerning this topic. Next, an explanation is provided for why this dissertation has given particular attention to the perspectives of primary health care providers and informal caregivers, and to hospital deaths among older persons with a dementia-related disease.

Subsequently, the research aims are stated, the study design and methodologies used are described, and an outline of this dissertation will be discussed.

## BACKGROUND

### CHANGED PATTERNS OF DEATH AND DYING

#### *Changes in the causes of death*

Mortality has changed profoundly since the late nineteenth century, as a result of several societal changes.<sup>4,5</sup> Improvements in standards of living, health behaviour, hygiene and nutrition, along with other public health measures, such as public sanitation and immunization, have resulted in an epidemiological transition.<sup>4</sup> Mortality at a young age has dropped dramatically, the average life expectancy has risen and the main causes of death have shifted from infectious diseases to chronic and degenerative diseases, such as cancer.<sup>4</sup>

Life expectancy at birth has risen globally from 48 years in 1955 to 70 in 2012, and as a result, the global population is ageing.<sup>6,7</sup> Moreover, the global older population is itself ageing, meaning that the proportion of the oldest old – those aged over 80 years – within the population of those aged older than 60, has increased from seven to 14% between 1950 and 2013.<sup>7</sup> As a result, it is estimated that there is and will be a growing number of people experiencing illnesses related to old-age, such as dementia-related diseases, and disability.<sup>7</sup>

As the main causes of death have shifted from infectious diseases to chronic and degenerative diseases, this also means that the time before death is characterised by longer periods of disability and longer dying trajectories with a higher prevalence of symptoms such as pain, breathlessness, mental confusion or incontinence.<sup>5</sup> A study in the USA indicated that symptom burden near the end of life even has increased between 1998 and 2010, despite end-of-life care policy and research aimed at reducing such burdens.<sup>8</sup> Also, it has been suggested that most people whose death would not be unexpected tend to follow one of three different trajectories of functional decline; those who maintain comfort and functioning for a substantial period, followed by a short period of evident decline – mostly cancer patients; those who have long-term limitations with intermittent exacerbations – mostly organ system failure patients; and those with ‘prolonged dwindling’ – mostly frail older patients and those with a dementia-related disease.<sup>9,10</sup>

#### *Changes in informal care*

The late twentieth century is characterised by changes in household structures (e.g. smaller family size or more two-earner households), which has made it more difficult to provide informal care at home.<sup>5</sup> Moreover, there is a growing propensity of older people living apart from their children and many of them living alone – mostly widows – as a result of gender differences in longevity and

marriage patterns (e.g. increase in number of divorces).<sup>5;11</sup> As a result, there is a reduced availability of informal caregivers, which is considered to be crucial in enabling people to die at home.<sup>12;13</sup>

### ***Hospitalisation of death trend***

The hospital setting has become a common place of death. Throughout the nineteenth and twentieth centuries, medical knowledge and care increasingly became consolidated in hospitals.<sup>14-16</sup> Moreover, a growing desire to postpone death and a belief in the ability of hospital medicine to do this, coupled with a reduced availability of home care for chronic and terminally ill patients, has led to an increase in the number of hospital deaths.<sup>12;16;17</sup> Consequently, the proportion of deaths occurring in hospital has been rising steadily throughout the twentieth century.<sup>5</sup> For example, between 1950 and 1994 the proportion of hospital deaths in Canada has increased from 51% to 81%,<sup>18</sup> and from 50% to 66% between 1960 and 1996 in England.<sup>5</sup> Studies exploring place of death in the twenty-first century showed that in most high-income countries the proportions of people dying in hospital are ranging between 34% in New Zealand and the Netherlands to 78% in Japan.<sup>1;19</sup>

## **AN INCREASED INTEREST IN PLACE OF DEATH: EARLY CRITICS OF HOSPITAL DEATH**

### ***The medicalization of death***

The medical profession during the eighteenth century could be best described as ‘bedside medicine’; pathology was speculative, diagnosis was founded upon extrapolation of the patient’s self-report of the course of the illness and practitioners were dependent on fees.<sup>15</sup> During this time period having a ‘natural death’ – a death that was not regarded as too early – and therefore being able to postpone it, had become a mark of distinction and privilege.<sup>14;20</sup> Dying of old age rather than suddenly was more likely to be for those who could afford it, the bourgeoisie in particular.<sup>14</sup>

As medicine became more effective in treating diseases throughout the twentieth century, death and dying has been brought under the scrutiny and control of the medical profession.<sup>17</sup> Moreover, dying while undergoing treatment by clinically trained doctors has increasingly become to be perceived as a civil right;<sup>14</sup> and death has become something that needed to be avoided.<sup>16</sup>

As a reaction, several social scientists have argued that death and care for the dying had become too medicalised; that death is viewed as a medical failure, a technical problem that needs to be prevented at all cost, rather than something natural, that is an inevitable, normal part of life and the image of people dying alone with tubes in the hospital was typically portrayed.<sup>14;17;21-24</sup> For example, one study in particular documented how the subject of death or limited life expectancy was generally avoided among hospital health professionals.<sup>25</sup>

### ***Institutionalisation of death***

Another widely used critique is that death has become institutionalized;<sup>5;21;24;26</sup> several social scientists have observed a segregation of the dying from society, into hospitals in particular - where people die isolated and alone.<sup>27</sup> From their point of view, death and dying has been removed from public view, and as a result of that, people increasingly are no longer used to the notion of death.<sup>26;28</sup> Moreover, as enabling people to die at home has become more difficult – given the reduced availability of informal care,<sup>5;17</sup> it is suggested that this might be a self-perpetuating process; as there is a decline in home deaths, families might increasingly be unprepared for providing end-of-life care at home and become inadequately supported to do so, eventually resulting in more hospital deaths.<sup>3;29</sup> Typically an institutionalized death is contrasted to a death at home, the latter being in familiar surroundings.<sup>12</sup>

### ***Palliative care and the good death***

Throughout the twentieth century a number of attitudinal and cultural changes have occurred, such as increased intolerance of pain and suffering, increased value being put on personal autonomy, individualism and the right to self-determination.<sup>5;11</sup> Dying, increasingly, has been subject to a wish for control, illustrated by the rising support for euthanasia.<sup>5;30;31</sup> As a result, there has been a rising concern about the circumstances in which death and dying takes place, and achieving a ‘good death’ has become more important in the minds of people in many high-income countries.<sup>11</sup> It is against this background, together with an increased concern about care for the dying among health professionals, that palliative care has emerged, on both sides of the Atlantic – a widely used milestone is the founding of the St. Christopher’s Hospice in 1967 by Dame Cicely Saunders.<sup>5;17;30;32</sup> From the start, there has been a firm belief that such a good death is less likely to be achieved in the hospital setting.<sup>30;33;34</sup>

## **HOME AS THE MOST DESIRABLE PLACE OF DEATH**

### ***The home as the most preferred place of death***

As place of death has become a growing area for end-of-life care research, there has been a growing number of studies exploring where people – mostly terminally ill patients – prefer to die.<sup>35</sup> Within these studies, it is generally concluded that the home setting is the most preferred place of death among patients with a life-threatening illness, and that a majority prefer to die out-of-hospital.<sup>35-41</sup> In Belgium, it has been found that of all chronic-terminally ill patients who stated such a preference, 58% preferred to die at home, 31% in a care home, 7% in a palliative care unit and only 5% in hospital.<sup>42</sup>

It is important to note that other studies have suggested that such a preference for the home setting as the place for end-of-life care or as place of death might change in favour of hospital as death approaches.<sup>43,44</sup> Moreover, while older people might prefer to die at home in ideal circumstances, they can imagine that they would choose to be cared for elsewhere when dying, if circumstances to achieve a good death were not ideal.<sup>45</sup> Reasons such as having limited informal care and preferring safe professional care can lead to patients preferring not to die at home.<sup>46,47</sup>

### ***Policy aimed at achieving home death***

Given that research has shown that a majority prefer to die at home, national health care policies in several high-income countries aim to support end-of-life care and death at home (or in familiar surroundings) for those residing at home or in the nursing home.<sup>11;35;48-50</sup> Furthermore, the setting is considered to be important for the quality of death, as it entails important aspects of care, such as the type and intensity of care that can be delivered and the relationship of the caregivers to the dying patient.<sup>51</sup> It is assumed that death at home contributes to the overall quality of life of patients and families.<sup>12;52-54</sup> The proportion of home deaths has been introduced as an indicator of quality of palliative care, in the sense that a higher proportion of home deaths reflects a better quality of end-of-life care provision.<sup>55</sup> Hence, an end-of-life care policy aimed at supporting patients to die at home, can improve the quality of life of patients at the end of life.

Moreover, it is assumed that facilitating home deaths might reduce health care expenditure;<sup>12</sup> inpatient deaths are shown to be more expensive than home deaths and shifting end-of-life care from the hospital to home might therefore reduce end-of-life care spending,<sup>3;11;53;56</sup> although conclusive evidence is lacking.<sup>57;58</sup> In Belgium, a non-profit sickness fund has shown that for cancer patients, health care costs for those who died in hospital were 100% higher than for those who died at home and 48% higher than for those who died in a nursing home.<sup>59</sup>

## **END-OF-LIFE CARE IN THE ACUTE HOSPITAL SETTING**

Research focusing on end-of-life care provision within the hospital setting has found that there are several cultural and structural aspects within the hospital setting that may impede adequate end-of-life care provision.<sup>60-64</sup> An important cultural aspect is its predominant focus on life-prolongation and cure, in which acts to save the patient's life are considered heroic and palliative care may be perceived as 'giving up on the patient' and hence is negatively approached.<sup>65</sup> Structural barriers have also been found; for example, because of strict standards and regulations for clinical care and infection control, it can sometimes be very difficult to achieve a comfortable, homely environment, properly adjusted to the patient's preferences,<sup>66</sup> and a lack of privacy can lead to patients being



dissatisfied with hospital care.<sup>67</sup> Moreover, several studies reported that health care professionals within this setting often experience discomfort in attending to dying patients and therefore experience difficulties in providing adequate end-of-life care, e.g. less attention is paid to dying patients.<sup>25;65;68</sup>

As it is shown that many patients are dying in the acute hospital setting,<sup>1</sup> this is in sharp contrast with the findings that the provision of end-of-life care in this setting is suboptimal.<sup>64;65</sup> One approach to improving this has been the development of pathways such as the Liverpool Care Pathway in the UK,<sup>64</sup> which provided guidelines for best practice, focusing on symptom control, appropriate discontinuation of active treatments and psychological, social and spiritual care of patients and their families.<sup>69</sup> However, more recently the use and appropriateness of such pathways in the acute hospital setting as a means to improve care in the last days of life has been subject to fierce debate.<sup>69-72</sup> New ways for improving end-of-life care provision in the acute hospital setting are being sought.<sup>71</sup>

## **HOSPITAL ADMISSIONS AT THE END OF LIFE**

Although the proportion of people dying in hospital has decreased slightly in several countries – e.g. in Belgium it has decreased from 55.1% to 51.7% between 1998 and 2007 – and despite countries such as the Netherlands or New Zealand reporting relatively low proportions (34%), the acute hospital setting consistently remains a frequent place of death in many high-income countries.<sup>1;2;18;57;73</sup> Moreover, as end-of-life care provision within this setting is considered to be suboptimal;<sup>65</sup> the need to further reduce the number of hospital deaths also remains.

To gain a wider picture in these hospital deaths there has been an increased interest in the use of hospital services in end-of-life care research.<sup>74-76</sup> Among patients who died non-suddenly it has been found that the use of hospital services increases exponentially in the last months and weeks of life.<sup>75;77;78</sup> Moreover, one recent study in the USA has found that – despite a decreasing proportion of hospital deaths – there has been an increase in the use of hospital services (such as intensive care) in the last month of life between 2000 and 2009, in a population of older people.<sup>79</sup> Therefore it might be assumed that it is not only the number of hospital deaths that needs to be reduced, but that reducing the number of end-of-life hospital admissions may also be considered appropriate.

Also in end-of-life care policy there has been a shift towards reducing the number of end-of-life hospital admissions,<sup>3;76;80;81</sup> which is therefore also aimed at reducing healthcare expenditure,<sup>59;80;82</sup> and improving the quality of end-of-life care.<sup>83-86</sup> Moreover, as nursing home residents – and those

with cognitive impairments in particular – experience various adverse events or negative effects during transfers to the hospital, such as emotional distress or increased confusion, the reduction of these end-of-life hospital admissions more recently has deserved particular attention.<sup>80;87;88</sup>

However, reducing the number end-of-life hospital admissions is not considered to be straightforward, and several issues have remained unresolved.<sup>76</sup> Considering that some patients might actually prefer to die in hospital – perhaps because dying at home might provoke concerns such as being a burden to family caregivers or due to the anticipation of inadequate care,<sup>46</sup> – it might be questioned whether these end-of-life hospital admissions should be considered inappropriate and whether there is a need to reduce them.<sup>76</sup> Furthermore, in order to be able to indicate whether end-of-life hospital admissions are inappropriate or not, a more thorough understanding about the appropriateness of such end-of-life hospital admissions is needed.<sup>3;76</sup>

Another important issue that remains unresolved is whether these end-of-life hospital admissions can be reduced or not. As some of the end-of-life hospital admissions might be considered necessary or unavoidable,<sup>89-91</sup> further research is needed on the extent to which such admissions preceding hospital death (i.e. terminal hospital admissions) might be considered avoidable and how they can be avoided.

## **PALLIATIVE CARE PROVISION IN BELGIUM**

Palliative care in Belgium is provided at home, in long-term care settings, day-care centres, hospitals and palliative care units.<sup>50</sup> There are 25 different palliative care networks in Belgium that have a pivotal role in promoting a palliative care culture within these settings, for example by informing the general public; improving physicians', nurses' and paramedics' knowledge of palliative care; and the coordination and support of palliative care services.<sup>50</sup>

Palliative care in Belgium aims to support end-of-life care and death at home for those patients who are residing at home or have the intention to die at home and for the greater part relies on primary health care professionals and informal caregivers to do so.<sup>50</sup> It is generally coordinated by a family physician, although informal caregivers, home care nurses, psychologists, volunteers or other caregivers may also be present. They can be supported in this by multidisciplinary palliative home care teams, although the regular primary health care providers and informal caregivers remain the most important caregivers. Furthermore, several measures have been developed to ensure that palliative care patients would not be restricted from receiving the same high-quality care as is

provided in the hospital setting for financial reasons, such as a palliative status or lump sum ('forfait').<sup>50</sup>

Palliative day care centres have been created as a complementary measure to home care.<sup>50;92</sup> Moreover, they are considered to support informal caregivers by providing specialized palliative care that would not be possible at home, for palliative patients with more complex needs in particular; they were set up in order to prevent unnecessary hospital admissions.<sup>50</sup>

Patients residing in a nursing home also need to be able to die in their familiar surroundings and this is also acknowledged in the Belgian palliative care policy.<sup>50</sup> Similar to the home care setting, the provision of palliative care usually relies on the regular nursing home caregivers, although they can be supported in this by the coordinating and advising physician ('CRA-arts') of the nursing home and a nurse that is specialized in palliative care ('reference nurse').<sup>93</sup>

Two structures have been set up for the provision of palliative care in hospitals.<sup>49;50</sup> Similar to the home care setting and the nursing home setting, regular caregivers (nurses, physicians and other paramedics) in the general hospital are considered to be the main providers of generalist palliative care.<sup>50</sup> They can be supported in doing this by a mobile palliative support team that is specialized in providing palliative care, which is composed of at least three part-time members: a hospital specialist, a nurse and a psychologist.<sup>93</sup>

The second hospital structure is a palliative care unit, which is considered to be for those patients who cannot be cared for at home and for whom an admission to the acute hospital setting might be considered unnecessary.<sup>50</sup> This unit, usually consisting of six to 12 beds that are spread over several hospital units, or united in an independent unit, has a multidisciplinary team that provides specialized palliative care, coordinated by a palliative care physician.<sup>93</sup> However, there are only 379 such beds available throughout the entire country.<sup>92</sup>

Considering the pivotal role of regular primary health care providers and informal caregivers in providing palliative care and given that they are frequently involved in deciding whether or not to admit a patient to hospital, or in dealing with such an admission in the hospital, their perspectives are considered to be essential in studying end-of-life hospital admissions. Moreover, given that almost 95% of the Belgian population has a family physician, whom they consult regularly (78% at least once a year) and that family physicians have a pivotal role in providing and coordinating out-of-hospital palliative care, their perspectives are considered to be crucial to this dissertation.

## **A PARTICULAR FOCUS ON DEMENTIA**

Dementia has increasingly become a major public health issue, particularly due to its rapidly growing global prevalence.<sup>94;95</sup> It has been estimated that 35.6 million people worldwide were living with dementia in 2010, and it is projected to double every 20 years.<sup>95</sup> Evidently, such an increase poses challenges to providing adequate end-of-life care.

Older people with dementia often experience medical problems at the end of life (e.g. pneumonia or hip fracture),<sup>96-99</sup> that may result in hospital admission.<sup>88</sup> However, for these patients in particular, the hospital setting as a place of death may be not ideal;<sup>63;100</sup> they may be more likely to experience delirium,<sup>101</sup> falls or other adverse events,<sup>102;103</sup> and often experience burdensome interventions or procedures that might be of little benefit, such as tube feeding.<sup>99;104-106</sup> Moreover, hospital admissions in this population are considered to be 'burdensome' when they occur in the last three days of life.<sup>107</sup>

In this dissertation particular attention will be given to the place of death of older people with dementia, considering it is increasingly becoming a vast proportion of the elderly population in contemporary society and given that it might be questioned whether admitting these patients to hospital at the end of life is considered proper end-of-life care or not.

## RESEARCH AIMS

The present dissertation has three main objectives, each with several research aims. The first objective is to examine the proportion of older people with a dementia-related disease who died in hospital in Belgium. The second objective is to explore family physicians' perspectives on their role in preventing and guiding hospital admissions at the end of life. The third objective is to gain insights into the reasons why patients are admitted to hospital at the end of life, whether and why this might be considered appropriate, and whether and how they can be avoided.

### **Objective 1: examine the proportion of older people with a dementia-related disease who died in hospital in Belgium.**

Older persons with a dementia-related disease are increasingly becoming a large proportion of the elderly population and it might be questioned whether admitting these patients to hospital is to be considered proper end-of-life care.<sup>63;94;95;100</sup> Although there have been several national studies exploring the location of death for older people with dementia and associated factors,<sup>108;109</sup> only one study has examined cross-national variations in five European countries.<sup>110</sup> More recent or larger cross-national studies, including non-European countries, on place of death focusing on dementia, are lacking. Therefore, a first research aim is to examine the place of death among older people who died from a dementia-related disease in fourteen different European and non-European countries and the extent to which hospital death is associated with socio-demographic factors, social support, residential factors and healthcare system factors and the cross-country variations in such hospital deaths when controlling for these different factors; so as to be able to estimate the difference between Belgium and other countries concerning the proportion of older people who died in hospital from a dementia-related disease. Moreover, older people with dementia often experience medical problems at the end of life (e.g. pneumonia or hip fracture),<sup>96-99</sup> that may result in hospital admission.<sup>88</sup> Therefore, a second research aim is to estimate the incidence of and factors associated with hospital death in people dying with dementia and pneumonia in Belgium; so as to be able to estimate whether patients with dementia have a higher chance of dying in hospital with a given medical complication (in this case pneumonia), compared to those without such a complication.

- 1) How does the proportion of hospital deaths among older people who died from a dementia-related disease vary between Belgium and thirteen other European and non-European countries; to what extent is hospital death associated with socio-demographic factors, social support, residential factors and healthcare factors and what is the cross-country variation in hospital death risk when controlling for these confounders?

- 2) Are people dying with dementia and pneumonia more likely to die in hospital than those without pneumonia? What is the incidence of hospital death in people dying with dementia and pneumonia? What are the factors associated with hospital death in people dying with dementia and pneumonia?

**Objective 2: explore family physicians' perspectives on their role in preventing and guiding hospital admissions at the end of life.**

A third research aim of this dissertation is to explore how family physicians perceive their own roles in avoiding and guiding hospital admissions at the end of life and the difficulties they experience within these roles; considering their pivotal role in providing end-of-life care and their limited gatekeeper role towards hospitalizations,<sup>22;93;111;112</sup> exploring these perceptions could elicit insights into their ability to prevent such end-of-life hospital admissions.

- 3) How do family physicians perceive their own roles in avoiding and guiding hospital admissions at the end of life and what difficulties do they experience within these roles?

**Objective 3: gain insights into the reasons why patients are admitted to hospital at the end of life, and the appropriateness and avoidability of such admissions.**

The third objective consists of four research aims. As most research has been focused mainly on the home setting as the ideal place of death, little is known about how the acute hospital setting is perceived as a place for end-of-life care or place of death.<sup>48</sup> Consequently, the fourth research aim of this dissertation is to explore the perspectives of family physicians, nurses and family caregivers concerning the acute hospital setting as a place of death; exploring these perceptions might elicit why patients are being admitted to hospital at the end of life. Furthermore, considering that some patients might actually prefer to die in hospital – perhaps due to concerns about burdening their family or anticipating inadequate care,<sup>46</sup> it might be questioned whether these end-of-life hospital admissions should be considered inappropriate and whether there is a need to reduce them.<sup>76</sup> Furthermore, in order to be able to indicate whether end-of-life hospital admissions are inappropriate or not, a more thorough understanding about the appropriateness of such end-of-life hospital admissions is needed.<sup>3;76</sup> Therefore, a fifth research aim is to explore in which situations family physicians and nurses consider an end-of-life hospital admission to be justified; as such perceptions could elicit a more thorough understanding of the aspects and reasons that are considered important to justify an end-of-life hospital admission. Moreover, studies exploring the reasons for terminal hospital admissions – i.e. admissions to an acute hospital setting prior to a hospital death – and other aspects that have contributed to the decision to admit the patient to

hospital at the very end of life are scarce.<sup>113</sup> Therefore, a sixth research aim is to explore which reasons and aspects regarding the patient's preferences, families' wishes, and the care setting have played a role in the decision to admit a patient to hospital at the end of life and the extent to which they are related to the characteristics of the patients, the care they received prior to the terminal hospital admission and the circumstances of the admission, according to family physicians; so as to be able to estimate the frequency of the reasons and aspects that necessitate an end-of-life hospital admission and in which circumstances they most frequently occur. Another important issue that remains unresolved is whether these end-of-life hospital admissions can be reduced or not. As some might be considered necessary or unavoidable,<sup>89-91</sup> further research is needed on the extent to which such admissions preceding hospital death (i.e. terminal hospital admissions) might be considered avoidable and how they can be avoided; and how many could be considered inappropriate. Consequently, a seventh research aim is to examine the proportion of terminal hospital admissions that family physicians consider to be potentially avoidable and/or potentially inappropriate, which patient, family physician or admission factors are associated with inappropriateness and avoidability, and which interventions that could have avoided potentially avoidable terminal hospital admissions, according to family physicians; so as to be able to estimate the frequency of inappropriate or avoidable terminal hospital admissions, the circumstances in which they occur most frequently and how potentially avoidable terminal admissions might be prevented.

- 4) How do family physicians, nurses and family caregivers perceive the acute hospital setting as a place for final care and as a place of death?
- 5) In what situations do family physicians and nurses consider an end-of-life hospital admission to be justified?
- 6) Which reasons and additional aspects regarding patients' preferences, families' wishes, and the care setting do family physicians consider to have played a role in the decision to admit a patient to hospital at the end of life and to what extent are these reasons and aspects related to characteristics of the patient, care received prior to the admission and the circumstances of the admission?
- 7) What proportion of terminal hospital admissions of their patients do family physicians consider to be potentially avoidable and/or potentially inappropriate; which patient, family physician and admission factors are associated with the inappropriateness or avoidability of terminal hospital admissions; and which interventions could have prevented potentially avoidable terminal hospital admissions, according to family physicians?

## **METHODOLOGY**

### **STUDY DESIGN**

Three different research methodologies were used to address the research aims. For the first research objective, death certificate data from Belgium as well as thirteen other European and non-European countries were used to study the place of death of older people who died from dementia. For the second and third research objectives a mixed method approach was used, combining qualitative research (focus groups with family physicians and nurses, and interviews with family caregivers) and a survey among family physicians concerning the terminal hospital admission of their patients.

### **ANALYSIS OF DEATH CERTIFICATE DATA**

We used death certificate data of all deaths in Belgium in 2008 to address research aim 2 and we included similar data from thirteen different European and non-European countries to address research aim 1.

In Belgium, death certificate data contain information about the place and cause of death and the socio-demographic characteristics of the deceased.<sup>114</sup> Information about the place of death is completed by a family physician who certifies the causal chain of diseases, starting with the underlying cause of death, which is primarily used in the studies of this dissertation. Information about socio-demographic characteristics (e.g. educational attainment, marital status and living arrangement) is provided by the municipal institutions. Information from the death certificates is processed; the causes of death are coded in ICD-10 codes and both medical and socio-demographic information is verified by a government agency.<sup>114;115</sup>

The cross-national study was part of the International study on Place of Death (IPOD), a collection of death certificate data over one year in multiple countries. Following an open call from the principal researchers and preliminary negotiations, 2008 was decided upon as reference year, given it was the most recent year available in all targeted countries at the time of data collection (2011-2013). Fourteen countries were able to obtain permission to use data from 2008 or the most recent available year: Belgium, Canada (Quebec excluded), Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, Spain (Andalusia; 2010), South Korea, USA (2007) and Wales. Datasets were integrated into one international database, coordinated by the principal researchers to ensure uniform coding.



In the first study (research aim 1) we included people whose underlying cause of death was dementia-related (henceforth also labelled as 'patients with dementia'): vascular dementia (ICD-10: F01), dementia in other diseases (ICD-10: F02), unspecified dementia (ICD-10: F03) and Alzheimer's disease (ICD-10: G30). Given the low prevalence of dementia-related diseases in those younger than 65, we selected only those aged 65 and older. For the second research aim we used all death certificates that contained a dementia-related disease as cause of death, using the same ICD-10 codes as research aim 1, as well as pneumonia. Pneumonia was defined as adenoviral pneumonia (ICD-10: J12), pneumonia due to streptococcus pneumonia (ICD-10: J13) pneumonia due to Haemophilus influenza (ICD-10: J14) bacterial pneumonia, not elsewhere classified (ICD-10: J15), pneumonia due to other infectious organisms, not elsewhere classified (ICD-10: J16), pneumonia in diseases classified elsewhere (ICD-10: J17) and pneumonia, organism unspecified (ICD-10: J18).

Separate analyses were conducted for research aim 1 and 2, and SPSS 22.0 was used for all computations.<sup>116</sup>

## **QUALITATIVE RESEARCH: FOCUS GROUPS AND INTERVIEWS**

Qualitative research was considered to be the best approach to address research aims 3, 4 and 5; focus groups were used to explore the perspectives of family physicians and nurses from different settings (home care, hospital and nursing home), and interviews to explore those of family caregivers whose relative had died in hospital. Data collection and analysis was guided by a research team that consisted of five medical sociologists, of whom one is also a nurse (T.R., D.H., R.P., J.C., L.D.) and for research aim 3 a family physician was added to this team (R.V.). Different focus groups were organized for nurses and family physicians, to increase homogeneity for both groups and to avoid that participants would feel restricted in providing their opinions due to (perceived) differences in hierarchy between them.<sup>117</sup>

### ***Focus groups***

Focus group discussions were considered to be most appropriate to explore the experiences and opinions of family physicians and nurses, given its meaningful process of sharing and comparing.<sup>118</sup> Eight focus groups were conducted in total, three with nurses (n=23) and five with family physicians (n=39).

Two nurse focus groups were composed by purposely selecting nurse participants according to the setting where they provide care, to maximize variation in experience and background.<sup>119</sup> Another nurse focus group consisted of nursing home nurses only, so as to be able to further elaborate on

specific situations and patients within this setting. All nurses were recruited by contacting several healthcare organizations and institutions (such as hospitals, nursing homes or multidisciplinary specialist palliative care teams), and participants were directly or indirectly asked to participate and to contact one researcher (T.R.). There was no structural relationship between these institutions and the researchers before the focus groups.

Family physician focus group participants were members of local peer-review groups ('LOK' groups). Using such pre-existing groups for focus group research has been shown to benefit discussions.<sup>120</sup> Nearly 97% of all full-time practicing family physicians in Belgium are affiliated to such a peer-review group, where they discuss aspects related to family care.<sup>121</sup> To maintain accreditation, they are obliged to attend at least two out of four meetings each year. We contacted several groups from different regions across Brussels Capital Region and Flanders and five groups were selected according to their availability.

Focus group discussions lasted between 60 and 120 minutes and were moderated and observed by two medical sociologists (T.R., D.H.) with experience in qualitative research and knowledge of the subject. They were held in conference rooms in a hotel or locations where participants usually met, between February and June 2012. A discussion guide was developed and reviewed within the research team. After each focus group it was modified slightly by two researchers (T.R., D.H.) to improve data collection, without compromising consistency.

After giving their written informed consent and completing a small questionnaire about their background, participants were asked about their experiences and opinions concerning end-of-life hospital admissions. Next, a discussion was generated about what could justify the hospital admission of a terminally ill patient, prompted by vignettes describing three different cases. Afterwards, participants were asked to identify key factors or reasons that would justify an end-of-life hospital admission. During focus group discussions, participants were encouraged to reflect on what they perceived to be their roles, or to express their opinions and experiences concerning the acute hospital as a setting for dying patients.

### *Interviews*

Additionally, the perspectives of family carers whose relative had died in the acute hospital setting were included, using semi-structured interviews. As we anticipated that discussing their experiences might provoke emotional reactions, we therefore considered face-to-face interviews to be more suitable than focus groups.<sup>122;123</sup> These family carers were recruited using purposive sampling which was mainly focused on including different cases from different disease trajectories, and using snowball sampling. In recruiting respondents it was considered important that they had cared for a

relative or friend with a chronic life-limiting disease (i.e. cancer, organ failure or dementia) and who had died in hospital between three months and two years before the interview. Several healthcare organizations were contacted, who informed their professional caregivers and placed announcements in their newsletters or on their websites, encouraging potential respondents to contact the researcher (T.R.). Family physicians and nurses who had participated in focus groups and other interview respondents, were also asked to contact other potential participants. When inclusion criteria were met, an interview was scheduled.

All interviews were conducted by one researcher (T.R.) and lasted on average 45 minutes. A topic guide was used to conduct the interviews, which was also developed by the research team and altered when necessary. Respondents were asked about their experiences and opinions of the acute hospital as a setting for end-of-life care and as a place of death, although the focus was mainly on the circumstances of the last hospital admission. Finally, respondents were asked how these experiences might have changed their own opinions on the acute hospital as a place of death. Respondents were a partner, sibling, son or daughter.

### ***Data analysis***

Focus group discussions and interview conversations were audio-recorded and transcribed verbatim, complemented with field notes. Analysis was guided by a constant comparative approach,<sup>124</sup> using qualitative data analysis software (QSR NVivo 10),<sup>125</sup> which progressed in several stages of coding and interpreting data. The research team was involved in each stage of data analysis. For each research aim (3, 4 or 5) a separate, although analogue process of data analysis was conducted.

In a first stage – also known as open coding – several transcripts were read and initially coded by one researcher (T.R.) to develop key concepts and categories.<sup>124</sup> An initial coding framework was developed by two researchers (T.R., D.H.) and slightly altered after discussion within the research team, with each team member having read a transcript. Next, one researcher (T.R.) coded all transcripts and modified the coding framework where necessary, in consensus with a second researcher (D.H.) – also described as ‘axial coding’.<sup>124</sup> The results were regularly discussed within the research team and each team member re-read or re-coded several transcripts – ‘selective coding’, to ensure consistency and validity.<sup>124</sup> A final framework was agreed and quotes were selected, translated from Dutch and approved by the research team.

### ***Ethics***

Ethics approval for this study was given by the Medical Ethics Commission for the Brussels University Hospital.

## **SURVEYS AMONG FAMILY PHYSICIANS**

To address research aims 6 and 7, a cross-sectional survey was conducted among family physicians of all patients that died in a large (+/- 1000 bed) university hospital in Belgium between January and August 2014.

All patients who died in the acute setting of the university hospital in the sampling period were identified in the hospital medical record system. Those under 18 years, those not residing in Belgium and those who died on a specialised palliative care unit, maternity ward or psychiatric ward were excluded, as they were not the focus of this study.

A research assistant was involved in the data collection procedure as intermediary between family physicians and the university hospital. The assistant received an extract of the hospital records of all deaths, including the patient's gender, postal code, date of birth, date of death, timing of admission, hospital ward where the patient died and their family physician's contact information. A questionnaire was sent to the family physician of every eligible death case. The accompanying letter included the gender of the deceased patient, postal code of the municipality of residence, date of birth and date of death so as to enable the family physicians to identify the patient when filling out the questionnaire.

Deaths were identified on a weekly basis during the study period and two weeks after the patient's death a four-page questionnaire was sent to the family physician, so as to limit the time between the death and the completion of the questionnaire. The Total Design Method was used to maximise the response to the questionnaire.<sup>126;127</sup> In cases where there was no response, a reminder was sent after three weeks, a second questionnaire as a reminder after five weeks and another reminder after seven weeks. After ten weeks a brief non-response questionnaire was sent for those cases where the family physician had not yet responded, to identify the reasons. Family physicians received questionnaires for a maximum of three patients, so as to limit the workload.

From the returned questionnaires, the research assistant coded all data and guaranteed that the research data could not be linked to the patient or the family physician. The questionnaire data was linked to the extract of hospital records, using a unique case number, while the patient's postal code and the family physician's contact information were deleted to guarantee anonymity.

The questionnaire concerned the circumstances of and reasons for the terminal hospital admission and its design was based on the results of the previous qualitative studies of this dissertation that explored the perspectives of family physicians, nurses and family carers on end-of-life hospital admissions, and on similar surveys that had been used in the Netherlands and Belgium.<sup>75;90</sup> The

questionnaire was developed within a research team that consisted of five medical sociologists (one of whom is also a nurse) and a family physician, all with experience in survey methodology and knowledge of the subject. The questionnaire was tested among five family physicians and their comments were incorporated into the final version. The questionnaire first asked to assess whether the patient's death had been sudden and totally unexpected, and if so they were prompted to go to the end of the questionnaire. Where the answer was no, closed questions followed concerning: the patient's care setting, the patient's illnesses (e.g. cause of death), the reasons for and circumstances of the terminal hospital admission (e.g. medical reasons necessitating the admission), the appropriateness and avoidability of this hospital admission, the patient's preferred place of death, and care that the patient received prior to the hospital admission (e.g. number of family physician contacts in the last month of life).

Separate analyses were conducted for research aim 6 and 7, and SPSS 22.0 was used for all computations.<sup>116</sup>

Ethical approval for this study was given by the Medical Ethics Commission of the Brussels University Hospital and Ghent University hospital, and an approval was given by the Sectorial Committee of Social Security and Health from the Belgian Commission for the Protection of Privacy.

## **OUTLINE OF THIS DISSERTATION**

The findings of the studies for this dissertation are provided in three subsequent parts, each covering a different research objective. Part II is devoted to the variation in place of death of older people who died with or from a dementia-related disease: Chapter 2 will explore cross-national variation in hospital death risk among older people who died from a dementia-related disease in fourteen different European and non-European countries and its association with different characteristics. In chapter 3 the place of death of older people in Belgium who died with dementia in 2008 will be explored, while considering whether they have a higher chance of dying in hospital with pneumonia than those who died without pneumonia.

Part III (Chapter 4) is concerned with family physicians' perspectives on their role in preventing and guiding end-of-life hospital admissions and the difficulties they experience in fulfilling these roles.

Part IV focuses on the reasons why patients are admitted to hospital at the end of life, as well as the appropriateness and avoidability of such admissions. Chapter 5 explores how the acute hospital is perceived as a setting for end-of-life care and as a place of death, from the perspectives of professional caregivers (family physicians and nurses) and family carers. Chapter 6 focuses on the justifications for end-of-life hospital admissions, as according to family physicians and nurses from different settings. In Chapter 7, the frequency of different reasons for end-of-life hospital admissions and aspects that played a role in the decision-making about the admission, according to family physicians, are explored. Chapter 8 examines the proportion of family physicians that consider the terminal hospital admissions of their patients to be appropriate and/or avoidable, further elaborates on what could have avoided potentially avoidable admissions and the characteristics of terminal hospital admissions that were considered potentially inappropriate or potentially avoidable.

Part V entails a summary and discussion of the findings of the studies involved in this dissertation. Methodological strengths and limitations will be discussed, as well as a summary of the most important findings. Finally, attention will be given to implications for end-of-life care practice, policy and research.

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# PART II

Hospital death among older  
people with dementia





## CHAPTER 2

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### International Variation in Place of Death of Older People Who Died From Dementia in 14 European and Non-European Countries

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## **ABSTRACT**

### **OBJECTIVES**

The objective of this study was to examine variation in place of death of older people dying from dementia in countries across 4 continents.

### **DESIGN**

Study of death certificate data.

### **METHODS**

We included deaths of older (65 + years) people whose underlying cause of death was a dementia-related disease (ICD-10: F01, F02, F03, G30) in Belgium, the Netherlands, England, Wales, France, Italy, Spain, Czech Republic, Hungary, New Zealand, United States, Canada, Mexico and South Korea. We examined associations between place of death and sociodemographic factors, social support, and residential and health care system factors.

### **RESULTS**

Overall, 4.8% of all deaths were from a dementia-related disease, ranging from 0.4% in Mexico to 6.9% in Canada. Of those deaths, the proportion occurring in hospital varied from 1.6% in the Netherlands to 73.6% in South Korea. When controlling for potential confounders, hospital death was more likely for men, those younger than 80, and those married or living in a region with a lower availability of long-term care beds, although this could not be concluded for each country. Hospital death was least likely in the Netherlands compared with other countries.

### **CONCLUSIONS**

Place of death of older people who died from a dementia-related disease differs substantially between countries, which might point to organizational differences in end-of-life care provision. Increasing the availability of long-term care beds might be important to reduce the number of hospital deaths, while focusing specialized end-of-life care services on married people or those aged 65 to 79 might be crucial for achieving home death. However, proper end-of-life care needs to be ensured in hospitals, should this be the most appropriate end-of-life care setting.

## **KEYWORDS**

Place of death – Dementia – End-of-life care – Death certificates

## INTRODUCTION

Dementia has become a major public health issue, particularly due to its rapidly increasing global prevalence.<sup>1,2</sup> It has been estimated that 35.6 million people worldwide were living with dementia in 2010 and this has been projected to double every 20 years, with 7.7 million new cases per year.<sup>1</sup> Evidently, such an increase poses challenges to providing adequate care, including end-of-life care,<sup>2,3</sup> for these patients, and countries tend to differ in how these challenges are approached. An international study on the place of death of older people dying from a dementia-related disease could provide important insights into such diversity.

Older people with dementia often experience medical problems at the end of life (e.g. pneumonia or hip fractures),<sup>3-8</sup> that may result in hospital admission.<sup>9,10</sup> Although hospitalization might be considered justified in some circumstances,<sup>10</sup> it also has been suggested that the acute hospital setting is not an adequate place for end-of-life care and death for chronic terminally ill patients and this might be particularly so for patients with advanced dementia.<sup>11-13</sup> In this setting, they may be more likely to experience delirium,<sup>14</sup> falls, or other adverse events,<sup>6,14-16</sup> and often experience burdensome interventions or procedures that might be of little benefit, such as tube feeding.<sup>4,5,15,17,18</sup> Moreover, relatives or family carers generally seem to be dissatisfied with hospital care,<sup>19,20</sup> whereas acute care staff often experience difficulties in caring for older people with dementia.<sup>11,12,21,22</sup>

Although there have been several national studies exploring the location of death for older people with dementia and associated factors,<sup>23,24</sup> only one study has examined cross-national variations in 5 European countries, showing that the proportion of hospital deaths of older people who died from a dementia-related disease differed substantially among countries.<sup>25</sup> More recent, larger cross-national studies, including non-European countries, on place of death focusing on dementia, are lacking.

The aim of this study was to examine variations in place of death of older people who died from a dementia-related disease and their association with sociodemographic factors, social support, residential, and health care system factors in European and non-European countries, across 4 continents, and the cross-national variations in place of death when controlling for these confounders. Studying variation in place of death across different countries could elicit important differences in where patients with dementia die and might be helpful in identifying policy priorities to monitor and safeguard the quality of end-of-life care for these patients.

## METHODS

### STUDY DESIGN AND DATA

This study is part of the International Place of Death study, a collection of death certificate data on all deaths of 1 year in multiple countries. Following an open call from the principal researchers and preliminary negotiations, it was decided that 2008 would be used as the reference year, given that this was the most recent year available in all targeted countries at the time of data collection (2011–2013). Fourteen countries were able to obtain permission to use the data from 2008 or the most recent available year in an international study: Belgium, Canada (Quebec excluded), Czech Republic, England, France, Hungary, Italy, Mexico, the Netherlands, New Zealand, Spain (Andalusia; 2010), South Korea, United States (2007), and Wales. Datasets were integrated into one international database, coordinated by the principal researchers to ensure uniform coding.

### POPULATION

We included deaths of people whose underlying cause of death was dementia-related (henceforth also labelled as “patients with dementia”): vascular dementia (ICD-10:F01), dementia in other diseases (ICD-10:F02), unspecified dementia (ICD-10:F03), and Alzheimer disease (ICD-10:G30). Given the low prevalence of dementia-related diseases in those younger than 65, we selected only those aged 65 and older.

### DATA AND MEASUREMENTS

The dependent variable in the analysis was the place of death as recorded on the death certificate, recoded into 5 categories: home, long-term care (LTC) setting (including nursing homes and care homes), palliative care institution (e.g. hospice), hospital, and other (e.g. public space). Exceptions were Hungary (only “hospital” or “other” were available as categories) and Mexico (only “home,” “hospital,” “other”). Furthermore, “palliative care institution” was recorded only in England, New Zealand, Wales, and United States.

The independent variables included factors known to affect place of death: sociodemographic factors, social support, residential factors, health care system factors, and country of residence.<sup>23;26</sup> Sociodemographic factors included gender, age (65–79, 80–89, 90 + years of age) and educational attainment (no formal or elementary, lower secondary, higher secondary, higher). Social support was measured by marital status (unmarried, married, widowed, divorced/separated); a residential factor

was the degree of urbanization in the municipality or region of residence; and health care system factors included the average number of hospital beds per 10,000 inhabitants, general practitioners (GPs) per 100,000 inhabitants, and LTC beds per 1000 inhabitants aged 65 + available in the health care region of the deceased. For Hungary, Czech Republic, and South Korea, health care system factors were provided for the country as a whole, as privacy regulations did not allow detailed information on the health care region of residence of the deceased. For Wales only, LTC beds per 1000 inhabitants aged 65+ were used, in the absence of available regional data.

## **ANALYSIS**

Study population characteristics and the distribution of place of death were described for each country using crude proportions. To examine the factors associated with dying in hospital versus other places within each country, a binomial multivariable logistic regression analysis was performed for each country using a forward stepwise likelihood selection procedure of variables. To examine the association between place of death and country of residence, taking into account potential confounders, multinomial logistic regression models (first with hospital as reference category, and second with home as reference category) were performed with the dependent variable recoded into 3 categories (home, hospital, and LTC setting). Each multinomial logistic regression model was built up in 3 consecutive steps: we estimated the unadjusted association between country of residence and place of death (Model 1), and subsequently added sociodemographic factors and social support (Model 2) and health care system factors (Model 3). Because of the lack of complete data, only 11 countries were included in the last model. We considered a *P*-value of .05 to be statistically significant. We used SPSS version 22.0 (IBM SPSS Statistics, IBM Corporation, Chicago, IL) for all statistical analyses.

## **RESULTS**

### **STUDY POPULATION CHARACTERISTICS**

In total, 4.8% of the population died from a dementia-related disease, with country proportions ranging from 0.4% in Mexico to 6.9% in Canada (**Table 1**). Approximately two-thirds or more of all older people dying from a dementia-related disease were women and older than 80 at the time of death (except in Czech Republic, 56%). In all countries, most of them were widowed.

**Table 1 Deaths from dementia in 2008\* (264,604)**

Country of Residence		BE	NL	ENG	WAL	FRA	ITA	ESP	HUN	CZR	NZE	USA	CAN	MEX	KOR
Number of Deaths		5207	8125	21454	1379	28684	21577	3471	2128	523	1386	152790	12566	2060	6236
(% of all deaths)		(5.1)	(6.0)	(4.5)	(4.3)	(5.3)	(3.7)	(6.0)	(1.6)	(0.5)	(4.7)	(6.3)	(6.9)	(0.4)	(2.5)
Gender (% of study population)	Male	32.0	27.1	29.0	30.2	30.1	31.6	33.8	33.4	39.0	31.9	29.8	32.8	38.4	30.1
	Female	68.0	72.9	71.0	69.8	69.9	68.4	66.2	66.6	61.0	68.1	70.2	67.2	61.6	69.9
Age (% of study population)	65-79	19.9	14.4	14.8	14.4	13.5	18.9	21.2	34.4 <sup>†</sup>	44.0	15.1	14.7	13.9	31.0	26.2
	80-89	56.0	51.7	50.5	51.9	53.3	53.2	57.4	50.9	50.1	50.2	48.2	48.8	46.3	53.4
	90+	24.0	33.9	34.7	33.7	33.2	27.9	21.4	14.7	5.9	34.7	37.0	37.3	22.6	20.4
Education (% of study population)	No formal/elementary	57.4	-	-	-	-	86.0	67.2	82.8	40.3	-	11.2	-	81.6	86.3
	Low sec	23.0	-	-	-	-	8.5	21.5	0.2	45.6	-	12.8	-	0.9	-
	High sec	13.8	-	-	-	-	3.8	8.9	10.0	9.1	-	45.4	-	7.0	10.7
	Higher	5.8	-	-	-	-	1.7	2.4	7.0	5.1	-	30.6	-	10.6	3.0
Marital Status (% of study population)	Unmarried	7.3	75.4	7.4	7.0	8.3	9.4	8.4	4.7	3.4	-	5.0	6.1	11.0	1.9
	Married	30.5	24.6	25.8	24.7	29.1	31.2	32.3	27.4	38.3	-	25.7	28.6	35.4	23.3
	Widowed	57.9	-	62.3	65.1	58.4	58.6	58.2	59.7	52.0	-	62.6	60.9	52.6	73.4
	Divorced/separated	4.2	-	4.4	3.3	4.3	0.8	1.1	8.3	6.3	-	6.7	4.4	1.0	1.5
Urbanization Level (% of study population)	Very strong/strong	62.0	49.7	77.7	67.5	30.7	42.0	51.1	33.2	-	-	-	80.9	-	12.4
	Average	24.4	20.9	20.9	21.2	33.4	23.0	42.2	37.3	-	-	-	-	-	17.4
	Weak/rural	13.5	29.4	1.3	11.3	35.8	35.0	6.6	29.5	-	-	-	19.1	-	70.2
Healthcare system factors	Hospital beds/10,000	51.9	30.8	31.1	43.9	69.5	34.1	26.8	71.0 <sup>‡</sup>	60.4 <sup>‡</sup>	43.9	27.0	29.8	3.3	83.0 <sup>‡</sup>
	LTC beds/ 1,000 65+	70.3	77.3	54.8	49.3 <sup>‡</sup>	59.2	34.6	18.8	32.7 <sup>‡</sup>	28.9 <sup>‡</sup>	49.3	41.5	58.1	-	17.5 <sup>‡</sup>
	GPs/100,000	201 <sup>§</sup>	54	66	65	87	76	74	65 <sup>‡</sup>	70 <sup>‡</sup>	65	131	101	-	75 <sup>‡</sup>

BE, Belgium; NL, Netherlands; ENG, England; WAL, Wales; FRA, France; ITA, Italy; ESP, Spain (Andalusia); HUN, Hungary; CZR, Czech Republic; NZE, New Zealand; USA, United States of America; CAN, Canada (Quebec excluded); MEX, Mexico; KOR, South Korea; -, corresponding variable or category was not registered in this country.

\*For Spain data from 2010 was used, for USA 2007.

† For Hungary age category 60-79 was used, as age was presented in 10-year categories due to privacy regulations. Given that age category 60-64 in most countries represented less than 1% of all dementia-related deaths, we believe this proportion in Hungary to be very small.

‡ Data were provided for country as a whole.

§ Number of GPs/100,000 for Belgium (201) might be overestimated, as it also includes non-practicing general practitioners.

## PLACE OF DEATH IN THE STUDY POPULATION

The proportion of hospital deaths among all older people who died from dementia varied between 1.6% in the Netherlands and 73.6% in South Korea, and in 3 countries, the hospital setting was the most frequent place of death (South Korea 73.6%, Hungary 62.3%, and France 35.9%) (**Table 2**). In 3 countries, home was the most frequent place of death (Italy 42.2%, Spain 46.1%, and Mexico 69.3%) and more than a fifth died at home in France and South Korea. In 8 countries, most deaths occurred in an LTC setting, ranging from 48.9% in Wales to 93.1% in the Netherlands.

**Table 2 Place of death of people who died from dementia in 2008\* (N=262,993)**

Country of Residence	BE	NL	ENG	WAL	FRA	ITA	ESP	HUN <sup>†</sup>	CZR	NZE	USA	CAN	MEX	KOR
Hospital	21.6	1.6	31.7	43.1	35.9	32.1	33.6	62.3	27.5	14.3	13.2	32.3	26.2	73.6
Home	11.2	3.8	5.0	4.2	27.2	42.2	46.1	-	10.6	4.5	15.3	3.4	69.3	20.5
LTC-setting	66.7	93.1	61.7	48.9	34.0	19.5	20.1	-	61.5	76.6	62.6	59.4	-	5.5
Palliative care institution	-	-	0.1	0.1	-	-	-	-	-	0.3	2.9	-	-	-
Other	0.5	1.5 <sup>‡</sup>	1.5	3.7	2.9	6.2	0.2	37.7	0.4	4.4	6.0	4.9	4.5	0.4

BE, Belgium; NL, Netherlands; ENG, England; WAL, Wales; FRA, France; ITA, Italy; ESP, Spain (Andalusia); HUN, Hungary; CZR, Czech Republic; NZE, New Zealand; USA, United States of America; CAN, Canada (Quebec excluded); MEX, Mexico; KOR, South Korea; -, corresponding variable or category was not registered in this country.

\*all percentages are valid column percentages; for Spain data from 2010 was used, for USA 2007.

<sup>†</sup> In Hungary place of death was registered as "hospital vs. other".

<sup>‡</sup>"Other" in the Netherlands is predominantly "death in a hospice".

## FACTORS ASSOCIATED WITH "HOSPITAL DEATH" IN THE STUDY POPULATION

Adjusted for potential confounders, men had higher chances than women of dying in a hospital setting in all countries, except Mexico (**Table 3**). Being younger than 80 years of age was associated with higher chances of dying in hospital in the Netherlands, Wales, France, Italy, Spain, United States, and Canada. More highly educated people had a higher chance of hospital death than those with lower or no formal education in Belgium (odds ratio [OR] 1.4, confidence interval [CI] 1.1–1.8), Mexico (OR 1.6, CI 1.2–2.1), and South Korea (OR 1.4, CI 1.2–1.7), whereas in the United States (OR 0.8, CI 0.8–0.9), the opposite was found. Being married significantly increased the chances of hospital death in Belgium (OR 1.6, CI 1.3–2.0), England (OR 1.3, CI 1.2–1.4), France (OR 1.4, CI 1.3–1.5), United States (OR 1.1, CI 1.0–1.1), and Canada (OR 1.3, CI 1.2–1.4), whereas the opposite was true in South Korea (OR 0.7, CI 0.6–0.8). In England, France, Italy, Spain, Hungary, Canada, and South Korea, the likelihood of dying in a hospital setting was higher in strongly urbanized regions. Living in a region with a higher number of hospital beds per 10,000 increased the chances of dying in a hospital in England, France, Italy, New Zealand, United States, and Canada. Further, living in a region with a higher number of LTC beds decreased the odds of dying in hospital in England, France, Italy, Spain,

New Zealand, and United States. The chances of dying in hospital also significantly decreased in regions with a larger number of GPs in Belgium, England, Wales, France, Italy, Spain, United States, and Canada, although the opposite was the case for New Zealand.

### **COUNTRY DIFFERENCES IN PLACE OF DEATH**

Country differences in place of death of older persons who died from a dementia-related disease did not substantially change when adjusting for differences in sociodemographic factors and social support (**Table 4**). Although health care system factors (hospital beds per 10,000 inhabitants, GPs per 100,000 inhabitants, and LTC beds per 1000 inhabitants 65+) substantially reduced country differences in place of death, notable differences remained after adjusting for these factors. For instance, the chances of dying at home rather than in a hospital setting were significantly higher in the Netherlands (OR 2.3; CI 1.8–2.9) and lower in all other countries when compared with France. When compared with France, the odds of dying in an LTC setting rather than in hospital were higher in Belgium (OR 1.4, CI 1.2–1.5), England (OR 1.4, CI 1.3–1.6), the United States (OR 2.6, CI 2.4–2.9), and Czech Republic (OR 3.9, CI 3.1–4.7), and particularly in the Netherlands (OR 38.0, CI 31.2–46.1). The odds of dying in an LTC setting (versus hospital) were lower in Spain (OR 0.6, CI 0.5–0.7), Italy (OR 0.5, CI 0.5–0.6), and South Korea (OR 0.1, CI 0.1–0.2) when compared to France. The odds of dying in an LTC setting rather than at home were significantly higher in the Netherlands, England, Wales, Czech Republic, Canada, Belgium, Spain, and the United States and lower in South Korea and Italy, when compared with France.



**Table 3 Multivariate binary logistic regression per country with hospital death versus elsewhere as dependent variable (N=231,672)**

Odds Ratio (95% Confidence Interval)														
Country of residence	BE N=2,816	NL N=3,486	ENG N=14,244	WAL N=963	FRA N=28,349	ITA N=6,683	ESP N=2,963	HUN N=2,012	CZR N=468	NZE N=1,369	USA N=148,144	CAN N=12,340	MEX N=1,802	KOR N=6,033
<b>Gender</b>									1.6 (1.0-2.4)	2.2 (1.6-3.0)	1.7 (1.6-1.8)	1.7 (1.6-1.9)	NS	1.4 (1.2-1.6)
Male (vs Female)	2.0 (1.6-2.4)	2.3 (1.6-3.3)	1.7 (1.6-1.8)	1.7 (1.4-2.2)	1.7 (1.6-1.8)	1.4 (1.3-1.5)	1.6 (1.4-1.9)	1.3 (1.1-1.6)						
<b>Age</b>														
<80 y (vs 80+ y)	NS	2.2 (1.5-3.2)	NS	1.5 (1.1-2.0)	1.2 (1.2-1.3)	1.3 (1.2-1.4)	1.3 (1.0-1.5)	NS <sup>†</sup>	NS	NS	1.3 (1.3-1.4)	1.2 (1.0-1.3)	NS	NS
<b>Education</b>														
Higher secondary/ higher (vs No formal/ low sec/ elementary)	1.4 (1.1-1.8)	-	-	-	-	NS	NS	NS	NS	-	0.8 (0.8-0.9)	-	1.6 (1.2-2.1)	1.4 (1.2-1.7)
<b>Marital status</b>														
Married (vs Not/ no longer married)	1.6 (1.3-2.0)	NS	1.3 (1.2-1.4)	NS	1.4 (1.3-1.5)	NS	NS	NS	NS	-	1.1 (1.0-1.1)	1.3 (1.2-1.4)	NS	0.7 (0.6-0.8)
<b>Urbanization level</b>														
Very strong/ strong (vs Average/ weak/ rural)	NS	NS	1.5 (1.4-1.6)	NS	1.1 (1.0-1.2)	1.3 (1.3-1.4)	1.3 (1.1-1.6)	2.7 (2.2-3.3)	-	-	-	1.2 (1.1-1.3)	-	1.6 (1.4-1.9)
<b>Hospital beds/10,000</b> (continuous)	NS	NS	1.1 (1.0-1.1)	NS	1.019 (1.015-1.024)	1.4 (1.3-1.4)	NS	‡	‡	1.0 (1.0-1.1)	1.012 (1.009-1.014)	1.10 (1.09-1.11)	NS	‡
<b>LTC beds/ 1,000 65+</b> (continuous)	NS	NS	0.98 (0.97-0.98)	‡	0.996 (0.992-0.999)	0.93 (0.92-0.94)	0.99 (0.98-1.00)	‡	‡	1.0 (0.9-1.0)	0.993 (0.992-0.995)	NS	-	‡
<b>GPs/ 100,000</b> (continuous)	0.997 <sup>§</sup> (0.994-1.0)	NS	0.96 (0.95-0.97)	0.91 (0.88-0.94)	0.976 (0.974-0.979)	0.91 (0.89-0.92)	0.994 (0.991-0.998)	‡	‡	1.01 (1.01-1.02)	0.999 (0.998-0.999)	0.96 (0.96-0.97)	-	‡
<b>Nagelkerke R<sup>2</sup></b>	0.07	0.03	0.06	0.06	0.05	0.08	0.03	0.06	0.01	0.06	0.02	0.08	0.01	0.02

BE, Belgium; NL, Netherlands; ENG, England; WAL, Wales; FRA, France; ITA, Italy; ESP, Spain (Andalusia); HUN, Hungary; CZR, Czech Republic; NZE, New Zealand; USA, United States of America; CAN, Canada (Quebec excluded); MEX, Mexico; KOR, South Korea; NS, Not significant; -, corresponding variable or category was not registered in this country.

\*For Spain, data from 2010 was used; for USA, 2007.

<sup>†</sup> For Hungary, age category 60-79 was used, given only categories 60-69, 70-79 were available for this age category.

‡ Data were provided for country as a whole, therefore not included.

§ Number of GPs/100,000 for Belgium (201) might be overestimated, as it also includes non-practicing general practitioners.

**Table 4: Multinomial logistic regression analyses for country differences in place of death: unadjusted (model 1); adjusted for sociodemographic factors and social support (model 2); and sociodemographic factors, social support, and health care system factors (model 3).**

Odds Ratio (95% Confidence Interval) <sup>*</sup>			
<i>Country of residence</i>	<i>Model 1</i> <sup>†</sup>	<i>Model 2</i> <sup>‡</sup>	<i>Model 3</i> <sup>§</sup>
Home death versus hospital death			
France	1.0	1.0	1.0
Belgium	0.7 (0.6 - 0.8)	0.7 (0.6 - 0.8)	0.5 (0.4 - 0.6)
Netherlands	3.1 (2.5 - 3.8)	3.1 (2.5 - 3.8)	2.3 (1.8 - 2.9)
England	0.2 (0.2 - 0.2)	0.2 (0.2 - 0.2)	0.1 (0.1 - 0.1)
Wales	0.1 (0.1 - 0.2)	0.1 (0.1 - 0.2)	0.1 (0.1 - 0.1)
Italy	1.7 (1.7 - 1.8)	1.8 (1.7 - 1.8)	0.7 (0.6 - 0.7)
Spain	1.8 (1.7 - 2.0)	1.9 (1.7 - 2.1)	0.5 (0.4 - 0.5)
Czech Republic	0.5 (0.4 - 0.7)	0.6 (0.4 - 0.8)	0.3 (0.2 - 0.4)
United States	1.5 (1.5 - 1.6)	1.6 (1.5 - 1.6)	0.5 (0.5 - 0.6)
Canada	0.1 (0.1 - 0.2)	0.1 (0.1 - 0.2)	0.1 (0.1 - 0.1)
South Korea	0.4 (0.3 - 0.4)	0.4 (0.4 - 0.4)	0.2 (0.2 - 0.3)
Death in LTC setting versus hospital death			
France	1.0	1.0	1.0
Belgium	3.3 (3.0 - 3.5)	3.6 (3.3 - 3.8)	1.4 (1.2 - 1.5)
Netherlands	60.6 (50.8 - 72.1)	63.3 (53.1 - 75.5)	38.0 (31.2 - 46.1)
England	2.1 (2.0 - 2.1)	2.1 (2.0 - 2.2)	1.4 (1.3 - 1.6)
Wales	1.2 (1.1 - 1.3)	1.2 (1.1 - 1.3)	1.1 (0.9 - 1.2)
Italy	0.6 (0.6 - 0.7)	0.7 (0.6 - 0.7)	0.5 (0.5 - 0.6)
Spain	0.6 (0.6 - 0.7)	0.7 (0.6 - 0.7)	0.6 (0.5 - 0.7)
Czech Republic	2.4 (1.9 - 2.9)	3.0 (2.4 - 3.7)	3.9 (3.1 - 4.7)
United States	5.0 (4.9 - 5.2)	5.1 (5.0 - 5.3)	2.6 (2.4 - 2.9)
Canada	1.9 (1.9 - 2.0)	2.0 (1.9 - 2.1)	1.0 (0.9 - 1.1)
South Korea	0.1 (0.1 - 0.1)	0.1 (0.1 - 0.1)	0.1 (0.1 - 0.2)
Death in LTC setting versus home death			
France	1.0	1.0	1.0
Belgium	4.8 (4.3 - 5.2)	5.0 (4.6 - 5.5)	2.7 (2.4 - 3.0)
Netherlands	19.8 (17.6 - 22.3)	20.4 (18.1 - 23.0)	16.4 (14.0 - 19.1)
England	9.8 (9.2 - 10.5)	9.9 (9.2 - 10.6)	13.8 (12.3 - 15.3)
Wales	9.4 (7.2 - 12.3)	9.2 (7.0 - 12.1)	14.2 (10.8 - 18.8)
Italy	0.4 (0.4 - 0.4)	0.4 (0.4 - 0.4)	0.8 (0.7 - 0.9)
Spain	0.3 (0.3 - 0.4)	0.3 (0.3 - 0.4)	1.3 (1.1 - 1.4)
Czech Republic	4.7 (3.5 - 6.2)	5.4 (4.0 - 7.2)	13.2 (9.8 - 17.8)
United States	3.3 (3.2 - 3.4)	3.3 (3.2 - 3.4)	5.0 (4.6 - 5.6)
Canada	14.2 (12.8 - 15.7)	14.5 (13.0 - 16.0)	13.9 (12.1 - 16.0)
South Korea	0.2 (0.2 - 0.2)	0.2 (0.2 - 0.2)	0.6 (0.5 - 0.7)

\*New Zealand was not included, given "marital status" was not registered; Mexico was not included, given "death in LTC setting" was not registered; Hungary was not included, given only "hospital" and "other" was registered as place of death.

† Unadjusted odds-ratios (N=241,017; Nagelkerke R<sup>2</sup>=0.22).

‡ Adjusted for sociodemographic factors and social support (N=240,402; Nagelkerke R<sup>2</sup>=0.25).

§ Adjusted for sociodemographic factors, social support and health care system factors (N=240,247; Nagelkerke R<sup>2</sup>=0.26).

## DISCUSSION

In this study, we examined the place of death of 264,604 older people who died from a dementia-related disease in 14 European and non-European countries. The results show that there are substantial variations in place of death among these countries, with a particularly low proportion of hospital deaths in the Netherlands (1.6%). Male and younger patients with dementia (aged 65–79) were generally more likely to die in a hospital setting and a higher availability of LTC beds in the health care region was often associated with a lower chance of hospital death. Although health care system factors did greatly reduce country differences in place of death, notable differences remained.

Using death certificate data to study cross-national variation in place of death may induce several limitations that need to be taken into account.<sup>27</sup> Dementia as cause of death is known to be underreported; mild dementia has a lower probability of being listed and dementia might not be recognized as a cause of death when other (immediate) causes of death are present.<sup>28</sup> However, by including only deaths of people whose underlying cause of death was dementia, (i.e. those who died from dementia and thus were probably in an advanced stage of their dementia-related condition at the time of death),<sup>28</sup> bias related to death certification may be limited. Nevertheless, it has to be noted that diagnostic or reporting differences might exist between countries or between different health care settings within one country.<sup>28</sup> Furthermore, not all variables known to affect place of death can be included in this study, as death certificates do not include important individual-level information, such as preferences and decision-making processes.<sup>26;27</sup> However, the use of death certificate data to study such cross-national variation has proved to be useful in other studies and makes whole country comparisons possible.<sup>25;29;30</sup> To our knowledge, this is the first study examining cross-national variation in place of death of older people who died from dementia in both European and non-European countries, and the sociodemographic, social support, residential, and health care system factors associated with place of death.

After adjusting for sociodemographic factors, social support, and health care factors, significant country differences in place of death within the study population remained. Although a previous study with a similar population reported most deaths occurring in the LTC setting in England, Belgium, the Netherlands, and Scotland,<sup>25</sup> the current study suggests this is true for most countries: Belgium, the Netherlands, England, Wales, Czech Republic, New Zealand, United States, and Canada. However, compared with these countries, death at home is relatively more frequent in Italy, Spain, and France, indicating that death and probably care for older people with dementia is less institutionalized in these countries.<sup>31;32</sup> Furthermore, the likelihood of dying in hospital was very high

in South Korea and Hungary, possibly indicating that out-of-hospital end-of-life care services are not optimal, which might be due to the more recent development of these services in these countries.<sup>33;34</sup>

These differences in place of death might suggest that the most appropriate setting as place of death might not be the same in each country (i.e. that a hospital setting might prove to be best in one country and a home setting in another), possibly reflecting organizational differences in end-of-life care provision. Furthermore, as one recent study shows that cross-country variation in health-behaviors might be explained by differences in cultural values, perhaps this might partially explain why older people with dementia in neighboring countries, such as Belgium and the Netherlands, have a different likelihood of dying in hospital.<sup>35</sup> As reducing the number of hospital deaths among older people with dementia might be beneficial in some countries,<sup>13</sup> our results suggest that expanding the number of LTC beds in a region might be the most appropriate way of doing so. However, given the high number of hospital deaths within the study population, and in some countries in particular, we suggest that specialized end-of-life care in this setting also needs to be ensured.

Among older patients who died from dementia, men and those aged 65 to 79 were generally more likely to die in a hospital setting, which resonates with the findings of previous studies.<sup>23-25;36</sup> In the United States, people with lower levels of education were more likely to die in hospital, which might be related to an increased likelihood of preferring life-sustaining treatments among these subpopulations, resulting in higher chances of dying in hospital.<sup>37</sup> However, the finding that more highly educated people were more likely to die in hospital in Belgium, Mexico, and South Korea, as well as those who are married in Belgium, England, France, United States, and Canada, is somewhat more surprising. In some countries with limited health care services (e.g. Mexico), hospital care may be available only to more affluent populations, explaining the higher chances of dying in hospital for the more highly educated. For the other countries, one possible explanation might be that older people with dementia who are more highly educated, or married, as well as those aged 65 to 79 and men in general, are more likely to reside at home, but are unable to remain there until the very end of life, resulting in an end-of-life hospital admission and hospital death.<sup>10;36;38</sup> One Dutch study found that for older people, 2 main scenarios were likely: residing in a nursing home, lowering the chances of hospital death, or staying at home as long as possible, with a higher likelihood of hospital death.<sup>39</sup> Consequently, it could be suggested that among older people with dementia, those who are most likely to reside at home, in particular, should be supported by specialist palliative care services to reduce the number of hospital deaths.<sup>40;41</sup>

## **CONCLUSION**

Place of death of older people who died from a dementia-related disease differs substantially among countries, which might point to organizational differences in end-of-life care provision. Increasing the availability of LTC beds might be important to reduce the number of hospital deaths, whereas focusing specialized end-of-life care services on married people or those aged 65 to 79 might be crucial for achieving home death. However, proper end-of-life care needs to be ensured in hospitals, should this be the most appropriate end-of-life care setting.

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## **DISCLOSURE STATEMENT**

The authors declare no conflicts of interest.

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## CHAPTER 3

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### Dying in Hospital with Dementia and Pneumonia: a Nationwide Study Using Death Certificate Data

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## **ABSTRACT**

### **BACKGROUND**

For people with dementia dying from pneumonia, hospitalization at the end of life may be of little benefit and result in unfavourable outcomes such as hospital death.

### **OBJECTIVE**

The aim of this study is to estimate the incidence of and factors associated with hospital death in people with dementia dying from pneumonia.

### **METHODS**

We used death certificate data of all deaths in Belgium in 2008 (n=101,685) to examine characteristics of deaths of people with dementia dying from pneumonia. Information about the urbanization level of the place of residence and the availability of hospital beds, residential (without continuous skilled nursing) and skilled nursing beds in long-term care settings was linked through the zip code of the place of residence.

### **RESULTS**

Of people with dementia dying from pneumonia (n=1,420), 47.2% died in hospital. Of those living in long-term care settings, 25.6% died in hospital. For people living in their own home, hospital death was more likely for those who were single (adjusted odds ratio (AOR) 2.83, 95% CI 1.30-6.16) and living in strongly urbanized areas (AOR 2.48 95% CI 1.47-4.18). For those living in long-term care settings, hospital death was more likely in regions with higher availability of residential beds (without continuous skilled nursing) in long-term care settings (AOR per unit 1.02, 95% CI 1.01-1.03).

### **CONCLUSION**

Almost half of all those with dementia dying from pneumonia and a quarter of those living in long-term care settings died in a hospital. These results suggest shortcomings in the Belgian healthcare system in preventing potentially avoidable terminal hospitalizations in a vulnerable population.

## **KEYWORDS**

Place of death – Hospitalization – Dementia – Pneumonia – Long-term care

## INTRODUCTION

Dementia is becoming a major public health issue in many countries given increasing life expectancy and the aging of populations.<sup>1</sup> Dementia is considered as a life-limiting condition and palliative care is often appropriate, especially in the advanced stages of the disease.<sup>2</sup> The incidence of dementia as a cause of death is expected to rise and in people with advanced dementia, pneumonia and pneumonia-related mortality is common.<sup>3,4</sup> In a US long-term care setting, 64% of residents had suspected pneumonia in the last 6 months of life.<sup>5</sup> Although hospitalizations for pneumonia occur frequently in people with dementia during the last months of life,<sup>3</sup> they may be of limited benefit and result in additional risks and poor outcomes with respect to quality of life,<sup>4,6</sup> and can be considered inconsistent with palliative care. In general, few older people would choose to die in hospital, and in the case of dementia a majority of older people would prefer a long-term care setting as their last place of care.<sup>7</sup> Therefore, hospital death in people with dementia, in particular in cases of pneumonia, can be considered an indicator of poor quality end-of-life care. Limiting potentially avoidable and inappropriate hospital stays in the last phase of life may also result in reducing healthcare expenditure.<sup>6,8</sup>

The incidence and determinants of hospital death in people with dementia dying from pneumonia have not previously been studied on a population and nationwide level. Determining risk factors for hospital death in this population may identify deficiencies in the provision of end-of-life care. In Belgium, end-of-life care is provided by the usual caregivers (i.e. general practitioners in home care and long-term care settings and hospitalists in hospitals) supported by palliative care specialists, trained multidisciplinary professionals offering support in home care and long-term care settings; in long-term care settings in-house palliative care consultants are also available. Most Belgian long-term care settings are a hybrid of homes for the elderly and nursing homes and have both residential beds and skilled nursing beds, though 24/7 nursing care is only available for skilled nursing beds.

The aim of this study is to examine the incidence of in-hospital deaths and factors related to them in people with dementia dying from pneumonia in Belgium, using death certificate data from 2008.

The research questions are: (1) Were people with dementia dying from pneumonia more likely to die in hospital than those without pneumonia? (2) What was the incidence of hospital death in people with dementia dying from pneumonia? (3) What were the factors related to hospital death in people with dementia dying from pneumonia?

## METHODS

We used death certificates covering all deaths in Belgium in 2008 to study place of death and factors related to hospital death. Using data from death certificates did not require ethical approval. In Belgium, death certificates contain information about the place and cause of death and the socio-demographic characteristics of the deceased. Information about the place and cause of death is provided by a physician who registers a causal chain of conditions related to cause of death starting with the underlying cause, followed by one or two intermediary causes and the immediate cause of death. Additionally, up to three additional causes of death or comorbidities can be registered.<sup>9</sup> The certifying physician is usually the patient's treating physician. The treating physician may be the patient's general practitioner if the patient is treated at home or in a long-term care setting or a hospitalist if the patient is treated in hospital. The municipality provides information on the socio-demographic characteristics of the deceased, e.g. educational attainment, marital status and living arrangements. Information from the death certificates is processed and the causes of death are coded in ICD-10 codes by a special coding team and both medical and socio-demographic information is checked by government agencies.<sup>10</sup>

All those whose death certificates contained both dementia and pneumonia as causes of death were included. All the registered causes of death were considered: underlying, intermediate, additional and immediate. Dementia was defined as F01 (vascular dementia), F03 (unspecified dementia), G30 (Alzheimer's disease), since Alzheimer's disease and vascular dementia are the most prevalent subtypes of dementia.<sup>11;12</sup> Because of the possibly unreliable determination of subtypes, the category unspecified dementia was also included. Pneumonia was defined as J12 (adenoviral pneumonia), J13 (pneumonia due to streptococcus pneumoniae) J14 (pneumonia due to haemophilus influenzae), J15 (bacterial pneumonia, not elsewhere classified), J16 (pneumonia due to other infectious organisms, not elsewhere classified), J17 pneumonia in disease classified elsewhere) and J18 (pneumonia, organism unspecified).

The dependent variable is place of death as recorded on the death certificate and recoded into three categories: long-term care setting, hospital and at home. Deaths in other places, such as public spaces, were excluded from analysis. The independent variables are related to the personal characteristics of the deceased and his or her environment. Information on the type of dementia (Alzheimer disease, vascular dementia, unspecified dementia), the deceased's demographic (age categorized as under 65 years, between 65 and 74, between 75 and 84, 85 years and over, and sex) and level of education (no formal or elementary, secondary, higher, other or unknown) and social support (living arrangement: living at home alone, at home with others, in a long-term care setting,

and marital status: unmarried, married, widowed, divorced or separated) is available from the death certificate data. Through the zip code of the place of residence of the deceased we linked the urbanization level of the municipality of residence (very strong, strong, average, weak) and the available healthcare resources in the proximity of the deceased: available hospital beds per 1,000 inhabitants; available residential (without continuous skilled nursing) and skilled nursing beds in long-term care settings per 1,000 inhabitants of 65 years or older.

The bivariate association between pneumonia and place of death in people with dementia, and the bivariate associations between personal and environmental characteristics and place of death in people with dementia dying from pneumonia were examined using contingency tables and  $\chi^2$  tests. We used multinomial logistic regression to examine associations between personal and environmental factors and place of death for those living at home at the time of death (death in hospital and death in long-term care setting vs. home death) and binomial logistic regression for those living in long-term care settings (death in hospital vs. in long-term care setting). For all logistic regression models a forward stepwise likelihood ratio procedure for selection of variables was used. All analyses were performed using IBM SPSS Statistics, version 19 (IBM Corp., Somers, N.Y., USA).

## RESULTS

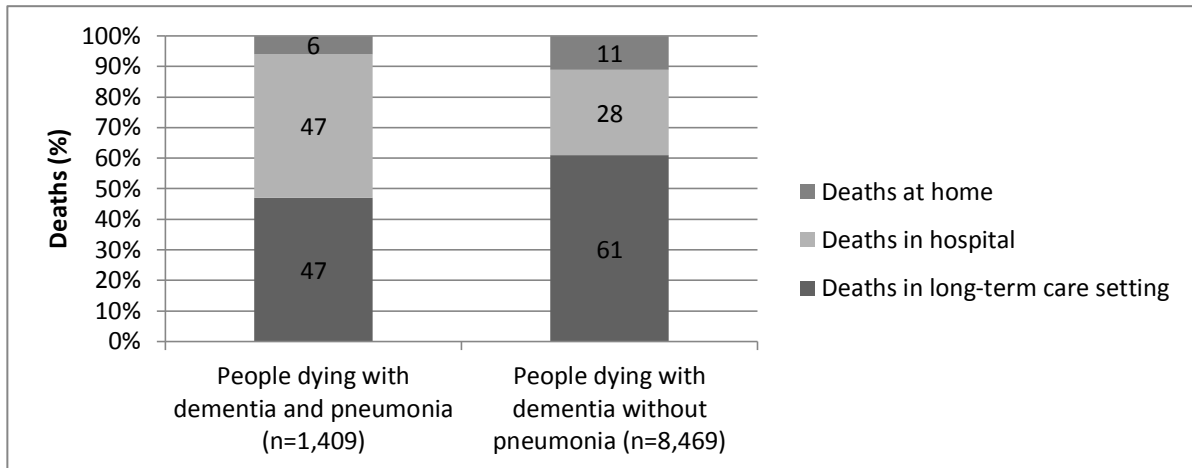
In Belgium, 9,931 of all those dying (9.8%) died with dementia. Of those dying with dementia, 1,420 (14.3%) were additionally certified with pneumonia as a cause of death or comorbidity.

People with dementia dying from pneumonia more often died in hospital (47%) compared with those dying with dementia without pneumonia (28%,  $p < 0.01$ ) (**fig. 1**). The results of a multivariate logistic regression analysis showed that dying from pneumonia was an independent risk factor for dying in hospital in people with dementia, both in those living at home (adjusted odds ratio [AOR] 3.21; 95% confidence interval [95% CI]) and in those living in long-term care settings (2.45-4.21; AOR 2.14, 95% CI 1.76-2.60), adjusted for type of dementia, age, sex, educational attainment, living arrangement, marital status, urbanization level, available hospital beds and residential and skilled nursing beds in long-term care settings (data not shown in table).

Of all those with dementia dying from pneumonia, equal proportion of deaths occurred in hospitals (47.2%) and long-term care settings (47.0%) while 5.8% died at home (**Table 1**). Hospital death was 25.6% in those living in long-term care settings, 67.4% in those living in a multi-person private household and 75.5% in those living at home alone. In those officially living at home alone at the

time of death, 20.7% died in a long-term care setting, in those living in multi-person household this was 19.0%. Half (50.7%) of our study population lived in long-term care settings at the time of death. More than half (57.8%) died of unspecified dementia and 33.9% of Alzheimer's disease, 52.7% were 85 years or older, 54.2% were women and 32.4% had no formal or elementary education.

**Fig.1. Place of death for people dying with dementia, with and without pneumonia (n=9,931). Deaths in a place other than long-term care setting, home or hospital were excluded from the analysis: n=53**



Death occurred relatively more often in a long-term care setting for people who died from Alzheimer disease, were older, female, unmarried or widowed and who were living in areas with lower availability of hospital beds and residential beds in long-term care settings (**Table 1**). The place of death was relatively more often hospital in those who lived alone, in those with vascular or unspecified dementia, were between 65 and 84 years of age, male, who were married or divorced, who lived in very strongly or strongly urbanized places and in regions with higher availability of hospital beds and residential beds in long-term care settings. Home death occurred relatively more often in those living in a multi-person household, with Alzheimer's disease or vascular dementia, were between 65 and 74 years of age, male, who were married, living in average or weakly urbanized places and in regions with lower availability of hospital beds.

Independent risk factors for hospital death after adjusting for a number of confounders are shown in **Table 2**. For people living at home at the time of death, hospital death compared with home death was less likely in those dying with Alzheimer's disease and more likely in those who were living at home alone, or living in a very strongly or strongly urbanized place. Death in a long-term care setting compared with home death for those living at home at the time of death was less likely in those with vascular dementia and those under the age of 75 years, and more likely in singles and those living in strongly or very strongly urbanized areas.

**Table 1 Population characteristics and place of death of people whose cause of death was both dementia and pneumonia (n=1,420)<sup>a</sup>**

	Total n (%)	LTC setting %	Hospital %	Home %	p value
ALL DEATHS	1409	47.0	47.2	5.8	
LIVING ARRANGEMENT <sup>b</sup>					< 0.001
LTC setting	706 (50.7)	73.4	25.6	1.0	
Multi-person household	478 (34.3)	19.0	67.4	13.6	
Single	208 (14.9)	20.7	75.5	3.8	
TYPE OF DEMENTIA					< 0.001
Alzheimer disease	477 (33.9)	56.0	35.4	8.6	
Vascular dementia	117 (8.3)	39.3	53.0	7.7	
Unspecified dementia	815 (57.8)	42.8	53.3	3.9	
AGE					< 0.001
< 65 years	14 (1.0)	50.0	42.9	7.1	
65-74 years	86 (6.1)	34.9	52.3	12.8	
75-84 years	566 (40.2)	42.6	50.2	7.2	
85+ years	743 (52.7)	51.7	44.4	3.9	
SEX					< 0.001
Male	646 (45.8)	39.6	53.6	6.8	
Female	763 (54.2)	53.2	41.8	5.0	
EDUCATIONAL ATTAINMENT					0.101
Other or unknown	610 (43.3)	47.7	45.7	6.6	
No formal or elementary	457 (32.4)	50.5	44.0	5.5	
Secondary	292 (20.7)	41.8	53.1	5.1	
Higher	50 (3.5)	36.0	60.0	4.0	
MARITAL STATUS <sup>b</sup>					< 0.001
Unmarried	93 (6.6)	52.7	47.3	0.0	
Married	499 (35.5)	34.7	55.1	10.2	
Widowed	762 (54.2)	55.1	41.2	3.7	
Divorced/ separated	52 (3.7)	36.5	57.7	5.8	
URBANIZATION LEVEL					0.003
Very strong/strong	858 (60.9)	46.0	49.7	4.3	
Average/weak	551 (39.1)	48.5	43.4	8.2	
HOSPITAL BEDS/1,000					< 0.001
≤ Median	692 (49.1)	51.6	41.5	6.9	
> Median	717 (50.9)	42.5	52.7	4.7	
RESIDENTIAL BEDS IN LTC SETTINGS /1,000 >65 YEARS					0.006
≤ Median	682 (48.4)	51.3	43.1	5.6	
> Median	727 (51.6)	42.9	51.0	6.1	
SKILLED NURSING BEDS IN LTC SETTINGS/1,000 >65 YEARS					0.147
≤ Median	675 (47.9)	44.6	48.7	6.7	
> Median	734 (51.2)	49.2	45.8	5.0	

LTC, Long-term Care.

<sup>a</sup> Deaths in a place other than LTC setting, hospital or home were excluded from analysis: n=11.

<sup>b</sup> Missing values living arrangement n=11 (0.8%), marital status n=3 (0.2%).

**Table 2 Factors associated with place of death of people (age ≥65 years) whose cause of death was both dementia and pneumonia in Belgium (2008) (n=1,420)**

	<u>People living at home (n=681)</u>		<u>People living in LTC settings (n=697)</u>
	AOR (CI 95%) <sup>a</sup>		AOR (CI 95%) <sup>a</sup>
	Death in hospital vs. at home	Death in LTC setting vs. at home	Death in hospital vs. in LTC setting
TYPE OF DEMENTIA (VS. UNSPECIFIED DEMENTIA)			
Alzheimer dementia	0.36 (0.20-0.62)	1.22 (0.65-2.29)	0.47 (0.31-0.70)
Vascular dementia	0.62 (0.26-1.49)	0.23 (0.06-0.96)	0.76 (0.40-1.46)
AGE (VS. 85+)			
65-74 years	0.58 (0.25-1.31)	0.21 (0.07-0.65)	NS <sup>b</sup>
75-84 years	0.82 (0.47-1.43)	0.54 (0.29-1.01)	
SEX (VS. FEMALE)			
Male	NS	NS	NS
EDUCATIONAL ATTAINMENT (VS. HIGHER EDUCATION)			
Other or unknown	NS	NS	NS
No formal or elementary			
Secondary			
LIVING ARRANGEMENT (VS. MULTI-PERSON HOUSEHOLD) <sup>c</sup>			
Single	2.83 (1.30-6.16)	3.00 (1.29-6.95)	
MARITAL STATUS (VS. MARRIED) <sup>d</sup>			
Unmarried			NS
Widowed			
Divorced/separated			
URBANIZATION LEVEL (VS. AVERAGE/WEAK/RURAL)			
Very strong/ strong	2.48 (1.47-4.18)	2.05 (1.12-3.75)	NS
HEALTHCARE RESOURCES			
Hospital beds/1,000	NS	NS	NS
Residential beds in LTC settings /1,000 >65 years	NS	NS	1.02 (1.01-1.03)
Skilled nursing beds in LTC settings/1,000 >65 years	NS	NS	NS

LTC=Long –term care.

<sup>a</sup> Parameter in italics: regression coefficient not significant at 5% significance level. <sup>b</sup> NS=Not significant. Variable was entered in the regression equation but not found significant in the stepwise selection procedure of variables. <sup>c</sup> Variable not entered in the equation (for people living in LTC settings) because the variable living arrangement is a constant: LTC setting. <sup>d</sup> Variable not entered in the equation (for people living at home) because of potential co-linearity with the variable living arrangement.

For those living in a long-term care setting at the time of death, hospital death was less likely in those with Alzheimer's disease and more likely in those living in areas with a higher availability of residential beds in long-term care settings.



## DISCUSSION

In this nationwide population-level study, we examined the incidence of and risk factors for hospital death in a vulnerable population of people with dementia who died from pneumonia. Pneumonia was identified as an independent risk factor for hospital death in those dying with dementia regardless of whether they lived in a long-term care setting or in their own home. Almost half of all people with dementia dying from pneumonia died in a hospital, as did a quarter of those living in long-term care settings.

This epidemiological study used population data from death certificates. The collection and processing of data from death certificates by the Belgian authorities is subject to several quality controls.<sup>10</sup> It was possible to examine the incidence and risk factors for hospital death separately for those living at home and those living in long-term care settings at the time of death, while the relationship between healthcare system factors and hospital death risk could be examined through linkage with the zip code of the place of residence of the deceased. Death in palliative care unit is registered as a hospital death on Belgian death certificates, although this has a limited effect on this study, as there is evidence that it is mainly cancer patients who die in palliative care units.<sup>13</sup> However, there are known issues which may result in an underestimation of dementia as cause of death;<sup>14;15</sup> the overrepresentation of deaths from unspecified dementia may be related to the difficulty of registering a specific dementia-related disease as cause of death in the absence of a clinical diagnosis. Since certifying dementia as cause of death on death certificates is more likely for people dying in long-term care settings, hospital death of people dying with dementia and pneumonia may be underestimated in our study. Pneumonia as cause of death may be underestimated outside hospitals because of the lack of diagnostic tools. Moreover, it cannot be excluded that part of our study population died of hospital-acquired pneumonia after admission to hospital for other reasons, since it was shown that 13.5% of pneumonia cases in Italian hospitals in 2007 were hospital acquired.<sup>16</sup> No information was available for a number of factors found to be related to place of death in previous research.<sup>17</sup>

Although there is evidence that pneumonia in people with dementia can be treated just as well or even better outside the hospital,<sup>6</sup> we found that people with dementia dying from pneumonia are still admitted to hospital at the end of life and, even more so, that pneumonia is an independent risk factor increasing the chances of hospital death. This was the case both for those living in long-term care settings and those still living at home. Whether the place of death was consistent with their wishes could not be studied and is questionable. Unfortunately, although many long-term care settings have institutional guidelines, wishes regarding future care and hospital admissions were

shown to be documented for only a small minority of residents with dementia.<sup>18-21</sup> Possibly, the prevalence of do-not-hospitalize orders in people with dementia still residing at home is even lower, since there are no institutional guidelines. Therefore, we must assume that most decisions to treat and to hospitalize for treatment of people with dementia dying from pneumonia were taken by relatives and professional caregivers.<sup>18</sup> In Belgium, general practitioners do not have a strong gate-keeping role in hospitalization as is they do in the Netherlands, a neighbouring country. Therefore, relatives can always take the decision to hospitalize a family member via the emergency admissions procedure and it may be that some admissions result from the belief of relatives that hospitalization is indicated in cases of pneumonia. We suspect however that a substantial proportion of these decisions are made because of the increased burden of care on the family in cases of pneumonia, which suggests that the Belgian healthcare system fails to provide sufficient support for people with dementia and their families to enable them to be cared for at home until the end of life. It may also be that palliative care services and health insurance reimbursement for end-of-life care at home may be tailored more to the needs of cancer patients,<sup>22</sup> than of those with dementia.

It is particularly striking that, despite the institutional setting, more than a quarter of terminally ill long-term care residents with dementia dying from pneumonia died in hospitals. Previous research shows that adequate staffing of long-term care settings is an important factor in reducing the risk of potentially avoidable hospitalizations of residents with dementia.<sup>23;24</sup> The finding that hospital death risk is more likely in areas with more residential beds in long-term care settings, with a lower level of skilled nursing care, is not surprising and points to the need for more skilled nursing care resources in order to prevent burdensome transitions.<sup>25</sup> In the Dutch healthcare system, care in long-term care settings is not managed by the resident's own general practitioner, as is the case in Belgium, but by in-house specialist elderly care physicians. This model has the advantage of strongly reducing the hospital death risk of long-term care residents with dementia compared with Belgium and other countries.<sup>23;26</sup> In Belgium, geriatricians mainly work in hospitals. Depending on the financial cost of this model and the characteristics of the healthcare systems, its implementation may be considered in other countries.

The higher risk of dying in hospital for those living alone and those in urban areas points to specific problems in the Belgian healthcare system in caring for people with a lower level of informal care. In people living alone at home, death in a long-term care setting was also more likely in urban areas and may be more appropriate than hospital death, though the lack of immediately available skilled nursing beds in long-term care settings may account for the finding that they still have a higher risk of hospital death. Living in urbanized areas was an independent risk factor for hospital death,<sup>27;28</sup> which may be partly related to the lack of social networks but possibly also to the cultural diversity

found in Belgian metropolitan regions and the associated communication problems.<sup>5;29</sup> Further, Belgian metropolitan populations are less likely to have a regular general practitioner and more likely to visit hospital emergency rooms as an alternative to primary care.<sup>30;31</sup> Our finding that a relatively large proportion of people with dementia dying from pneumonia died in a hospital suggests that a significant proportion of terminal hospitalizations of people dying with dementia may be avoidable. To reduce these potentially avoidable and burdensome hospitalizations, public health policy should aim to better support primary healthcare providers in providing palliative and end-of-life care to their patients in their usual place of residence, through training, financial compensation and support from specialist teams. All healthcare professionals should be trained and motivated to instigate timely conversations about preferences for future care including hospitalizations at the end of life.<sup>32</sup> Additionally, investment should be made in easily accessible long-term care settings for vulnerable populations such as those living alone or those in urbanized areas, in order to provide adequate alternatives to hospital. Moreover, investment in skilled nursing capacity in long-term care settings is essential.

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## **DISCLOSURE STATEMENT**

The authors have no conflicts of interest to disclose

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# PART III

Family physicians' perspectives  
on their role in end-of-life  
hospital admissions





## CHAPTER 4

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# The Family Physician's Perceived Role in Preventing and Guiding Hospital Admissions at the End of Life: a Focus Group Study

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## **ABSTRACT**

### **PURPOSE**

Family physicians play a pivotal role in providing end-of-life care and in enabling terminally ill patients to die in familiar surroundings. The purpose of this study was to explore the family physicians' perceptions of their role and the difficulties they have in preventing and guiding hospital admissions at the end of life.

### **METHODS**

Five focus groups were held with family physicians (N= 39) in Belgium. Discussions were transcribed verbatim and analyzed using a constant comparative approach.

### **RESULTS**

Five key roles in preventing and guiding hospital admissions at the end of life were identified: as a care planner, anticipating future scenarios; as an initiator of decisions in acute situations, mostly in an advisory manner; as a provider of end-of-life care, in which competency and attitude is considered important; as a provider of support, particularly by being available during acute situations; and as a decision maker, taking overall responsibility.

### **CONCLUSIONS**

Family physicians face many different and complex roles and difficulties in preventing and guiding hospital admissions at the end of life. Enhancing the family physician's role as a gatekeeper to hospital services, offering the physicians more end-of-life care training, and developing or expanding initiatives to support them could contribute to a lower proportion of hospital admissions at the end of life.

## **KEYWORDS**

Family Practice – Hospitalization – Terminally ill – Palliative Care – Qualitative Research –

Focus Groups

## INTRODUCTION

Despite national end-of-life care policies aiming at home death and most patients preferring not to die in hospital, the acute hospital setting remains a common place of final care and death in most countries.<sup>1;2</sup> In Belgium, the proportion of hospital deaths has decreased slightly during the last decade, from 55.1% to 51.7% between 1998 and 2007, similar to decreases found in other countries.<sup>3-6</sup> When compared with countries that have lower proportions of hospital deaths, e.g. 34% in The Netherlands and New Zealand or 40% in Denmark,<sup>2;7</sup> and countries that have reported larger decreases in hospital deaths, e.g. from 49% to 36% in the United States between 1989 and 2007,<sup>8</sup> the proportion for Belgium remains persistently high.

Furthermore, despite a decreasing proportion of hospital deaths, the use of hospital services at the very end of life remains high and might even increase. In an elderly population in the United States, intensive care unit use in the last month of life has been shown to have increased from 24.3% to 29.2% between 2000 and 2009.<sup>9</sup> Moreover, in Belgium, as in other countries, the hospitalization rates of patients who died after a gradual decline have been found to increase exponentially in the last months of life.<sup>9-14</sup> In-depth research regarding the critical role of the family physician in preventing such hospital admissions at the very end of life is lacking, however.

Family physicians are thought to play a pivotal role in providing end-of-life care and in enabling terminally ill patients to die at home or in the nursing home where they reside.<sup>15;16</sup> It has been shown that most people would prefer to be cared for and to die in familiar surroundings,<sup>17;18</sup> and that these preferences are more likely to be met when the family physician is aware of them.<sup>17;19;20</sup> Additionally, a nursing home or home death seems to be more likely when the family physician makes more visits in the last 3 months before death,<sup>21-23</sup> and continuity of care at the end of life by the family physician seems to reduce emergency department use and hospital death.<sup>24;25</sup> Such continuity is a rare achievement, and being available at all times can be difficult and demanding.<sup>26-28</sup> Moreover, family physicians might sometimes feel unable to provide up-to-date and adequate end-of life care,<sup>26;27;29</sup> and decisions about a transfer to a hospital at the end of life can be complex and multifaceted.<sup>30</sup>

In Belgium there is a strong emphasis on primary care, with almost 95% of the population having a family physician whom they consult regularly (78% at least once a year).<sup>31</sup> Moreover, as end-of-life care is integrated into the regular care system, family physicians usually coordinate and provide out-of-hospital end-of-life care.<sup>32</sup> They can be supported by specialist palliative care providers, usually at the family physician's request, e.g. when the physician does not feel sufficiently competent. Family physicians are therefore considered to be instrumental in preventing inappropriate end-of-life

hospital admissions. The family physician's gatekeeper role to hospital services is limited in Belgium,<sup>33;34</sup> however, because patients or families may autonomously decide to go to a hospital for specific problems without consulting any family physician.<sup>34-36</sup> The aim of this study was to explore the family physicians' perspectives of how they perceive their own role in preventing and guiding end-of-life hospital admissions and the difficulties they experience within such a role. Unravelling the expectations and tasks family physicians encounter, as well as the difficulties that can arise regarding these end-of-life hospital admissions, might shed some light on the complexity of their role as primary caregiver at the end of their patient's life, as well as any opportunities for improvement in providing adequate end-of-life care.

## **METHODS**

A focus group methodology was considered to be most suitable to comprehend the experiences and opinions of family physicians, given its meaningful process of sharing and comparing.<sup>37</sup> We recruited 5 focus groups of family physicians (N = 39) and analyzed verbatim transcriptions using a constant comparative analysis.

### **PARTICIPANTS**

Focus groups participants were members of local peer-review groups. Nearly 97% of all full-time practicing family physicians in Belgium are affiliated with a peer-review group where they discuss aspects related to family practice.<sup>38</sup> To maintain accreditation, they are obliged to attend at least 2 of 4 meetings each year. Using pre-existing groups for focus groups has been shown to benefit discussions.<sup>39</sup> We contacted by e-mail several groups from different regions across Belgium, and 5 groups were selected according to their availability.

### **DATA COLLECTION**

The focus group discussions lasted between 60 and 120 minutes and were moderated and observed by 2 medical sociologists with experience in qualitative research and knowledge of the items needed to be discussed (T.R., D.H.). The data used in this study were collected in the context of a wider study exploring the justifications provided for hospital admissions at the end of life. After completing a short questionnaire and an informed consent form, participants were asked about their experiences and opinions concerning end-of-life hospital admissions in general. Next, a discussion prompted by

case descriptions was generated about whether an end-of-life hospital admission would be appropriate or justified—defined as the only or best option for the patient, given the circumstances. During focus group discussions participants were asked to reflect on what they perceived to be their roles as a family physician and what difficulties might arise.

**Data Analysis**

The focus group discussions were audio-recorded and transcribed verbatim. Analysis was guided by a constant comparative method. After reading and initially coding several transcripts, the 2 medical sociologists developed a coding framework for categorizing the family physicians’ roles in preventing and guiding hospital admissions. This initial framework was discussed within the research team (4 medical sociologists, 1 family physician, and 1 nurse). One researcher (T.R.) coded all transcripts and modified the framework where necessary and in consensus with another researcher (D.H.). Results were regularly discussed within the research team, with each team member rereading and recoding several transcripts to ensure consistency and validity. A final thematic framework was agreed upon, and quotes were selected, translated and approved by the research team. Qualitative data were analyzed using QSR NVivo 10.

Ethics approval for this study was given by the Medical Ethics Commission of the Brussels University Hospital.

**RESULTS**

Characteristics of the participants in the focus groups are displayed in **Table 1**. After analysis, we identified 5 key interrelated roles family physicians played in preventing and guiding hospital admissions at the end of life: as a care planner, as an initiator of decisions, as a provider of end-of-life care, as a provider of support, and as a decision maker.

**Table 1. Characteristics of Focus Group Participants**

Characteristic	FG1	FG2	FG3	FG4	FG5	Total
Participants, No.	7	5	9	13	5	39
Age, average years	53.9	74.6	56.3	55.7	58.4	56.82
Sex						
Male	5	5	8	10	4	32
Female	2	0	1	3	1	7

FG=Focus Group.

**ADVANCE ASSESSMENT AND PLANNING CARE: A CONTINUOUS PROCESS**

To be able to prevent hospital admissions during end-of-life care, family physicians take on the role of care planner. Care planning is considered to be a two-way process. First, it is essential that the patient and the patient's family are adequately informed about all options and possibilities associated with end-of-life care. After they clarify their preferences, the family physician can assess the capacity of the care setting and take into account their expectations and preferences.

*If the patient eventually reaches a decision, after you have given him all the [information], you are going to respect that wish, I think. It is so, you obviously first have to give a lot of information to that patient, lots of elements which he may not previously have taken into account (Focus Group 1 [FG1]).*

Subsequently, care planning is considered to be a continuous process as arrangements and agreements are made throughout the dying phase in an effort to anticipate or forego future hospital admissions.

Participants indicated that it can be difficult to anticipate future scenarios, considering how assessments can change. Moreover, a major problem expressed by participants is that they sometimes feel excluded by hospital specialists and lose sight of patients who are in treatment. As a result, they have to make end-of-life plans at the very end of life, rather than in advance, which hinders their ability to organize adequate care.

*I also do think it is a problem, you get them back when they [hospital specialists] themselves do not see where to take it from there, you see. ... And then you have to start making arrangements and discuss the prospects they [the patients] have and, yes, indeed, that is a problem, I agree. And they even may have been hearing something completely different for 6 months or so (FG5).*

**INITIATING DECISIONS IN ACUTE SITUATIONS**

Deciding whether to hospitalize in an acute situation involves many different perspectives: the family physician's, the patient's, family members', and caregivers'. Participants indicated that, as a family physician, they sometimes need to mediate these perspectives to avoid conflicts, which would otherwise hinder their ability to initiate decisions and to find common ground among those involved.

Moreover, because in the Belgian health care system the family physician's role in deciding whether to admit a patient to hospital is merely advisory, patients' and family caregivers' preferences were generally seen as carrying more weight.

*...[S]o you cannot create a conflict. I think you can negotiate, but if he says, "I'm going [to the hospital]," well, then he's going, right. ... And I can [explain] it even further, I am not for it, but that is my opinion, it is his decision (FG3).*

### **PROVIDING END-OF-LIFE CARE: COMPETENCIES AND ATTITUDES**

Some study participants indicated that the physician's competence and attitude regarding end-of-life care are important in avoiding hospital admissions at the end of life. Family physicians who were more skilled in end-of-life care were considered to be more effective in keeping the patient at home or in the nursing home. Being able or wanting to keep a patient at home or in the nursing home, however, can also depend highly on the family physician's attitude toward end-of-life care.

*I think the avoidability and inappropriateness of hospitalizations at the end of life diminishes depending on your competence of dealing with controlling symptoms. I am sure of that. What is avoidable for one colleague is not necessarily avoidable for another. ...I think it also has to do with the doctor's own attitude. How you think about these things as a person.... If you are convinced that you have to try and save the patient's life in every case and at all cost, with all possible means,... the patient will sooner be admitted to the hospital... (FG1).*

Also, being supported by a local palliative care services specialist was considered important and helpful.

*Therefore I also found it important to work with a palliative home team for once, to give you some breathing space. ... I think that it also benefits the...family physician's strength when you work with these people (FG4).*

**PROVIDING SUPPORT: BEING AVAILABLE DURING ACUTE SITUATIONS**

Participants believed it was expected that family physicians need to be able to support dying patients at all times and therefore be available continuously, and that being available, where appropriate, can prevent patients from going to hospital. They need to be present in acute situations to support the patients and to convince them and their relatives that the patients can stay at home or in the nursing home.

Some participants, however, also admitted that they cannot always be available as a family physician or they feel more comfortable in admitting a patient to hospital, particularly during weekends.

*...[A]nd sometimes we also feel safer when he is in the hospital, you see. That is how it is, that is our responsibility partly given to someone else, on a Friday night, which is also a bit more comfortable, I do admit that (FG1).*

**TAKING RESPONSIBILITY: BEING ABLE TO MAKE DECISIONS**

Participants explained that family physicians sometimes do need to make decisions themselves about whether to admit a patient to hospital. They believed a family physician should be prepared to make these decisions.

*I think that at a certain moment you have to decide for yourself and tell the family clearly: "Look, we can admit the patient to the hospital, he may pull through, but...have you already said your good-byes? Yes or no?" And if they all [say], "Look, we have said our good-byes...," then I think you have to say firmly, "OK, so no admission" (Participant 1, FG4).*

*But in that case [the family must] unanimously agree in fact and also [suppose]: part wants it and another part does not, it's not simple in that case, and then you have to take your responsibility as a doctor, in a way, I think (Participant 2, FG4).*

Some participants indicated that in some situations, for example when they are not sure they can provide adequate care or when they are not sure about the patient's medical situation, they decide to admit a patient to a hospital, particularly when they are on duty after-hours and information is lacking.



## DISCUSSION

To our knowledge this study is the first to use a focus group methodology to explore the experiences of family physicians in their roles of preventing and guiding hospital admissions at the very end of life, as well as the difficulties they experience, while focusing on different care settings and disease trajectories. Family physicians in our study indicated that they face many different and complex roles in dealing with hospital admissions at the end of life and encounter barriers to fulfilling those roles. They need to plan care so they can anticipate future scenarios, initiate decisions in an advisory manner, and try to avoid conflicts. Their own attitudes and expertise in end-of-life care are considered important in enabling patients to remain at home until the end of life. They need to provide support, mostly by being available at all times and particularly in acute situations; and they need to be able to make decisions themselves and to be prepared to take responsibility.

There are several limitations to this study. Despite the advantages of using pre-existing groups of family physicians,<sup>39</sup> this method might mean that some participants restricted reporting their thoughts or opinions — they might have felt safer not questioning their own or others' competencies in front of their colleagues. Furthermore, although the proportion of male practicing family physicians in this sample is similar to representative national figures, the average age of 57 years was older compared with the national average of 49 years.<sup>38</sup> Because there is no clear indication that our recruitment procedure selected for older physicians, and because the short questionnaires completed before discussions showed a great variety of experience and training, we believe the older age has not biased the results, though it should be taken into account. The research team consisted of 4 medical sociologists, 1 family physician, and 1 nurse, all with experience in qualitative research in social health sciences. This multidisciplinary composition of the team provides a good guarantee for adequate reiteration and triangulation of the data interpretation from various perspectives, but they might have guided data interpretation and analysis in the sense that a social health perspective was dominant. Finally, it has to be noted that this study focused on the family physician's role specifically, although such a role is evidently intertwined with other factors.

An important finding in this study is that the Belgian family physicians' limited gatekeeper function might have a considerable effect on their ability to prevent end-of-life hospital admissions, despite their prominent role in enabling patients to die in familiar surroundings. This limited function substantially hinders their ability as care planner and diminishes the weight of their decisions in acute situations. It might also, in part, explain why countries where family physicians are stronger gatekeepers to hospital services, e.g., The Netherlands or Denmark, have fewer patients hospitalized in the last 3 months of life,<sup>35;40;41</sup> or have a lower proportion of hospital deaths.<sup>2;7</sup> It could be

suggested, therefore, that adopting a system by which the usual family physician refers patients for most specialized services would be a good starting point to reduce the number of end-of-life hospital admissions. Family physicians would be included earlier in the end-of-life trajectory, thereby improving their role as care planners and their ability to provide continuity of care,<sup>42</sup> as well as further strengthen their position as end-of-life care providers.

Another important finding of this study is that the family physician's expertise and attitude toward end-of-life care are shown to be essential in preventing an end-of-life hospital admission. Family physicians appear to differ in their competencies and attitudes toward prevention of hospital admissions at the end of life in that family physicians who do not feel competent are more likely to send a patient to a hospital. Furthermore, feeling incompetent to deal with dying patients might prevent family physicians from taking responsibility for keeping the patient at home or to being available to them. That family physicians are more familiar with cancer end-of-life trajectories,<sup>43;44</sup> might also partially explain why cancer patients are more likely to die at home or less likely to die in hospital, compared with patients dying of other causes.<sup>3;4;14;45;46</sup> Improving competencies and attitudes through adequate end-of-life care training therefore seems to be essential to reducing the number of end-of-life hospital admissions. Preferably, improved competencies can be accomplished by ensuring basic end-of-life care training is incorporated into family practice curricula. Furthermore, we found that family physicians feel more competent and confident when supported by specialist end-of-life caregivers. Services that support and assist family physicians in providing end-of-life care are important to enable them to keep a patient at home or in the nursing home.

Family physicians face many different roles and difficulties in guiding and preventing hospital admissions at the end of life. Enhancing family physician continuity by assigning them a more restrictive gatekeeper role in access to hospital services and improving their competence and attitudes, preferably by basic end-of-life care training, could prevent more terminally ill patients from dying in a hospital and improve end-of-life care in general.

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## **DISCLOSURE STATEMENT**

Conflicts of interest: authors report none.

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# PART IV

Reasons for, appropriateness and  
avoidability of hospital admissions  
at the end of life



## CHAPTER 5

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### The Acute Hospital Setting as a Place of Death and Final Care: a Qualitative Study on Perspectives of Family Physicians, Nurses and Family carers

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Thijs Reyniers; Dirk Houttekier; Joachim Cohen;  
H. Roeline Pasman; Luc Deliens

## **ABSTRACT**

While the focus of end-of-life care research and policy has predominantly been on 'death in a homelike environment', little is known about perceptions of the acute hospital setting as a place of final care or death. Using a qualitative design and constant comparative analysis, the perspectives of family physicians, nurses and family carers were explored. Participants generally perceived the acute hospital setting to be inadequate for terminally ill patients, although they indicated that in some circumstances it might be a 'safe haven'. This implies that a higher quality of end-of-life care provision in the acute hospital setting needs to be ensured, preferably by improving communication skills. At the same time alternatives to the acute hospital setting need to be developed or expanded.

## **HIGHLIGHTS**

- Explores the perception of the acute hospital setting as a place of death.
- Acute hospital care was considered to be inadequate for terminally ill patients.
- In certain situations the acute hospital setting was perceived as a safe haven.
- Adequate alternatives to acute hospital care could reduce hospital deaths.
- Proper end-of-life care needs to be ensured in all acute hospitals.

## **KEYWORDS**

Place of Death – Location of Death – Hospitals – Palliative Care – Terminal Care

## INTRODUCTION

The debate about the appropriateness of different care settings as a place of final care and death started at least two decades ago, but the issue remains alive and relevant to this day.<sup>1</sup> Following a rising proportion of people dying in hospital throughout the 20th century, the proportion of hospital death has slightly decreased in several countries during the last decade, e.g. in Belgium from 55.1% to 51.7% between 1998 and 2007, indicating a potential shift in end-of-life care from the hospital towards other locations.<sup>2-4</sup> However, despite national policies aimed at increasing home death, the proportion of people dying in a hospital setting remains persistently high.<sup>5-8</sup>

Because home has been consistently reported as the preferred place for end-of-life care in many populations around the world, end-of-life care policies generally support the home as the most desirable place of death;<sup>6;8;9</sup> dying at home is considered to be a condition for a 'good death', and is often assumed to be the gold standard.<sup>10</sup>

On the other hand, some studies have suggested that a preference for the home setting as the place of final care and death might change in favour of hospital as death approaches.<sup>9;11</sup> Another study suggests that, while older people might prefer a home death in ideal circumstances, a relatively large proportion can imagine that they would choose to be cared for elsewhere when dying if circumstances were not ideal.<sup>12</sup> Reasons such as having limited informal care and preferring safe professional care can lead to patients preferring not to die at home.<sup>13;14</sup>

Furthermore, it has been suggested that the acute hospital setting is perceived to be inadequate and too medicalized to provide proper end-of-life care.<sup>15</sup> It is a place where death might be perceived as a technical or medical problem and it has been suggested that there is an inclination in the acute hospital setting to engage in more aggressive treatment and to routinely use all available technological options.<sup>16-18</sup> Moreover, achieving a comfortable or homely environment may prove to be difficult in such a clinically focused setting.<sup>19;20</sup>

In Belgium, 25 palliative care networks, each covering around 300,000 inhabitants, generally coordinate the intervention of palliative care services and integrate them into the regular health care system.<sup>21;22</sup> Family physicians, home care and nursing home nurses have a pivotal role in providing end-of-life care outside of the hospital, while hospital physicians and nurses provide such care within the hospital setting. All professional caregivers, as well as family caregivers, can be supported and assisted by specialist palliative care providers, who are part of such a palliative care network. Furthermore, there are 51 palliative care units that are generally located on a hospital campus, although they are considered independent of the acute hospital setting.<sup>22</sup> Given there are only 379

such palliative beds in Belgium, which is insufficient in view of the palliative care demand, every acute hospital also has an intramural palliative support team.<sup>21</sup> Given their pivotal role in end-of-life care and end-of-life hospital admission experiences, professional and family caregivers' perspectives are considered essential in this study.

Like the relevant health care policies, most research has been focused mainly on the home setting as the ideal place of death. As a result, little is known about how the acute hospital setting is perceived as a place of final care or place of death. Considering that many people eventually die within this setting, an adequate understanding of the perceptions and experiences of the acute hospital setting as the place of final care and death is important as this might indicate areas for improvement regarding the quality of end-of-life care provision within the hospital.

The aim of this study is to explore the perspectives of family physicians, nurses from different care settings (home, nursing home and hospital) and family carers of those who died in an acute hospital setting concerning the acute hospital setting as a place of final care or death.

## **METHODS**

In order to be able to comprehend adequately the experiences and opinions of family physicians, nurses and family carers and to develop an understanding about their perceptions of the acute hospital as a place of final care and death a qualitative design was considered most suitable.<sup>23</sup> Eight focus groups were used, three with nurses ( $N=23$ ) and five with family physicians ( $N=39$ ) and 17 semi-structured interviews with bereaved family carers were conducted.

### **FOCUS GROUPS**

Focus group discussions were considered to be the best approach to explore the opinions and experiences of nurses and family physicians, given its meaningful process of sharing and comparing.<sup>24</sup> Participants were purposively selected from different care settings (nursing home, hospital or home setting) for the nurse focus groups in order to maximize variation in experience and background, as shown in Table 1.<sup>25</sup> To recruit family physicians, existing peer-review groups for family physicians were invited to participate via email and five from Flanders and Brussels were planned because of their availability. Nearly 97% of all family physicians in Belgium are affiliated to such a peer-review group and are obliged to attend at least two out of four meetings per year for accreditation, where

they discuss aspects related to family physician practice.<sup>26</sup> The data used in this study were collected in the context of a wider study exploring the justifications given for hospital admissions at the end of life, for which a topic guide was developed by the research team and slightly modified after each focus group. After given their written informed consent, participants were asked about their experiences and opinions concerning the acute hospital as a final place of care or death and end-of-life hospital admissions. Next, a discussion was generated about what, when and why an end-of-life hospital admission would be appropriate or justified, by using vignettes describing three different cases. Lastly, participants had to identify key factors that would justify an end-of-life hospital admission. During focus group discussions, participants were encouraged to express their opinions and experiences concerning the acute hospital as a setting for dying patients. For each focus group the number of participants and their professions are shown in **Table 1**.

**Table 1. Focus Group Characteristics**

	Focus Group	N1	N2	N3	FP1	FP2	FP3	FP4	FP5	Total
Care Setting	Family physician				7	5	9	13	5	39
	Nursing Home Nurse	2	1	7						10
	Hospital Nurse	4	4							8
	Home Care Nurse	2	3							5

N=Nurses; FP=Family Physicians

## INTERVIEWS

Additionally, the perspectives of family carers of people who had died within an acute hospital were included using semi-structured interviews. We anticipated that discussing their experiences might provoke emotional reactions and therefore would most suitably be explored in depth through face to face interviews.<sup>27;28</sup> These family carers were recruited using purposive and snowball sampling, which was mainly focused on including different disease trajectories, as shown in **Table 2**. In recruiting respondents it was considered important that they had cared for a family member or friend with a chronic life-limiting disease (i.e. cancer, organ failure or dementia) during the last phase of life and who had died in a hospital between three months and two years before the interview. Several health care organizations were contacted who informed their professional caregivers and placed announcements in their newsletters or on their websites, encouraging potential respondents to contact the researchers (TR), while family physicians and nurses who had participated in focus groups and other interview respondents were also asked to contact potential family carers. When inclusion criteria were met, an interview was scheduled. As shown in **Table 2**, respondents were either a partner, sibling, son or daughter.

**Table 2 Family Carer characteristics**

Family carer relationship to patient	Illness of patient family carer took care of		
	Cancer	Organ Failure	Dementia or frailty
Partner	FC2, FC8, FC9	FC5, FC12, FC16, FC17	FC10, FC14, FC15
Sibling	FC3		FC7
Son	FC4		FC6
Daughter	FC1, FC13	FC11	

FC=Family Carer

All interviews were conducted by one researcher (TR) and lasted around 45 min, using a topic list, which was developed by the research team and altered when necessary. Respondents were asked about their opinions of and attitudes towards the acute hospital as a place of final care and death and about their experiences concerning hospital admissions in the last phase of the patient's life, although the focus was mainly on the last hospital admission. Finally respondents were asked how these experiences might have changed their own opinions on the acute hospital as a place of death.

## DATA ANALYSIS

Focus group discussions and interviews were audio-recorded, transcribed verbatim and analysed using qualitative data analysis software (QSR NVIVO 10) and data analysis was guided by a constant comparative approach.<sup>29</sup> The focus was on discovering themes and categories that were similar in all focus groups and interviews rather than analysing for differences between perspectives. A preliminary coding framework was developed by two researchers (DH, TR) and discussed within the research team after all members had read and initially coded several focus group and interview transcripts. Next, all transcripts were coded and analysed by one researcher (TR) and the coding framework was adjusted where needed, in consensus with another researcher (DH). The results were regularly discussed within the research team, after rereading and recoding several transcripts, to ensure validity and consistency. A final framework, including results and quotes used, was agreed within the research team.

## ETHICS

Ethics approval for this study was given by the Medical Ethics Commission of the Brussels University Hospital.



## RESULTS

Three key themes were identified: the acute hospital as an inadequate care setting for the terminally ill, as a safe haven and as a setting where attitudes towards end-of-life care are changing.

### THE ACUTE HOSPITAL AS AN INADEQUATE CARE SETTING FOR THE TERMINALLY ILL

In general, participants indicated that the acute hospital setting is not an adequate setting for care at the end of life, and terminally ill patients generally do not belong in the acute hospital setting. Care in the acute hospital setting was perceived to be poorly adjusted to the needs of dying patients, too much focused on curative and life-prolonging treatment and with communication sometimes poor or contradictory. As these hospital nurses explain, a hospital is no place to die in:

Participant 1 *I question to what extent people at the end of their life, terminal phase, still belong in an acute hospital ward.*

Participant 2 *They don't.*

Participant 1 *I completely agree [...]*

Participant 2 *I think, a hospital is no place to die in. A hospital isn't made to die in. A hospital is made to cure ill people. Dying is never appropriate in a hospital. Because at 6 am they need to measure temperature, at 8 am it's breakfast time, at 12 am it's lunch time. An ill person cannot die in a hospital.*

Participant 1 *They cannot die pre-planned there. (N1)*

However, it has to be noted that some participants indicated that differences exist between acute hospitals, and between wards within the same hospital, regarding the quality of end-of-life care provision and the ability to deal with terminally ill patients, which implies that they perceive various hospitals or wards differently in terms of the appropriateness of this setting as a place of final care or death. For example, the following family carers notice such differences between wards and hospitals respectively:

*But in the meantime I've had some discussions with the nurses of cardiology. They aren't used to this, no. They aren't used to having a palliative person on their unit. They aren't used to not resuscitating. Cardiology is an island that is totally different from, for instance, oncology or geriatrics. (FC11)*

*She had been waiting there for 2 hours in the emergency room before someone came. If she would've called me, I actually would have told her "Don't go to hospital A, go to hospital B.". Because I know that in my opinion, that hospital actually isn't sufficiently equipped to provide that kind of support. (FC6)*

### ***Inadequate to the needs of the dying patient***

Study participants indicated that care provided in the acute hospital setting is not properly adjusted to the needs of dying patients. The acute hospital setting is a place of routine and there is usually not enough time or staff to permit variations in standardized care or questioning what is necessary or perhaps unwanted. The following family carer explains how her frail older husband was not able to get the rest he wanted:

*What did bother him in the end was, as he said: "I'm getting so little rest in the hospital, I'm tired and I want to sleep and then they come to draw blood and then they come to weigh me and then they come to check my blood pressure and then they come to take my temperature and then they come to clean and then they bring food and I can't get any rest.". (FC10)*

There seems to be little or no room for a personal approach, which implies that patients and their families have little control over the care that is being given, as the following family carer shows:

*I've got the idea that you've got little to say in this [...]. I often felt very frustrated because you can only watch helplessly how things happen over there. But of course, I do understand to a certain degree that there needs to be a routine [...] and they are used to their way of working. But there are few possibilities for an individual approach. (FC14)*

### ***Curative care and care focused on life-prolongation***

The acute hospital setting was also considered to be a place where care can be too focused on cure and life-prolongation and where tests and treatments are used routinely without questioning whether they are actually necessary. For example, one family carer explained that although her father had given up all medication and treatments and was ready to die, he was taken to hospital because his defibrillator kept shocking him overnight, was reanimated after a first surgery and died alone after a second:

*Because if you heard the specialist talking then he would have fixed it all right, because they are the fixers! "Yeah, but I will fix that and [a surgery] like that, it's very successful." [the physician said]. But my mother said: "Yeah but, well, is there no other option, because an intervention like that, can he handle all that? Is it necessary?" and the answer she got was literally and we'll never forget it, because we'll never forgive him: "I refuse to throw in the towel, madam." that's what he said. (FC11)*

Furthermore, respondents indicated that by being offered treatment the patient is often given false hope for recovery or life-prolongation, possibly resulting in extra loss of quality of life. A home care nurse and a specialist palliative care nurse explain how this can happen:

*[...] physicians still more often give the explanation: "We can still do this and we can still do that.", and while there's life there's hope, right. And people frequently accept whatever they can get. (N1)*

*While the patient has already completed a part of a palliative trajectory and yet the physician proposes another treatment and the patient accepts [and this restores his/her] hope and in the end it leads to nothing and that patient didn't even get the time and opportunity to properly bid farewell to his/her family. (N2)*

### ***Poor and contradictory communication***

Participants also indicated that communication in the hospital setting is frequently rather poor. Different doctors sometimes convey different messages, or messages are not well put across and hence not well understood. Such unclear or contradictory communication is considered to be burdensome for patients and their families, as the following family physician explains:

*But what is sometimes difficult on an acute unit, is that patients and family receive different messages. Some physicians are accepting, like "Look, we're going for a comfort treatment now, we're approaching death", and then all of a sudden other physicians come saying "But no, that person is still doing way too well?! And haven't they tried this yet? And won't they do that one more time?", and that's actually really hard for the family. (FP4)*

The following family caregiver explains how straight-forward communication was lacking in times of need:

*We actually asked the physician: "What are we supposed to do now? Are you asking us to make a decision? Do we have to say okay fine, perform euthanasia or what". But he didn't respond, really. This actually wasn't clear. We were actually left behind wondering "What do they actually expect us to do? Do they expect us to say okay put him to sleep? What do they expect?". This process wasn't adequately supported. (FC6)*

### **THE ACUTE HOSPITAL AS A SAFE HAVEN**

Sometimes the acute hospital setting is considered a 'safe haven', a place where people can be at ease because they feel safer there. Some might fear death and hope to recover or to prolong life, others might fear that they would not be able to receive the best possible care during the dying phase, at home or in the nursing home, and therefore feel safer in a hospital setting. Furthermore, some people might regard the acute hospital setting as a familiar care environment because they are used to being there. Sometimes, however, it is seen as the only alternative, the last resort.

#### ***Fear of death and dying***

Although patients and their families know they are terminally ill, many may still fear death and hope to prolong life or even to recover, and this is most likely in an acute hospital setting. The acute hospital setting is therefore perceived as a place where 'they can still do things', should this be possible. A family physician explains how he had to oppose family pressure to send a dying patient to hospital:

*Even then there is sometimes pressure from families to say "Look send him to the hospital.", I've experienced this only last week, that a woman had had a brain aneurysm, was paralysed, and couldn't talk anymore, was fed directly to the stomach actually and she had been lying there for over a year and she catches a pneumonia and that family almost forced me and said: "Look, you have to admit her to the hospital, because they can still do something over there.". (FP2)*

Some participants even indicated that it might be possible that many patients and their families panic during the dying phase, mostly because they are no longer used to the idea of ‘death and dying’, and therefore prefer admission to an acute hospital setting, as the following family physicians have noticed:

*I think if people are panicking [...] and I feel there’s a lot of anxiety, to my opinion, to see someone dying [and then a hospital admission might be good]. People no longer know how a person dies. (FP3)*

*But I also think death has become somewhat of a taboo, people no longer like someone dying at home, the confrontation with death scares a lot of people in this day and age. (FP2)*

### ***Perceived better care and continuous support***

As noted above, study participants indicated that the acute hospital setting is an inadequate setting for terminally ill patients; however it was also suggested that patients or their families sometimes perceive it as providing the best possible care, or at least better care than, for example, is available at home. The acute hospital setting is considered to be a place where professional care is available 24/7, where all possible means for symptom and pain control are available. In one interview a family carer explained how she, as well as her dying husband, believed care would be best in the hospital:

Interviewer:	<i>What do you mean for your peace of mind?</i>
Respondent:	<i>You’re not certain, if something happens, in the hospital they’re with you right away, if something goes wrong or if something isn’t possible and so on, so like that. Probably we wouldn’t have gotten much sleep if he would’ve been here.</i>
Interviewer:	<i>You told me he said “I think it’s better if I stay here.”, but do you know why he might have said that?</i>
Respondent:	<i>Yes, because I think he was convinced that he would be able receive the best care in the hospital. (FC9)</i>

It is important to note that, although end-of-life care is not always ideal in the acute hospital setting – as the previous theme illustrates – patients and their families and perhaps even professional caregivers may have the perception that adequate end-of-life care is available there. Whether care is

actually better within this setting or not, the perception, the feeling of safety that some people have that it is a safe place of final care and death, can be particularly dominant. A family physician explains how he had to reassure a patient that a hospital admission was not necessary:

*My last patient who did stay at home, I really had to convince him, all the time, like “We can do that at home too and we’ll be there for you.”, and [patient responded:] “In a hospital there’s always someone to help me.”, [answers FP:] “Yeah, but we’ll make sure that someone is there too and when things get worse, well, I’ll make sure that I am here too.”, [patient responds:] “Yeah, but you’re not close, are you and in a hospital [assistance is available].”. So, Yeah, it’s really this feeling of safety you get in the hospital, whether this is correct or not. (FP5)*

### ***The hospital as familiar environment***

The acute hospital setting may become a familiar environment to some patients and their families; if they have had frequent contacts over the course of their illness they may have become familiar with nurses, doctors and other staff and therefore might prefer their final care or death to take place in a specific acute ward that they feel connected with, as the following specialist palliative care nurse explains:

*People often attend for a very long period of time one particular ward for their treatment, then all of a sudden enter a palliative program, go home, but it doesn’t work out, but over the years they’ve actually developed strong bonds with an acute oncology unit, so when they are admitted to the hospital, they ask: “Please, put me in that acute unit, because I know all nurses there, I feel good there and this gives me peace of mind.”. (N1)*

In one interview a family carer even stated that her husband was transferred to the hospital to die on the ward he preferred, with an explicit request for euthanasia:

*He wanted this in his familiar hospital, where he had been a patient for 30 years, with his trusted nurse, who he had known for as long as he knew me. We had been married for 2 years when he became ill, so his nurse was his girlfriend, right [laughs]. (FC17)*

***The hospital as a last resort***

Study participants indicated that in some circumstances the acute hospital setting is perceived as the only alternative, the last resort, where patients and their families go when there is no other place left to go. The following family caregiver, whose husband was diagnosed with dementia at a relatively young age, was unable to find any setting that would have him:

Interviewer:	<i>In your opinion, when is it a good thing to do, going to a hospital?</i>
Respondent:	<i>When it's no longer possible for the partner at home, like it was with me [laughs], but then you have no other choice, have you? There's no other solution.[...] It was always: "[sighs] Yeah, we have to, because there's no other way." [...]</i>
Interviewer:	<i>And, according to you, under which circumstances should it be avoided, going to a hospital?</i>
Respondent:	<i>[sighs] To be avoided? You can't, can you? You can't. For certain needs you just can't. I would've avoided that for [him] but yeah, he had nowhere else to go. (FC14)</i>

This is also more likely to be the case for those with a small family or none at all and in particular surviving partners, because there is no family carer to provide care until the end, as the following palliative care support team nurse explains:

*Also, not everyone has caregivers around them. Because more and more people can be alone, never married, no kids, no family around. So yeah, for those people a hospital admission is sometimes the only option, right? (N2)*

## **THE ACUTE HOSPITAL AS A PLACE WHERE ATTITUDES REGARDING END-OF-LIFE CARE ARE CHANGING**

Participants also acknowledged that some acute hospitals are changing their attitudes towards quality end-of-life care, indicating that there might have been an improvement in their end-of-life care provision. The following family physician and family caregiver notice how hospitals have been changing overtime:

*Yeah, but nevertheless, my experience in recent months is [that we receive telephone calls from the intensive care unit] to ask “Look this is the situation, as far as we’re concerned, it stops here.” [...] And I think this is a conversation that was totally unthinkable a couple of years ago, especially coming from the hospitals. We had been aware of this for a while longer, but in the specialist world and especially in intensive care units [...] this definitely wasn’t evident. (FP4)*

*I think [nowadays] hospitals have really improved a lot, compared to before. Yeah, I do think they have. [...] And I also think they deal with the families more humanely than they used to. I think more consideration is given to it, you can feel it. (FC2)*

## **DISCUSSION**

Although the acute hospital setting is predominantly perceived as an inadequate setting for terminally ill patients, there is also some ambiguity demonstrated in this study in the perceptions held by family physicians, nurses and family carers. Acute hospital care was considered to be inadequate to the needs of dying patients, too focused on cure or life-prolongation and sometimes having poor or contradictory communication. However, the acute hospital setting is also perceived as a ‘safe haven’ in some situations at the end of life, be it as a setting to escape from the fear of dying, a last resort option, a setting with perceived better care and continuous support or a familiar environment.

Considering that national end-of-life care policies and previous research have predominantly focused on the home care setting as the most desirable place of final care or death,<sup>6,8,9</sup> the present study is, to our knowledge, the first to explore how the acute hospital setting is perceived as a place of final care and death. A multi-perspective qualitative design was used, enabling the researchers to explore a meaningful range of experiences and opinions. Although it was not the intention of this study to compare these perspectives and given that great attention was paid to avoid potential over-interpretation of the results, some differences between them were found. For example, because hospital nurses’ opinions frequently conflicted with those working in other care settings, nurse focus groups were often vibrant. Family physicians on the other hand had a pragmatic perspective and problem-solving view. Focus group participants mainly discussed cases that were common within their practices, although they sometimes indicated several as excessive, while the interviews with



family carers were more restricted to the experiences and opinions they had regarding their family member's hospital stay(s) and they tended to clearly indicate whether this was a good or bad experience. An important limitation of this study is that, as a result of the recruitment procedure, those nurses who agreed to participate might already have had an increased interest, and perhaps expertise, in end-of-life care; we do not believe this to be the case for the family physicians, as we used existing peer review groups. Participants, including interview respondents, might also have been inclined to participate in order to report or to express particular positive or negative experiences they may have had, which should be taken into account. Furthermore, some effects of a posteriori justification of the hospital as a place of death, particularly by the bereaved family carers, cannot be ruled out. Generalizing the results of this study may prove to be difficult, given they might be setting- and country-specific and due to the nature of the research methodology.

That the acute hospital setting was perceived to be inadequate for terminally ill patients seems to be in line with previous research,<sup>17;18;30-32</sup> and corresponds with national end-of-life care policies focusing on out-of-hospital death.<sup>6;8</sup> However, our results suggest that certain nuances need to be taken into account. The finding that on some occasions the acute hospital setting can be perceived as a safe haven at the end of life, a place where a dying person can go to in times of need or because no other option is available, suggests that it is, and will probably continue to be, an essential end-of-life care setting in certain situations and is considered to be an important contribution to the existing body of knowledge.

This finding seems to imply that the dominant discourse circulating in end-of-life care literature and research and in national end-of-life care policies, which is focused on the 'home setting' as a desirable place of terminal care, should be treated with some caution. The acute hospital setting is, and probably will continue to be, a meaningful end-of-life care setting, as there are some people who prefer to die there and this will probably continue to be the case. Accordingly, proper end-of-life care provision should not only be directed towards dying at home or in a nursing home, but adequate end-of-life care within the hospital setting also needs to be available – preferring to spend ones last days in the hospital setting must not mean being excluded from adequate end-of-life care.

It has to be noted from our findings however, that a preference for an acute hospital setting generally reflects a negative choice; the hospital setting becomes the preferred setting only when care at home or in the nursing home of residence is perceived to be inadequate.<sup>13;33</sup> This might partially explain the persistently high rates of hospital death, despite the hospital setting not being the initial preferred place of death.<sup>5-7</sup> The reasons for not dying at home or in a nursing home can therefore be considered 'justified', although this does not necessarily imply that the hospital setting

actually is the most appropriate one.<sup>34</sup> This might suggest that alternatives to the acute hospital setting such as palliative care units or hospices need to be developed or further expanded and that this might lead to hospital admissions being avoided. This seems to be essential when considering the decreasing caring capacity of families and the growing proportion of frail elderly people in many countries.<sup>35</sup> Furthermore, given the higher proportion of hospital deaths in metropolitan regions, which perhaps reflects a situation where proper end-of-life care is less accessible and social support is less available,<sup>7,36</sup> one could suggest that such alternatives are even more crucial in these regions. However, it has to be noted that expanding such alternatives is unlikely to be feasible everywhere, for example due to resource restrictions.

On the other hand our findings also suggest that there is still some work left to do in challenging the predominant discourse and culture around care within the hospital setting. This discourse is one of curing patients and saving lives,<sup>16-18</sup> and needs some adaptation in order to allow for a healthy environment to develop, suitable for the provision of proper end-of-life care. Given that participants indicated that patients and their families sometimes have little control over care given in an acute hospital, or that communication can be very poor or contradictory, it might be suggested that when improving end-of-life care provision in the acute hospital setting the focus should be on communication skills in particular. Effective training in communication skills for physicians and other hospital caregivers not only improves communication with patients and relatives, but might also bring about an earlier transition to palliative care, possibly resulting in care that is more adequate to the needs of terminally ill patients.<sup>17,37,38</sup> Such communication trainings could therefore ensure a higher quality of end-of-life care in the acute hospital setting and might contribute to challenging the predominant discourse and culture within the acute hospital setting. That the acute hospital was perceived by several participants as a setting where attitudes towards end-of-life care are changing is perhaps an indication that we are already on the way towards challenging the traditional approach.

## **CONCLUSION**

Although the acute hospital in principle is perceived as an inadequate setting for terminally ill patients, in certain situations it is seen as a safe haven for patients and their families at the end of life. We suggest that end-of-life policy-makers should consider to develop and expand 'hospital-replacing' alternatives to this setting, such as hospices or palliative care units and to ensure a higher standard of end-of-life care in all hospitals, preferably by focusing on improving communication skills.

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## **CONFLICT OF INTEREST**

The authors have no conflicts of interest to declare.

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## CHAPTER 6

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### What Justifies a Hospital Admission at the End of Life? A Focus Group Study on Perspectives of Family Physicians and Nurses

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## **ABSTRACT**

### **BACKGROUND**

Despite a majority preferring not to die in hospital and health policies aimed at increasing home death, the proportion of hospital deaths remains high. Gaining insight into professional caregiver perspectives about what justifies them could be helpful in understanding the persistently high rates of such hospital admissions and hospital deaths.

### **AIM**

To explore the perspectives of nurses from nursing homes, home care and hospitals, and family physicians concerning hospital admissions at the end of life and the circumstances in which they consider them to be justified.

### **DESIGN**

Focus groups, transcribed verbatim and analysed using a constant comparative approach.

### **SETTING/PARTICIPANTS**

Five focus groups were held with family physicians (n = 39), two focus groups (n = 16) with nurses from different care settings (nursing home, home care and hospital) and one with nursing home nurses (n = 7) in Belgium.

### **RESULTS**

Participants indicated that although they considered death at home or in the nursing home of residence the most preferable outcome, there are a number of scenarios that they consider to justify a hospital admission at the end of life: when the patient prefers a hospital admission, when the caring capacity of the care setting is considered to be inadequate and when one of a number of acute medical situations occurs.

### **CONCLUSION**

A number of situations have been identified in which nurses and family physicians consider a hospital admission to be justified. Adequate advance care planning and improved psychosocial support to both family and professional caregivers could reduce the number of hospital deaths.

## **KEYWORDS**

Hospitalisation – Focus Groups – Palliative Care – Patient Admission – Patient Transfer –

Terminal Care



## INTRODUCTION

Initially, most terminally ill patients prefer not to die in hospital but at home or in their nursing home of residence,<sup>1,2</sup> which seems to reflect popular understandings about what constitutes a 'good death'.<sup>3</sup> End-of-life hospital admissions have been found to be burdensome for patients and their relatives,<sup>4-7</sup> and are associated with poor outcomes regarding quality of life,<sup>8-13</sup> which is in line with national policies aimed at increasing home death.<sup>14</sup> However, despite a slight decrease in the proportion of hospital deaths in several countries, for example, in Belgium from 55.1% to 51.7% between 1998 and 2007,<sup>15</sup> the hospital setting remains a common place of death,<sup>16;17</sup> and the use of hospital services (such as intensive care unit (ICU) services) in the last month of life remains high,<sup>18</sup> as has been shown in the United States.<sup>19</sup> Given the persistently high frequency of end-of-life hospital admissions, there is a need to further study the reasons and situations preceding these hospital admissions. Furthermore, not every hospital admission at the end of life is unwanted or inappropriate, as dying at home can provoke concerns such as dying alone, not wanting to be a burden to family members or anticipating inadequate caring capacity,<sup>10;20;21</sup> and some of them might be considered necessary or unavoidable.<sup>22</sup> Therefore, in this study, the focus is on situations that justify an end-of-life hospital admission, where a hospital admission is considered to be the best option, given the circumstances.

Family physicians (FPs), nursing home and home care nurses have a pivotal role in providing end-of-life care and are frequently involved in deciding whether or not to admit a patient to hospital, while hospital nurses are frequently involved in dealing with such hospital admissions. Therefore, their perspectives can be considered essential in studying what justifies an end-of-life hospital admission, from their point of view. One study was found that explored the opinions of generalist palliative care providers with respect to hospital admissions of people with palliative care needs and found that the 'appropriateness' of such a hospital admission was generally discussed in relation to what is considered to be a good death.<sup>3</sup> However, little is known about what reasons may justify a hospital admission at the very end of life, taking into account a variety of factors such as medical, personal and social from a professional caregiver perspective.

## METHODS

The aim of this study is to explore the perspectives of nurses and FPs on the situations that could justify a hospital admission at the very end of life, from their point of view. In order to be able to adequately comprehend their opinions and experiences, a focus group methodology was considered most suitable, given its meaningful process of sharing and comparing.<sup>23</sup> A constant comparative approach was chosen,<sup>24</sup> and the research team consisted of five medical sociologists (T.R., MSc; D.H., PhD; J.C., PhD; R.P., PhD; L.D., PhD) of whom one is a nurse, all with experience in qualitative research in social health sciences. Eight focus groups were conducted, three with nurses (n = 23) and five with FPs (n = 39).

### PARTICIPANTS

Two nurse focus groups were composed by purposely selecting participants according to the setting where they provide care, to maximise variation in experience and background.<sup>25</sup> By contacting several health-care organisations and institutions (such as hospitals, nursing homes and multidisciplinary specialist palliative care teams), participants were indirectly asked to participate and to contact one researcher (T.R.) when they were prepared to do so. There was no structural relationship between these institutions and the researchers before the focus groups and of those willing to participate, none declined. One focus group consisted of nursing home nurses only, to be able to further elaborate on specific situations and patients within this setting. To recruit FPs, established peer-review groups for FPs were used. Nearly 97% of all FPs in Belgium are affiliated to such a peer-review group and are obliged to attend two out of four meetings per year, for accreditation.<sup>26</sup> Several groups were contacted and five were selected from Brussels and Flanders because of their availability, although researchers did not have control over the number of participants in advance. More information on focus groups and participants can be found in Table 1.

### DATA COLLECTION

The focus group discussions were moderated and observed by two male researchers (D.H. and T.R.) and lasted between 1 and 2 h. They were held in conference rooms in a hotel or locations where participants usually met, between February and June 2012. A discussion guide was developed and reviewed within the research team, and after each focus group it has been modified slightly by two researchers (T.R. and D.H.) to improve data collection, without compromising consistency. After giving their written informed consent and completing a small questionnaire about their background,

participants were asked about their experiences and opinions concerning end-of-life hospital admissions. Next, a discussion was generated about what justifies the admission of a terminally ill patient to hospital, prompted by vignettes describing three different cases that can be found in Table 2. Finally, participants were asked to identify key factors in deciding whether or not a hospital admission was justified. After the researchers evaluated that saturation had been reached, one more focus group was conducted, given it was already planned. Neither transcripts nor findings have been returned to the participants.

**Table 1. Focus Group Characteristics**

Focus Group		N1	N2	N3	FP1	FP2	FP3	FP4	FP5	Total
Care Setting	Family physician				7	5	9	13	5	39
	Nursing Home Nurse	2	1	7						10
	Hospital Nurse	4	4							8
	Home Care Nurse	2	3							5

N=Nurses; FP=Family Physicians

## DATA ANALYSIS

Focus group discussions were audio-recorded and transcribed verbatim, complemented with field notes. Analysis was guided by a constant comparative approach, and qualitative data analysis software (QSR NVivo 10) was used.<sup>24</sup> After reading and initially coding several transcripts, key categories of justifications of end-of-life hospital admissions were identified, and a coding framework was developed by two researchers (T.R. and D.H.). After discussing this initial framework within the research team, one researcher (T.R.) coded all transcripts and modified the coding framework where necessary, in consensus with a second researcher (D.H.). Results were regularly discussed within the research team, and each team member reread several transcripts and recoded several others to ensure consistency and validity. A final thematic framework was agreed and quotes were selected, translated from Dutch and approved by the research team.

## ETHICS

Ethics approval for this study was given by the Medical Ethics Commission of the Brussels University Hospital.

**Table 2. Vignettes used during focus group discussions**

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Case - COPD

Frans, a 70-year-old male, is suffering from COPD. He received his diagnosis a while ago. He has learned to cope since, which wasn't easy. Recently it has become worse. He has been frequently hospitalised lately. He always received a thorough treatment there, involving medication and physical rehabilitation, and again and again he was 'patched up'. Every single time and every time a little more. He is in an advanced stage of COPD now. Currently the disease is prevailing again and is again getting worse.

Case – dementia

Two years ago, Mrs. Vander Vliet moved into a residential care facility. She is in an advanced stage of dementia. Her cognitive abilities have become quite low and she recognises only few of her visitors. Her family visits her almost every weekend. She gets a pneumonia. Her son asks you if she needs to be hospitalised?

Case - Cancer

After some complaints and tests it became apparent that Johan had a strong opponent: oesophageal cancer. In surgery they removed a piece of the oesophagus and as a result he went through a rough period. He recovered really quickly, but after a while metastases were found at three sites. Johan has already endured several chemo treatments and has pulled through each time. But lately it is really going downhill. He's tired, exhausted,...

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COPD=Chronic Obstructive Pulmonary Disease

## RESULTS

### DEATH IN FAMILIAR SURROUNDINGS AS FIRST OBJECTIVE

Many participants indicated that although in principle they preferred a chronic–terminally ill patient – whose death would not be unexpected – to remain at home or in the nursing home during the last phase of life, a hospital admission might sometimes be ‘the best alternative’ or ‘the only available option’. As much as they would like to support the patient and his or her family in keeping them at home or in the nursing home, they sometimes feel themselves unable to prevent hospital admissions at the end of life:

*Family physician: [...] when patients, in agreement with their environment, choose to die at home [...] and express this clearly, sometimes you get into a situation where you're faced with the fact that it's not possible. Despite the fact that you did promise this to the patient [...] or agreed this somehow with the family, and those are of course the kind of situations, when there is a palliative situation that you actually would like to end at home, that you do not succeed in doing this and that you sometimes still, because of certain reasons, either medical, psychosocial, or because of the caring capacity of the family or the home situation that suddenly [collapses], and that you sometimes still hospitalise someone and then they die on the unit or in the hospital one or two days after. And then sometimes I think 'My God, that's a pity, because I'd really have preferred it to happen here at home'. (FP1)*

Consequently, almost all participants reported various situations that they considered to justify an end-of-life hospital admission. Participants had considerable difficulty in labelling hospital admissions as ‘appropriate’ or ‘avoidable’ and indicated that a hospital admission was ‘justified’ in various situations. Particularly in mixed nurse focus groups, there was a considerable discussion about what could justify such a hospital admission, possibly due to the composition of these groups. These justifications were then further analysed and three separate, though interrelated, themes emerged that were used to identify whether a hospital admission at the end of life could be justified or not: the patient’s preferences, the caring capacity of the care setting and the presence of an acute medical situation.

## THE PATIENT'S PREFERENCES

Almost all participants agreed that the patient's preferences should be the starting point when considering whether a hospital admission was justified. In general, participants agreed that if a patient prefers to be admitted to hospital, such a hospitalisation was justified because it clearly benefits the patient's well-being, for example, it takes away anxiety, the patient is at ease or the hospital might be a familiar environment:

*Home care nurse: Little benefits [the patient]? Maybe not from a medical-nursing point of view, but it does with regard to the fear factor for example. The factor of 'I can still be cared for, [...] I can go to that hospital, they know me by now, or they get to know me there, they have been informed of my needs', even if they are of a psychological, social, or even spiritual nature. (N2)*

However, many participants stressed the importance of the patient being adequately informed. While some may still be hoping to recover or prolong life, others might want a transfer because they are worried about the care provided in the current setting and/or believe better care will be provided in hospital. Although participants did not say at what point they assume a patient is sufficiently informed, almost all agreed that when anxiety or false hope cannot be taken away by providing more information and the patient persistently requests to be transferred to hospital for further care or to die, their autonomy in this regard should not be questioned:

*Family physician: But the patient wants to [be hospitalised] and we think it's better not to? Then I try to convince him, then I try to say 'Look, what do you expect from this hospitalisation? Do you expect to get better there? Then I'm afraid that's not going to happen', then I will honestly tell him that. If he, while being sufficiently informed, eventually still decides to go then that's his choice. I do not think you, as a physician, [should resist this]. (FP5)*

Participants explained that they preferred to use their own judgement based on previous discussions with the patient or relied on advance directives or well-informed relatives – those most involved in the patient's situation – should the patient not be capable of expressing his or her preferences. However, there was no consensus on which of these were preferable, and they were considered as guidance rather than absolutes. Furthermore, many participants explained that they sometimes have to oppose the family's persistence in requesting a hospital admission, which is not always possible:

Family physician A: *If the patient has only few possibilities left to express his own thoughts, because that is of course always most significant, then if the family [does not agree] you can say: 'If my father or my mother ...', and that's always a fairly weighty argument, but if someone still says 'Yes, I'd still prefer she'd go to the hospital', if they really keep insisting, then it's hard to get around this.*

Family physician B: *Unless you are informed of the patient's choice, if he has prepared an advance directive, then I think you can hold your ground, but if this is not the case and he is no longer mentally competent, then it's hard to do anything about it. (FP5)*

In addition, some participants stated that a hospital admission might be justified in order to change a patient's preference. This could help the patient realise that an acute hospital setting is not the right place to be cared for at the end of life:

Nursing home nurse A: *You can explain why you think it may not be necessary but you shouldn't argue, let that person experience this himself, and then say 'Listen, we want to take care of you just as good, so please come back as soon as possible', and then they'll come back quickly.*

Nursing home nurse B: *Or [a patient says:] 'I'd like to, but I haven't found it in the hospital either, so I came back anyway'. They sometimes need this confirmation that there is nothing else left.*

Nursing home Nurse C: *[...] and then they become at peace with themselves, but you can't give them this kind of peace if you don't go along with the patient, I think. (N3)*

## THE CARING CAPACITY OF THE CARE SETTING

All participants agreed that irrespective of their preferences in terms of care setting, the priority is that the patient should receive continuous adequate care. When caregivers in the current care setting can no longer provide adequate care and no other options are readily available, participants considered a hospital admission justified. However, participants agreed that there was a considerable difference in caring capacity between a home care setting and a nursing home:

*Family physician: It's also true that a lot of people now die in a nursing home setting, where there are a lot more possibilities in terms of support, and in that sense a hospitalisation is a little less required, when they are already residing in a nursing home. If they are still in home care then I often see that people just can't cope providing care that is required at home and so the patient is hospitalised, sometimes with all consequences involved. (FP5)*

Regarding the caring capacity of the home care setting, participants indicated that there are many psychosocial circumstances that could justify a hospital admission, for example, where the informal caregiver does not want to care for the patient or where they are unable to accept that the patient is dying. It is also possible that they do want to care for the patient but find the care burden or sense of responsibility too much, or they are too anxious about the impending death. All participants agreed that where this happens and an adequate alternative care setting cannot be found, or is not available (e.g. when nursing homes have long waiting lists), a hospital admission is justified:

*Family physician: But yeah, if the family can't cope anymore or doesn't want to anymore, then a hospital admission is [justified] anyway, because you no longer receive the care you need at home. [...] Now, I'm reluctant to keep someone at home if the entire family is saying 'We won't take care of him any longer, we can't handle it', if they have to lie awake day and night because he is constantly choking, you can't do that to someone, can you? You can't make them do it, can you? If they can't cope it, they can't cope! (FP4)*

Where family caregivers are not available or do not have enough financial, social or practical resources to provide continuous adequate care, a hospital admission was also considered justified. Sometimes, this is the only option:

*Hospital nurse: Also, not everyone has caregivers around them. Because more and more people are alone, never married, no kids, have no family around. So yeah, for those people a hospital admission is sometimes the only option. (N2)*



Some participants explained that the quality of nursing home care was not always optimal, for example, in level of staffing, skills or competence in pain relief and symptom management. In these situations, a hospital admission was considered a suitable alternative because end-of-life care is perceived better there:

Family physician A: *I've also got two nursing homes of which I say: 'I won't let anyone die there, [because] I know they will suffer horribly'. Basic care, [bedsores] et cetera, yeah, pain control and things like that, you just can't trust them.*

Family physician B: *You say 'This will fail, that person will suffer, it's useless'.*

Family physician C: *[...] and then it can only be less bad in the hospital. (FP4)*

Some participants stated that a hospital admission can be justified as a temporary relief to caregivers, thereby avoiding longer or unplanned hospital admissions in the future:

Hospital nurse: *From the family's point of view, I can sometimes understand that they ask for a brief time-out or a brief hospital admission to get everything back on the right track, to get everyone on the same page, to make new arrangements [...]. Sometimes a hospital admission of one day or two days can [...] already be sufficient to straighten out the situation at home. (N2)*

## **ACUTE MEDICAL SITUATIONS**

Most participants agreed that when an uncontrollable acute medical situation occurs (e.g. an obstruction, sudden massive bleeding or uncontrollable pain) and a diagnosis or specific comfort treatment is needed, a hospital admission is considered justified:

Family physician A: *Refractory symptoms, you can't treat those at home, because you're technically limited.*

Family physician B: *Oh yeah, I think so too. Yeah, someone who has an episode of massive haemoptysis [...]. Blood is still very [frightening] to a layman, especially massive blood loss, that's one of those things of which people say 'Oh, we'll never get this under control here', even if you start palliative sedation. (FP1)*

However, participants were not able to agree upon which specific medical problems would justify a hospitalisation and which would not:

Nursing home nurse: *I think, for those patients I ask myself the question 'What is medically necessary?'* (N2)

Moreover, participants indicated that such acute medical situations generally justified a hospital admission because they cannot always be anticipated. Furthermore, it is possible in these situations that a patient might change his or her preferences and choose a hospital admission or that the capacity of the care setting to cope falls short, further justifying an admission, particularly at night or at weekends. Participants did not agree, however, whether enough alternative care settings are available in these situations, although many did acknowledge that inpatient palliative care units would be the best option, although often no beds are immediately available:

Nursing home nurse A: *In some way it's a shame, lots of hospitals have palliative care units, and [do] a wonderful job, but they are always full.*

Hospital nurse A: *And they have long waiting lists.*

Nursing home nurse A: *And [...] someone who is hospitalised because his care setting can't cope anymore should not be taken to an acute hospital unit, but be referred to a [palliative care unit].* (N1)

In addition, participants stated that depending on the patient's preferences and the caring capacity of the care setting, medical decisions such as palliative sedation may be considered in order to avoid a hospital admission:

Family physician: *And if you then ask people [whether they want me to stay] then I stay with them, then that's the alternative. And then you have to indeed start sedating and give morphine, then you have to stay, there is no other way, otherwise it is indeed hospitalisation.* (FP1)

Many participants also suggested that if a hospital admission is necessary for an acute medical problem, then unnecessary additional tests and treatments should be avoided. The problem at hand should be remedied so the patient can return quickly and safely to his or her familiar surroundings:

Family physician A: *Now, what you can do is contact the clinic and not have them do another 100.000 examinations [...].*

Family physician B: *So she doesn't end up on that carousel. (FP4)*

## DISCUSSION

Although the FPs and nurses in our study agreed that, in principle, death in familiar surroundings should be one of the goals of good end-of-life care, they also indicated several scenarios that would justify an end-of-life hospital admission. The patient's preferences are generally used as a starting point when considering whether a hospital admission is justified, although many considered the caring capacity of the care setting as equally important. Moreover, in situations in which an uncontrollable acute medical problem occurs, a hospital admission was also considered justified.

This study is considered to be one of the first to explore the perspectives of FPs and nurses from different care settings on justifications for hospital admissions at the very end of life and to use a focus group methodology to do so. The research team consisted of five medical sociologists, all with experience in qualitative research in social health sciences, which provided a good guarantee for adequate reiteration and triangulation from different perspectives, but might have guided data interpretation and analysis in the sense that a social health perspective was dominant. Furthermore, participants might have had an increased interest and even expertise in end-of-life care as a result of the recruitment procedure, although completed questionnaires show this was not the case. Despite the advantages of using a focus group methodology,<sup>23</sup> some participants may have felt restricted in reporting their thoughts or opinions, particularly in the established peer-review groups of FPs. This might have biased the results in the sense that the reasons that could justify an end-of-life hospital admission, provided by the focus group participants, were generally located outside of their control and therefore might have posed less of a threat to their perception of their own role as caregivers.<sup>27</sup>

The results in this study suggest that nurses and FPs actually might have limited ability to prevent such end-of-life hospital admissions, which is an important finding. For example, it was surprising that participants (including FPs) considered a hospital admission to be justified when this reflected the patient's preferences, with or without a clinical need necessitating the admission. Although this might be due to the organisation of the health-care system in Belgium, where the FP's role is advisory rather than decisive,<sup>28;29</sup> it remains questionable whether these 'justified' hospital

admissions could have been prevented or not and whether this 'preventability' has something to do with their own competence, expertise or workload.<sup>30</sup>

One other study was found that explored the appropriateness of end-of-life hospital admissions from a generalist palliative care provider perspective.<sup>3</sup> This study found that, for example, being admitted to hospital at the end of life because the family caregiver could not cope was considered inappropriate because this contradicted respondents' views of a good death. This study explored the perspectives of FPs and nurses from different care settings, with a wide variety of expertise, knowledge and competence in end-of-life care, and their views reflected a more pragmatic outlook. The results in this study suggest that where, for example, a family caregiver is not able to cope, indicating that the caring capacity is insufficient, this was considered to be a justified reason for hospital admission. Whether this was inappropriate given the patient's needs, or potentially avoidable, they felt that it was the best or only option, which is an important nuance and a significant finding. Therefore, it might be suggested that future research should study to what extent end-of-life hospital admissions are justified – being the best option under given circumstances – and to what extent they would be appropriate – to reflect the perception of a good death.

The results in this study suggest that the patient's preferences are considered to be essential in assessing whether a hospital admission could be justified. However, identifying these preferences can be rather complex, and the question might be raised whether such a preference for hospital admission might have been genuine or just pragmatic.<sup>31</sup> Taking into account the importance of these patient preferences in justifying a hospital admission by nurses and FPs, there appears to be a need to explore further how the hospital setting is actually perceived as a place of final care or death.

When adequate end-of-life care cannot be provided, participants considered hospital to be a more suitable setting for terminal care, which might suggest that out-of-hospital end-of-life care needs improvement. Concerning the home care setting, participants indicated that the psychosocial burden that home care places on family caregivers is an important component of the caring capacity, which might explain why patients residing at home generally have a higher risk of dying in a hospital compared with those living in residential care.<sup>2,32</sup> End-of-life care should therefore include adequate preparation and continuous support (including psychosocial care) to enable both professional and family caregivers to cope with the impending death and therefore possibly prevent an end-of-life hospital admission. Acute medical situations were also considered a justification for hospital admissions, although it should be noted that adequate advance care planning might prevent some of these ad hoc admissions.<sup>33-38</sup>

## CONCLUSION AND FUTURE RESEARCH

This study suggests that although many FPs and nurses prefer a terminally ill patient to remain at home or in the nursing home, many reasons have been identified which justify a hospital admission from their point of view because they feel no other or better options exist. Adequate advance care planning and improved psychosocial support to both family and professional caregivers could reduce the number of hospital deaths. Future research is needed to provide additional insights into the complexity of reasons for hospital admissions at the end of life in order to identify which of them can be considered 'inappropriate', 'potentially avoidable' or 'unjustified'.

<b>What is already known about the topic?</b>
<ul style="list-style-type: none"> <li>• Despite a majority preferring not to die in hospital and policies aimed at reducing hospital death, the hospital setting remains a common place of death.</li> <li>• Not every hospital admission at the end of life is unwanted or inappropriate.</li> <li>• Little is known about what justifies a hospital admission at the end of life from a professional caregiver perspective.</li> </ul>
<b>What this study adds?</b>
<ul style="list-style-type: none"> <li>• It is suggested that although hospital death is not ideal, an end-of-life hospital admission in certain circumstances can be the only option or the best alternative.</li> <li>• This study also suggests that nurses and family physicians sometimes have little ability to actually prevent end-of-life hospital admissions.</li> </ul>
<b>Implications for practice, theory or policy</b>
<ul style="list-style-type: none"> <li>• More research is needed on how the hospital setting is being perceived as a place of death and to what extent end-of-life hospital admissions are justified, avoidable or appropriate.</li> <li>• Adequate advance care planning and improved psychosocial support to both family and professional caregivers could reduce the number of hospital deaths.</li> </ul>

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## **CONFLICT OF INTEREST**

The authors declare that there is no conflict of interest.

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## CHAPTER 7

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### Reasons for terminal hospital admissions: results of a survey among family physicians

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*Submitted*

## **ABSTRACT**

### **OBJECTIVE**

To examine the reasons for terminal hospital admissions and other aspects that have played a role in the decision-making about the admission, according to family physicians; and the extent to which these reasons and aspects are related to the characteristics of the patient, of the care they received prior to admission and of the circumstances of that admission.

### **DESIGN**

Survey among family physicians, linked to medical record data.

### **SETTING**

A University hospital in Belgium.

### **POPULATION**

Patients who had died non-suddenly in an acute hospital setting between January and August 2014.

### **MAIN OUTCOME MEASURES**

Reasons for terminal hospital admissions and aspects that played a role in decision-making about the admission and their associations with patient, care and admission characteristics.

### **RESULTS**

We received 245 completed questionnaires (response rate 70%) and 77% of those hospital deaths (n=189) were considered to be non-sudden. Family physicians indicated that 55% of terminal hospital admissions were for palliative reasons and 26% were for curative or life-prolonging reasons. The patient feeling safer in hospital (35%), family members believing care to be better in hospital (54%) or an inadequate care setting (85%) were also frequently considered to have played a role in the decision to admit the patient to hospital, according to the FPs. When patients were admitted with a limited anticipated life expectancy, family physicians were more likely to indicate that the admission had been for palliative reasons ( $p<0.001$ ) and that an inadequate caring capacity of the care setting had played a role in the decision to admit the patient to hospital ( $p=0.002$ ).

### **CONCLUSIONS**

End-of-life care in Belgium is rather hospital-centric, as many of those who die in an acute hospital have been admitted for palliative reasons. To reduce the number of hospital deaths a combination of structural support for out-of-hospital end-of-life care, more timely referral to out-of-hospital palliative care services and a strengthened gatekeeper role of the family physician to hospital services may be needed.

## **KEYWORDS**

Hospitalization – patient admission – hospital death – hospital records – family physician

## INTRODUCTION

A large number of frail older people and patients with a life-limiting illness are admitted to hospital at the end of life,<sup>1-6</sup> and the acute hospital setting is a frequent and persistent place of death in many developed countries.<sup>7-9</sup> However, the acute hospital setting is considered not to be an ideal setting for end-of-life care, or as a place of death.<sup>10-12</sup> Care in the acute hospital setting is predominantly focused on cure and life-prolongation,<sup>10;11;13-15</sup> and is perceived to be inadequately adjusted to the needs of dying patients.<sup>11;16</sup> Moreover, research shows that most people prefer not to die in a hospital.<sup>17-24</sup> As a result, end-of-life care policies in a number of countries such as Belgium and England advocate for dying at home or in familiar surroundings.<sup>25-28</sup> Reducing the number of end-of-life hospital admissions has become a policy issue.<sup>29-31</sup> However, several studies show that preferences for place of death may also change from home to hospital as death approaches – circumstances change and aspirations become more realistic.<sup>24;32-34</sup> In some situations, an end-of-life hospital admission might be considered justified.<sup>35</sup>

Studies exploring the reasons for terminal hospital admissions – admissions to an acute hospital setting prior to hospital death – and other aspects that might have contributed to a decision to admit the patient at the very end of life, are scarce.<sup>36</sup> To be able to reduce the number of terminal hospital admissions, more evidence about the reasons and aspects that necessitate such admissions is needed.

The present study aims to examine the reasons for terminal hospital admissions and other aspects that have played a role in the decision-making about the admission, according to family physicians (FPs); and the extent to which these reasons and aspects are related to the characteristics of the patient, to the care they received prior to the terminal admission and to the circumstances of that admission.

## **METHODS**

### **DESIGN**

A cross-sectional survey was conducted among the FPs of all patients who died in a large (+/- 1,000 bed) university hospital in Belgium between January and August 2014, to collect data on the circumstances of the admission.

In Belgium almost 95% of the population have an FP whom they consult regularly (78% at least once a year).<sup>37</sup> FPs are considered to have a pivotal role in providing out-of-hospital end-of-life care,<sup>38</sup> and to be well informed about the patient's medical and social situation. Consequently, their perspectives are considered to be crucial to inquire about the circumstances prior to the terminal hospital admission and the reasons and circumstances necessitating such an admission.

### **STUDY POPULATION**

All patients who died in an acute hospital in the sampling period were identified in the hospital medical record system. Those under 18, those not residing in Belgium and those who died on a specialised palliative care unit, maternity ward or psychiatric ward were excluded as they were not the focus of this study.

### **DATA COLLECTION**

A research assistant was involved in the data collection procedure as intermediary between FPs and the university hospital. The assistant received an extract of the hospital records of all deaths, including the patient's gender, postal code, date of birth, date of death, timing of admission, hospital ward where they died and their FP's contact information. A questionnaire was sent to the FP of every eligible death case. The accompanying letter included the gender of the deceased patient, postal code of the municipality of residence, date of birth and date of death so as to enable the FPs to identify the patient when filling out the questionnaire.

Deaths were identified on a weekly basis during the study period and two weeks after the patient's death a four-page questionnaire was sent to the FP, so as to limit the time between the death and the completion of the questionnaire. The Total Design Method was used to maximise the response to the questionnaire.<sup>39,40</sup> In cases where there was no response, a reminder was sent after three weeks, a second questionnaire as a reminder after five weeks and another reminder after seven weeks. After ten weeks a brief non-response questionnaire was sent for those cases where the FP had not

yet responded, to identify the reasons. FPs received questionnaires for a maximum of three patients to limit the workload.

From the returned questionnaires, the research assistant coded all data and guaranteed that the research data could not be linked to the patient or the FP. The questionnaire data was linked to the extract of hospital records, using a unique case number, while the patient's postal code and the FP's contact information were deleted to guarantee anonymity.

## **QUESTIONNAIRES**

The questionnaire concerned the circumstances of and reasons for the terminal hospital admission and its design was based on the results of three previous qualitative studies that explored the perspectives of FPs, nurses and family carers on end-of-life hospital admissions, and on similar surveys that had been used in the Netherlands and Belgium.<sup>3;5;11;35;38;41</sup> The questionnaire was developed within a research team that consisted of five medical sociologists (one of whom is also a nurse) and an FP, all with experience in survey methodology and knowledge of the subject. The questionnaire was tested among five FPs and their comments were incorporated into the final version.

In a first question FPs were asked to assess whether the patient's death was sudden and totally unexpected, and if so they were prompted to go to the end of the questionnaire. Where the answer was no, closed questions followed regarding the patient's situation and illnesses (e.g. cause of death), the terminal hospital admission (e.g. the person who initiated the admission) and the care that the patient received prior to the admission (e.g. number of FP contacts in the last month of life).

The questionnaire also included questions about the reasons (i.e. clinical intent) that necessitated the terminal hospital admission: palliative (palliative treatments or symptom control), curative or life-prolonging, diagnostic, and social or other; and about other aspects (i.e. circumstantial drivers) that had played a role in the decision to admit the patient to hospital: aspects relating to the patient's preferences, regarding the wishes of relatives, or related to the care setting. Several answering options were provided for the latter question, based on the results of two previous qualitative studies.<sup>11;35</sup>

## HOSPITAL RECORDS

From the hospital records the patient's age, gender, length of stay, whether the admission was out-of-hours or at the weekend and the ward where the patient had died were extracted.

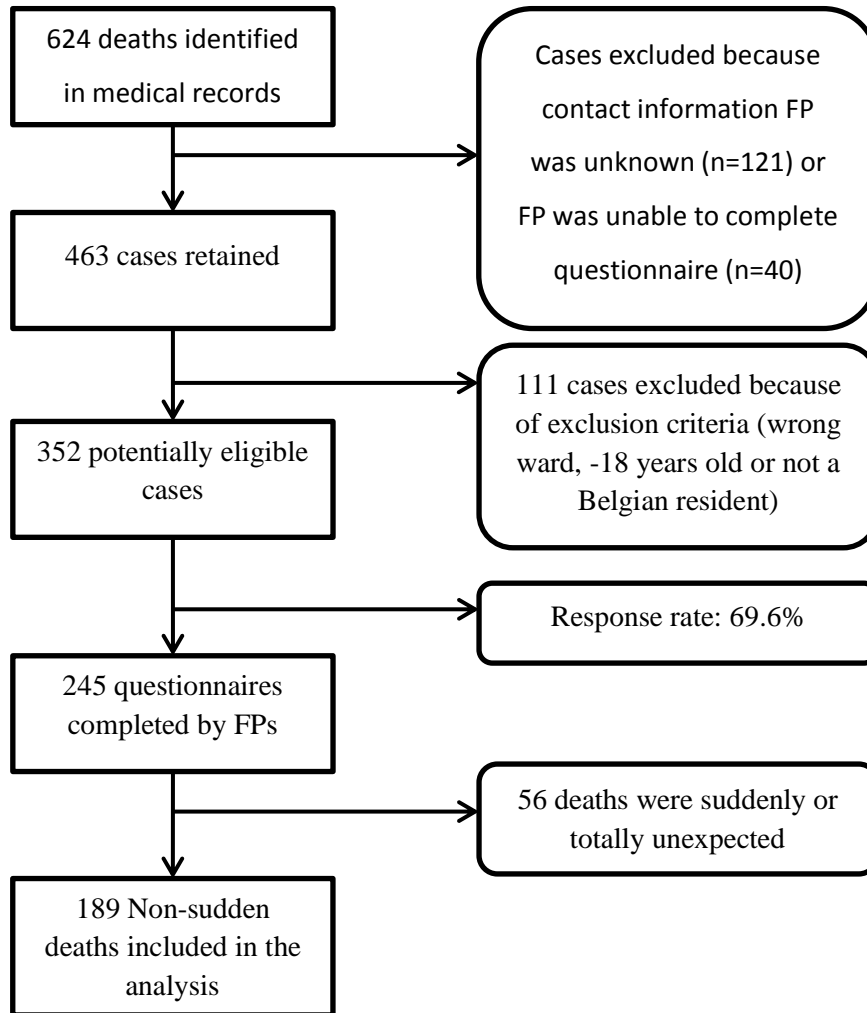
## DATA ANALYSIS

Only deaths that were considered to be non-sudden (i.e. not sudden or totally unexpected) by the FP were included. Reasons for and aspects playing a role in the terminal hospitalisation were described using descriptive statistics. To evaluate how these reasons and aspects were associated with several patient, care and admission characteristics, we dichotomised 'aspects related to the patient's preferences'; in which the FP indicated that at least one item regarding the patient's preferences had played a role in decision-making about the terminal hospital admission (1) or no such items were indicated (0). The same was done for 'aspects related to the wishes of relatives', and 'aspects related to the care setting'. Chi-square or Fisher's exact test (in case of a limited number of cases) were used. SPSS 22.0 was used for all computations.

## RESULTS

In total, 624 hospital deaths were identified in the hospital medical records; 121 of those were excluded because the FP's contact information was unknown and another 40 because the FP indicated that he/she was unable to complete the questionnaire (e.g. the FP no longer had contact with the patient at the time of admission) (**Figure 1**). There were 111 hospital deaths that did not meet the inclusion criteria: four patients were not residing in Belgium, 28 were less than 18 years old and 79 had died on the palliative care unit. We received 245 completed questionnaires out of 352 potentially eligible cases (response rate 69.6%). Reasons for non-response, as identified through the non-response survey, were 'no time' (n=12), or 'other' (n=3); three FPs indicated that they objected to the methods or objectives of this kind of research. According to FPs, 77.1% (n=189) of the remaining hospital deaths were considered to be non-sudden and were included in the analysis. The patient's age and gender did not substantially differ between cases for which the FP responded and those for which they did not.



**Figure 1 Flow chart of non-sudden deaths included in the analysis**

## REASONS FOR TERMINAL HOSPITAL ADMISSIONS AND ASPECTS THAT PLAYED A ROLE IN DECISION-MAKING ABOUT THE TERMINAL HOSPITAL ADMISSION

According to the FPs, almost 55% of all terminal hospital admissions were for palliative reasons (**Table 1**); 30% had a diagnostic purpose; and 26% were for curative or life-prolonging reasons.

For 155 terminal hospital admissions (85%), FPs reported that an inadequate care setting had played a role in the decision-making about the admission: mostly because there was an acute situation for which the care setting was not prepared (57%) (**Table 1**). For 138 terminal hospital admissions (76%), FPs reported that patient preferences had played a role in the decision-making about the admission: because the patient preferred to be treated in hospital (39%) or because the patient felt safer there (35%). For 99 terminal hospital admissions (54%), FPs reported that families were convinced that care was better in hospital and that this had played a role in the decision-making about the admission.

**Table 1 Reasons and aspects that played a role in decision-making about the terminal hospital admission, according to family physicians (N=189)**

<b>Reasons*</b>	<b>n</b>	<b>(%)</b>
Palliative reasons	103	55
Diagnostic reasons	56	30
Curative or life-prolonging reasons	49	26
Other or social problems	9	5
<b>Aspects†</b>		
<i>Aspects related to the care setting</i>	155	85
There was an acute situation for which the care setting was unprepared	104	57
Adequate end-of-life care was impossible in the setting where the patient was residing	41	23
The caring capacity of informal care was insufficient	30	17
The caring capacity of professional care was insufficient	9	5
<i>Aspects regarding the patient's preferences</i>	138	76
Patient received treatments he/she preferred	71	39
Patient felt safer in the hospital	63	35
Patient was more familiar with hospital surroundings and caregivers	48	26
Patient was able to die in their preferred place	11	6
<i>Aspects related to wishes of relatives</i>	123	68
Family member(s) believed care to be better in hospital	99	54
Family member(s) panicked	29	16
Family member(s) pressured to admit	18	10
Due to a disagreement among family or friends the decision was made to admit	1	1

\*Multiple answers were possible; 2 missings were excluded from the analysis.

†Multiple answers were possible; 7 missings were excluded from the analysis.

### **PATIENT, CARE AND ADMISSION FACTORS ASSOCIATED WITH REASONS AND ASPECTS THAT PLAYED A ROLE IN DECISION-MAKING ABOUT THE TERMINAL HOSPITAL ADMISSION**

Terminal hospital admissions were less likely to be considered as being for curative or life-prolonging reasons by the FPs where death was from cancer (14%) than for those who died from other chronic terminal illnesses (40%;  $p < 0.001$ ); and more often for palliative reasons for those who died of cancer (67%) than for those who died of other chronic terminal illnesses (43%;  $p = 0.001$ ) (**Table 2**).

FPs were more likely to report that the patient's preferences had played a role in decision-making about the terminal hospital admission when they considered themselves to be involved in their patient's end-of-life trajectory, when patients had had more than three FP visits in the last month of life and when the preferred place of death was known to the FP (57% preferred to die in hospital; 35% at home) (**Table 3**). They were also more likely to report that relatives' wishes had played a role in deciding to admit the patient to hospital when FPs considered themselves to be involved in their patient's end-of-life trajectory and when family care was provided.

**Table 2 Patient characteristics associated with reasons or aspects that played a role in decision-making about the terminal hospital admission, as indicated by family physicians (N=189)\***

	Total	Curative or life-prolonging reason (n=48) <sup>‡</sup>		Palliative reason (n=110)		Aspects related to patient's preferences (n=138)		Aspects related to wishes of relatives (n=123)		Aspects related to the care setting (n=155)	
	n	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>
<b>Gender</b>			0.096		0.890		0.580		0.362		0.825
Male	120	30		56		77		65		86	
Female	69	19		54		73		72		84	
<b>Age</b>			0.734		0.093		0.851		0.677		0.658
≤64 years	57	23		67		74		63		82	
65-79 years	80	27		48		78		70		87	
80+ years	52	29		53		75		69		86	
<b>Usual place of residence</b>			0.203		0.857		>0.999		0.774		0.395
Home	174	25		55		75		68		84	
Nursing home	14	43		57		79		64		93	
<b>Financial status</b>			0.108		0.482		0.708		0.547		0.267
Low/rather low	32	25		63		71		61		87	
Average	114	22		51		77		68		87	
High/rather high	38	40		58		79		74		76	
<b>Cause of death</b>			<0.001		0.001		0.073		0.367		0.424
Cancer	94	14		67		81		71		88	
Non-cancer	89	40		43		70		65		84	
<b>Patient had accepted approaching death<sup>†</sup></b>			0.107		0.778		0.633		0.393		0.188
Unaccepted	32	9		59		77		61		77	
Neither accepted, or unaccepted	23	26		61		87		74		96	
Accepted	88	28		54		83		74		85	

\*Diagnostic reasons were excluded from the analysis, as we estimated that differences regarding this variable were improbable; Missings ranged between 2 and 12 and were excluded from the analysis.

<sup>†</sup>Category 'don't know' (n=42) was excluded from the analysis.

<sup>‡</sup> %=row percentages of total ; only 'yes' (for reasons) or 'at least one item of this aspect had played a role in decision-making' (for aspects) are provided in the table.

<sup>§</sup> Chi-square test or Fisher Exact test for associations between reason or aspects and patient characteristics.

**Table 3 Characteristics of care received prior to the terminal hospital admission, associated with reasons or aspects that played a role in decision-making about the terminal hospital admission, as indicated by family physicians (N=189)\***

	Total	Curative or life-prolonging reason (n=48)		Palliative reason (n=110)		Aspects related to patient's preferences (n=138)		Aspects related to wishes of relatives (n=123)		Aspects related to the care setting (n=155)	
	n	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>
<b>Specialist palliative care initiated<sup>†</sup></b>			0.386		0.044		0.598		0.482		0.936
No (never)	122	27		50		76		70		86	
Yes	48	21		67		72		64		85	
<b>Preferred place of death known by family physician</b>			0.121		0.333		0.048		0.945		0.060
No	135	23		58		73		68		89	
Yes	46	35		50		87		67		78	
<b>FP involved in end-of-life trajectory</b>			0.559		0.292		0.023		0.037		0.396
No	94	28		52		69		61		83	
Yes	91	24		59		83		76		88	
<b>Number of FP visits in last month of life<sup>  </sup></b>			0.257		0.316		0.011		0.097		0.822
≤3	101	30		52		68		62		86	
4+	86	22		59		85		74		85	
<b>FP Self-assessed experience in palliative care</b>			0.359		0.498		0.636		0.564		0.799
Little or no experience	46	22		59		79		72		86	
Experienced	137	29		53		76		67		84	
<b>FP had training in palliative care</b>			0.378		0.795		0.641		0.634		0.102
None	57	23		55		80		70		80	
In basic physician training	34	38		47		74		68		79	
In post-academic or postgraduate training	59	25		58		71		62		86	
Other or in-service training	36	22		56		80		74		97	
<b>Family care<sup>¶</sup></b>			0.963		0.299		0.150		0.013		0.416
None	17	24		41		69		38		75	
Partner	108	27		59		73		72		85	
Son/daughter or other family member	50	25		51		85		77		88	

\*FP= 'Family Physician'; Diagnostic reasons were excluded from the analysis, as we estimated that differences regarding this variable were improbable; Missings ranged between 3 and 14 and were excluded from the analysis.

<sup>†</sup>Category 'don't know' (n=14) was excluded from the analysis.

<sup>‡</sup> N (row percentages); only 'yes' (for reasons) or 'at least one item of this aspect had played a role in decision-making' (for aspects) are provided in the table.

<sup>§</sup> Chi-square test or Fisher Exact test for associations between reasons or aspects and care characteristics.

<sup>||</sup> Total number of contacts dichotomized at its median value (=3).

<sup>¶</sup> 'Other' (n=5) was excluded from the analysis.

FPs more often reported the terminal hospital admission as being for palliative reasons for patients whose anticipated life expectancy at the time of admission was less than a few weeks (71%) than for those whose life expectancy was considered to be longer (41%;  $p < 0.001$ ); and for those who died on the oncology ward ( $p = 0.009$ ) (**Table 4**). FPs more often reported that an inadequate care setting had played a role in the decision to admit the patient to hospital for patients whose anticipated life expectancy at the time of admission was less than a few weeks (94%) compared with those with a longer life expectancy (77%;  $p = 0.002$ ); and more likely for patients whose admission was unplanned (92%) than for those whose admissions were planned (i.e. admissions in agreement with the hospital, prior to the transfer) (59%;  $p < 0.001$ ). FPs were more likely to indicate that relatives' wishes had played a role in deciding to admit the patient to hospital when the admission was unplanned and when the patient's anticipated life expectancy at the time of admission was less than a few weeks.

## DISCUSSION

Our study focused on terminal hospital admissions to an acute care setting of a university hospital of patients for whom death could – at least to some extent – have been anticipated. We found that 55% of these admissions were for palliative reasons and 26% for curative or life-prolonging reasons according to these patients' FPs. The patient feeling safer in hospital (35%), family members believing care to be better in hospital (54%) or an inadequate care setting (85%) were also frequently considered to have played a role in the decision to admit the patient to hospital, according to the FPs. When patients were admitted with a limited anticipated life expectancy, FPs were more likely to indicate that the admission had been for palliative reasons and that an inadequate caring capacity of the care setting had played a role in the decision to admit the patient to hospital.

To our knowledge, this study is one of the first to examine the reasons for and additional aspects that played a role in the decision-making about the terminal hospital admission of patients that who died non-suddenly. Hospital admissions of all non-sudden deaths in an eight-month period in a university hospital were included. That the study sample comprised deaths in a university hospital may mean that the proportion of terminal hospital admissions for palliative reasons may have been underestimated and that this proportion might be even higher in a general hospital. Therefore, the findings may not be generalizable to other hospitals and repetition of our study on a larger (regional or nationwide) scale, with the inclusion of all hospitals in the catchment area, is warranted. Information about the patient's terminal hospital admission was provided by their FP, whom they consult regularly and who is considered to be important in guiding or preventing such end-of-life

**Table 4 Admission characteristics associated with reasons or aspects that played a role in decision-making about the terminal hospital admission, as indicated by family physicians (N=189)\***

	Total	Curative or life-prolonging reason (n=48)		Palliative reason (n=110)		Aspects related to patient's preferences (n=138)		Aspects related to wishes of relatives (n=123)		Aspects related to the care setting (n=155)	
	n	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>	% <sup>‡</sup>	p-value <sup>§</sup>
<b>Life expectancy at time of admission<sup>†</sup></b>			0.004		<0.001		0.711		0.008		0.002
Less than a few weeks	84	16		71		78		77		94	
More than a few weeks	85	35		41		75		57		77	
<b>Admission was out-of-hours</b>			0.436		0.117		0.827		0.453		0.086
No	135	25		52		75		69		82	
Yes	54	30		64		77		64		92	
<b>Admission was during weekend</b>			0.212		0.193		0.582		0.227		0.007
No	143	24		58		77		65		81	
Yes	46	33		47		73		75		98	
<b>Admission was planned</b>			0.569		0.985		0.822		<0.001		<0.001
No	147	26		55		75		75		92	
Yes	40	30		55		77		44		59	
<b>Person who took initiative for admission<sup>  </sup></b>			0.287		0.136		0.004		0.038		0.014
Family physician	67	22		49		73		65		89	
Patient	26	28		52		100		65		69	
Partner	19	11		74		72		83		94	
Family (not partner)	18	28		61		88		94		100	
Family physician out-of-hours	15	43		29		71		71		93	
Specialist	29	35		62		62		52		72	
<b>Length of stay<sup>¶</sup></b>			0.150		0.019		0.737		0.485		0.103
≤9	91	21		64		75		70		90	
10+	98	31		47		77		65		81	
<b>Ward where the patient died<sup>*</sup></b>			0.280		0.009		0.027		0.084		0.082
Internal medicine	72	24		60		82		69		86	
Intensive Care & Emergency	51	30		44		60		54		77	
Geriatrics	30	30		40		80		73		90	
Oncology	21	10		81		90		84		100	

\*Diagnostic reasons were excluded from the analysis, as we estimated that differences regarding this variable were improbable; Missings ranged between 1 and 9 and were excluded from the analysis.

†Category 'don't know' (n=20) was excluded from the analysis.

‡%=row percentages of total ; only 'yes' (for reasons) or 'at least one item of this aspect had played a role in decision-making' (for aspects) are provided in the table.

§ Chi-square test or Fisher Exact test for associations between reasons or aspects and admission characteristics.

|| 'Other' (n=6), 'don't know' (n=5) and 'nurse' (n=1) were excluded from the analysis, given the low numbers.

¶ Total number of days dichotomized at its median value (=9); \*Other wards (n=15) were excluded from the analysis.

hospital admissions, given that they are most likely to be well informed about the patient's medical and social situation.<sup>38</sup> The response rate of 70% was satisfying compared with other surveys among FPs,<sup>41-44</sup> and an additional non-response analysis showed that there was no non-response bias regarding the patient's age or gender. Questionnaires were sent two weeks after the patient's death to limit recall bias. As FPs in Belgium perceive their own role in preventing and guiding these admissions to be important,<sup>38</sup> and given that questionnaires were sent from and to the university hospital, there might have been a tendency towards providing answers that would be considered as good medical practice.<sup>45</sup> Therefore, a post-hoc rationalisation element in the answers of FPs cannot be excluded. Furthermore, only FPs' perspectives were reported in this study, while patients, relatives or other healthcare professionals might have reported different results.<sup>46</sup>

That more than half of all terminal hospital admissions were for palliative reasons was a surprising finding. This is all the more striking as we did not consider admissions to the palliative care unit of the hospital in our study, hence these were admissions to an acute ward (e.g. an oncology ward). However, given that the acute hospital setting is considered to be an inadequate setting as place of death,<sup>10;11;13</sup> it might be questioned whether this reflects proper end-of-life care. A pertinent question therefore remains as to why more than one in two patients admitted to an academic hospital prior to hospital death are being admitted for palliative reasons. A first possible explanation relates to the inadequacy of out-of-hospital palliative care. Our findings indicate that in 85% of all terminal hospital admissions FPs considered that an inadequate care setting had played a role in deciding to admit the patient to hospital; this was more likely for those with a more limited anticipated life expectancy (i.e. less than a few weeks). This might indicate that for these patients there was inadequate support to provide sufficient end-of-life or palliative care at the setting where they were residing, although death was not unexpected. A second plausible explanation might be that the acute hospital setting is sometimes perceived to be a safe haven.<sup>11</sup> FPs indicated that in almost one in two admissions families believed care was better in hospital and that it had played a role in the decision to admit, as well as in one out three cases the patient had felt they would be safer there. This might indicate that despite a majority preferring out-of-hospital death,<sup>22</sup> for a given number of patients the acute hospital setting might be perceived as a valid option at the end of life.<sup>11</sup> Whether care is actually better or not, this perception appears to be persistent,<sup>11</sup> and a hospital admission might be justified in such cases.<sup>35</sup> This might point to the medicalised nature of death and dying in contemporary society.<sup>10;31;47</sup> Moreover, we are socialised into responding to a serious health event – even when death might not be unexpected – by seeking medical treatment and in Belgium an easily-accessible setting such as the hospital might be regarded as a desirable option in these circumstances.<sup>31;47</sup>

These results suggest that end-of-life care in Belgium is rather hospital-centric. This seems to be in line with studies indicating that Belgium has a relatively large proportion of hospital deaths in cancer patients,<sup>7;48</sup> and Belgian cancer patients being more likely to have two or more hospital admissions in the last 30 days of life than their counterparts in the Netherlands, Italy or Spain.<sup>49</sup> Moreover, patients who died non-suddenly in Belgium are more likely to have used hospital-based specialised palliative care than their counterparts in these countries.<sup>50</sup> Furthermore, only one out of four patients in our study sample had used specialist palliative care services (e.g. the hospital palliative support team or multidisciplinary palliative home care team) according to FPs – although death was non-sudden in retrospect. Therefore, it might be suggested that in order to reduce the number of hospital deaths in Belgium, more out-of-hospital palliative care needs to be initiated,<sup>50</sup> a more timely referral to these services is needed,<sup>51;52</sup> and perhaps even more so in illness trajectories other than cancer.<sup>52;53</sup>

As previous studies have indicated, our findings may be related to the limited gatekeeper role of FPs in practice in Belgium.<sup>38;54;55</sup> In a study about hospital admissions in the last three months of life in the Netherlands, these admissions were initiated by patients and/or family in 10% of the admissions, as compared with 36% in our study.<sup>36</sup> This could partially explain why the proportion of patients dying in hospital is substantially lower in the Netherlands than in Belgium.<sup>7;38;56</sup> Adopting a system by which the usual FP is consulted and the FP refers the patient to hospital would be a good starting point in reducing the number of hospital deaths in Belgium.<sup>38</sup>

## **CONCLUSION**

End-of-life care in Belgium is rather hospital-centric, as many people dying in an acute hospital have been admitted for palliative reasons. To reduce the number of hospital deaths in Belgium, a combination of structural support for out-of-hospital end-of-life care, more timely referral to out-of-hospital palliative care services and a strengthened gatekeeper role to hospital services for the family physician may be needed.

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<b>What is already known about the topic</b>
<ul style="list-style-type: none"> <li>• The acute hospital setting is considered not to be an ideal setting as place of death.</li> <li>• However, many patients are admitted to an acute hospital setting at the end of life, and subsequently die there.</li> <li>• Little is known about the reasons and circumstances that lead to such terminal hospital admissions.</li> </ul>
<b>What this study adds</b>
<ul style="list-style-type: none"> <li>• Most terminal hospital admissions are for palliative reasons.</li> <li>• The acute hospital setting sometimes represents a safe haven for patients and families, which points to the medicalised nature of death and dying in contemporary society.</li> <li>• In a vast majority of the terminal hospital admissions an inadequate care setting had also played a role in the decision to admit; more structural support for out-of-hospital end-of-life care is needed.</li> </ul>

## CONTRIBUTORS

All authors contributed to the data analysis and interpretation of the results, and reviewed and approved the final manuscript. TR had full access to all of the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis. TR is guarantor.

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## ETHICAL APPROVAL

Ethical approval for this study was given by the Medial Ethics Commission of the Brussels University hospital and Ghent University hospital and approval was given by Sectorial Committee of Social Security and Health from the Belgian Commission for the Protection of Privacy.

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# Appropriateness and avoidability of terminal hospital admissions – Results of a survey among family physicians

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## **ABSTRACT**

### **PURPOSE**

To examine what proportion of terminal hospital admissions among their own patients family physicians consider to have been avoidable and/or inappropriate; which patient, family physician and admission factors are associated with the perceived inappropriateness or avoidability of terminal hospital admissions; and which interventions could have prevented them, from the perspective of family physicians.

### **METHODS**

Survey among family physicians about those of their patients who had died non-suddenly in an acute university hospital setting in Belgium between January and August 2014. Questions were asked about the circumstances, appropriateness and avoidability of the terminal hospitalization, about the patient's situation an illnesses and about the family physician.

### **RESULTS**

We received 245 completed questionnaires (response rate 70%) and 77% of those hospital deaths (n=189) were considered to be non-sudden. Almost 14% of all terminal hospital admissions were considered to be potentially inappropriate, almost 14% potentially avoidable and 8% both, according to family physicians. The terminal hospital admission was more likely to be considered potentially inappropriate or potentially avoidable for patients who had died of cancer, by family physicians who had had palliative care training at basic, postgraduate or post-academic level, when the patient's life expectancy at the time of admission was limited and when the admission was initiated by the patient, partner or other family.

### **CONCLUSIONS**

Timely communication with the patient about their limited life expectancy and the provision of better support to family caregivers may be important strategies in reducing the number of hospital deaths, according to family physicians.

## **KEYWORDS**

Hospitalization – patient admission – hospital death – hospital records – family physician



## INTRODUCTION

Many patients are hospitalized at the end of life,<sup>1-4</sup> and hospital use seems to increase exponentially in the last months and weeks of life.<sup>5</sup> Moreover, research shows that the acute hospital setting remains a frequent and persistent place of death in many developed countries.<sup>6-8</sup> However, the acute hospital setting is considered not to be an ideal setting as a place of death, as care is not properly adjusted to the needs of dying patients.<sup>9</sup> It is a setting which is predominantly focused on cure and life-prolongation,<sup>10;11</sup> where death is seen as failure.<sup>12</sup> Furthermore, most people prefer not to die in hospital.<sup>13-17</sup> Although, studies also show that such a preference might change in favour of hospital death as death approaches, as aspirations become more 'realistic' and/or when circumstances for dying at home are not ideal.<sup>15;18-21</sup> In these situations, a terminal hospital admission might be considered appropriate or justified – being the best option for the patient, considering the circumstances.<sup>22</sup>

There are several national end-of-life care policies aimed at reducing the number of terminal hospital admissions and hospital deaths;<sup>23-25</sup> in part to reduce health care expenditure.<sup>26;27</sup> However, research into the extent to which these terminal hospital admissions can be reduced is scarce.<sup>28;29</sup> More data on the avoidability and appropriateness of such terminal hospital admissions (i.e. those preceding hospital death) could inform policy on the extent to which they can be prevented and how.<sup>22;30</sup>

The present study aims to examine what proportion of terminal hospital admissions of their patients family physicians (FPs) consider to be avoidable and/or inappropriate; which patient, FP and admission factors are associated with the inappropriateness or avoidability of terminal hospital admissions; and which interventions could have prevented potentially avoidable terminal hospital admissions, according to FPs.

## METHODS

### DESIGN

A cross-sectional survey was conducted among the FPs of all patients who died in a large (+/-1,000 bed) university hospital in Belgium between January and August 2014, to collect data on the circumstances of the admission.

In Belgium almost 95% of the population has an FP whom they consult regularly (78% at least once a year).<sup>31</sup> FPs are considered to have a pivotal role in providing out-of-hospital end-of-life care,<sup>32</sup> and to be best informed about the patient's medical and social situation. Consequently, their perspectives are considered to be crucial in assessing whether an end-of-life hospital admission could have been avoided and whether it was inappropriate.

### STUDY POPULATION

All patients who died in an acute hospital in the sampling period were identified in the hospital's medical record system. Those under 18 years, those not residing in Belgium and those who died on a specialised palliative care unit, maternity ward or psychiatric ward were excluded as they were not the focus of this study.

### DATA COLLECTION

A research assistant was involved in the data collection procedure as intermediary between FPs and the university hospital. The assistant received an extract of the hospital records of all deaths, including the patient's gender, postal code, date of birth, date of death, timing of admission, hospital ward where they died and their FP's contact information. A questionnaire was sent to the FP of every eligible death case. The accompanying letter included the gender of the deceased patient, postal code of the municipality of residence, date of birth and date of death, so as to enable the FPs to identify the patient when filling out the questionnaire.

Deaths were identified on a weekly basis during the study period and two weeks after the patient's death a four-page questionnaire was sent to the FP, so as to limit the time between the death and the completion of the questionnaire. The Total Design Method was used to maximise the response to the questionnaire.<sup>33;34</sup> In cases where there was no response, a reminder was sent after three weeks, a second questionnaire as a reminder after five weeks and another reminder after seven weeks. After ten weeks a brief nonresponse questionnaire was sent for those cases where the FP had not yet

responded, to identify the reasons. FPs received questionnaires for a maximum of three patients, so as to limit the workload.

From the returned questionnaires, the research assistant coded all data and guaranteed that the research data could not be linked to the patient or to the FP. The questionnaire data was linked to the extract of hospital records, using a unique case number, while the patient's postal code and the FP's contact information were deleted to guarantee anonymity.

## QUESTIONNAIRES

The questionnaire concerned the circumstances of and reasons for the terminal hospital admission and its design was based on the results of three previous qualitative studies that explored the perspectives of FPs, nurses and family carers on end-of-life hospital admissions, and on similar surveys that had been used in the Netherlands and Belgium.<sup>1;5;9;29;32;35</sup> The questionnaire was developed within a research team that consisted of five medical sociologists (one of whom is also a nurse) and an FP, all with experience in survey methodology and knowledge of the subject. The questionnaire was tested among five FPs and their comments were incorporated into the final version.

In a first question FPs were asked to assess whether the patient's death was sudden and totally unexpected, and if so they were prompted to go to the end of the questionnaire. Where the answer was no, closed questions followed regarding the patient's situation and illnesses (e.g. cause of death), the terminal hospital admission (e.g. the person who initiated the admission) and the FP (e.g. number of FP contacts in the last month of life).

A five-point Likert scale (-2 to +2) was used to measure appropriateness and avoidability. Appropriateness in the questionnaire was defined as 'the best option for the patient, considering the circumstances'; and avoidability as 'medically unnecessary'. Where FPs indicated that the hospital admission was not unavoidable (-2 to 0 on the avoidability scale) they were prompted to indicate which interventions could have prevented the admission. Several options were provided for this question based on a Dutch study (modified to the Belgian situation) and on the results of previous qualitative studies.<sup>9;29;32;35</sup>

## HOSPITAL RECORDS

From the hospital records the patient's age and gender, the length of stay and whether the admission was out-of-hours or at the weekend were extracted.

## DATA ANALYSIS

Only deaths that were considered to be non-sudden (i.e. not sudden or totally unexpected) by the FPs were included, given that having a palliative approach and deciding not to admit these patients to hospital might have been an alternative to the admission.<sup>22</sup> The scores on the 'appropriateness' variable were recoded into two categories: scores +1 and +2 were considered to denote a judgement of appropriateness, all other scores were considered to denote an absence of this judgement (i.e. potentially inappropriate). The same was done for avoidability. We examined the associations between several patient, FP and admission factors, and the inappropriateness and avoidability of terminal hospital admissions, using chi-square or Fisher's exact test (in case of limited number of cases). SPSS 22.0 was used for all computations.

## ETHICS

Ethical approval for this study was given by the Medial Ethics Commission of the Brussels university hospital and Ghent university hospital and approval was given by Sectorial Committee of Social Security and Health from the Belgian Commission for the Protection of Privacy.

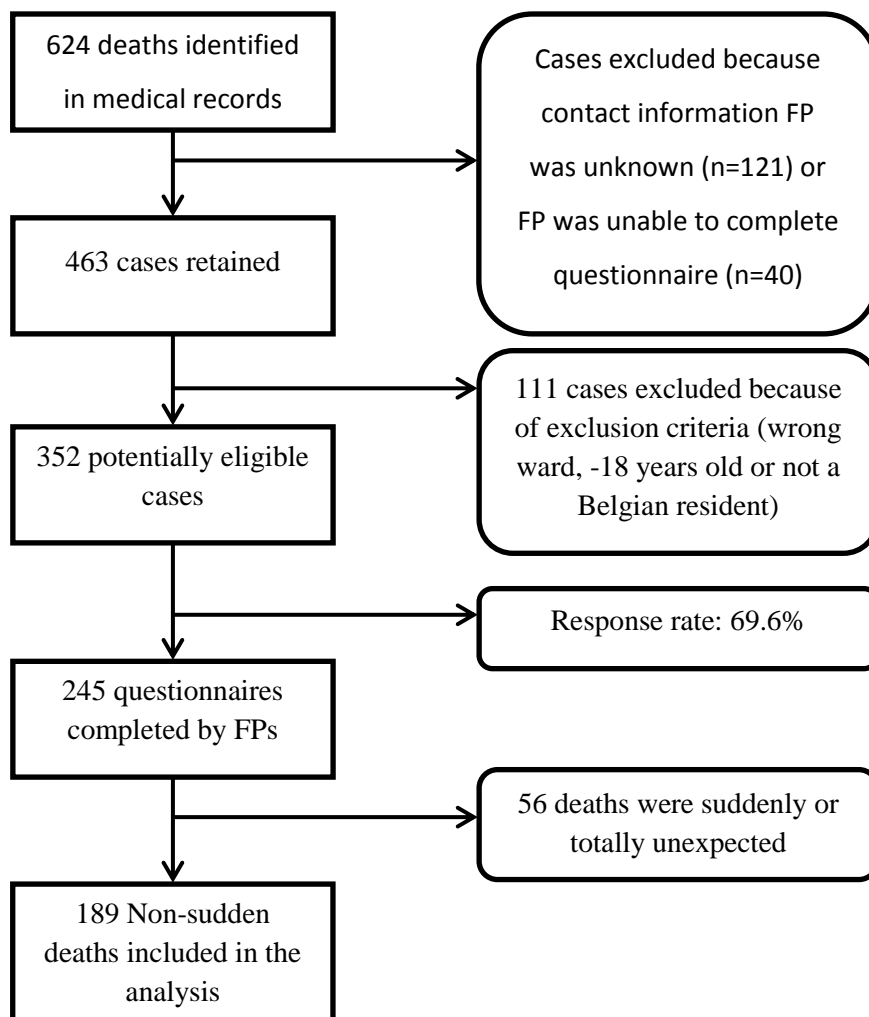
## RESULTS

### DATA COLLECTION AND NONRESPONSE ANALYSIS

In total, 624 hospital deaths were identified in the hospital medical records; 121 of those were excluded because the FP's contact information was unknown and another 40 because the FP indicated that he/she was unable to complete the questionnaire during the data collection period (e.g. the FP no longer had contact with the patient at the time of the admission) (**Figure 1**). There were 111 hospital deaths that did not meet the inclusion criteria: four patients were not residing in Belgium, 28 were less than 18 years old and 79 had died on the inpatient palliative care unit. We received 245 completed questionnaires out of 352 potentially eligible cases (response rate 69.6%). Reasons for nonresponse, as identified through the nonresponse survey, were 'no time' (n=12), or

'other' (n=3); three FPs indicated that they objected the methods or objectives of this kind of research. No significant differences were found between cases for which we received a completed questionnaire and the completed nonresponse questionnaires regarding the inappropriateness and/or avoidability of the terminal hospital admissions. According to FPs, 77.1% (n=189) of the remaining hospital deaths were considered to be non-sudden and were included in the analysis. There were no significant differences in age and gender between those cases for which the FP responded and those for which they did not.

**Figure 1 Flow chart of non-sudden deaths included in the analysis**



## AVOIDABILITY AND INAPPROPRIATENESS OF TERMINAL HOSPITAL ADMISSIONS

FPs considered a majority (n=147; 80.3%) of all terminal hospital admissions to be both unavoidable and appropriate (**Table 1**). They indicated that 26 (14.2%) terminal hospital admissions were potentially avoidable and 25 (13.7%) potentially inappropriate. They considered 15 (8.2%) admissions to be both potentially inappropriate and potentially avoidable.

**Table 1 Avoidability and appropriateness of terminal hospital admissions, according to the FP \* (N=189)**

	Unavoidable	Potentially avoidable	Total <sup>‡</sup>
Appropriate	147 (80.3)	11 (6.0)	158 (86.3)
Potentially inappropriate	10 (5.5)	15 (8.2)	25 (13.7)
Total <sup>†</sup>	157 (85.8)	26 (14.2)	183 (100.0)

\*6 missing answers for one of both questions; N (%) of all terminal hospital admissions.

† n (%) within avoidability of all terminal hospital admissions.

‡ n (%) within appropriateness of all terminal hospital admissions.

## FACTORS ASSOCIATED WITH INAPPROPRIATENESS AND/OR AVOIDABILITY OF TERMINAL HOSPITAL ADMISSIONS

Admissions were more often considered to be potentially inappropriate by FPs in patients dying of cancer; in cases reported by FPs who have had palliative care training at basic, postgraduate or post-academic level (**Table 2**); in patients with a life expectancy of less than a day to a few weeks at the time of admission; when the admission lasted less than 10 days; and when the admission was initiated by the patient, the patient's partner or other family members (**Table 3**).

The terminal hospital admission was more likely to be considered potentially avoidable by FPs in patients residing in nursing homes (**Table 2**); in those with a life expectancy of less than a day to a few weeks at the time of admission, in admissions that lasted less than 10 days, in admissions initiated by the patient, the patient's partner or other family members, and in admissions for social or other non-medical reasons (**Table 3**). Admissions were less likely to be considered potentially avoidable by FPs when they were for diagnostic purposes.

**Table 2 Inappropriateness and avoidability of terminal hospital admissions by patient, family physician factors (N=189)\***

	Total	Potentially inappropriate (n=25)		Potentially avoidable (n=26)	
	n	(%) <sup>†</sup>	p-value <sup>‡</sup>	(%) <sup>†</sup>	p-value <sup>‡</sup>
<i>Patient Factors</i>					
Gender			0.637		0.807
Male	120	14.4		14.5	
Female	69	11.9		13.2	
Age			0.789		0.687
≤64 years	57	15.8		15.8	
65-79 years	80	11.7		11.5	
80+ years	52	13.7		16.0	
Usual place of residence			>0.999		0.026
Home	174	12.9		11.8	
Nursing home	14	14.3		35.7	
Financial status			0.087		0.668
Low/rather low	32	3.1		12.5	
Average	114	13.4		13.3	
High/rather high	38	21.1		18.4	
Cause of death			0.033		0.276
Cancer	89	19.1		17.2	
Non-cancer	94	8.1		11.5	
<i>Family physician factors</i>					
FP involved in end-of-life trajectory			0.111		0.607
No	94	9.7		12.9	
Yes	91	17.8		15.6	
Number of FP visits in last month of life <sup>§</sup>			0.278		0.655
≤3	101	11.0		13.0	
4+	85	16.5		15.3	
FP Self-assessed experience in palliative care			0.231		0.719
Inexperienced	8	0.0		0.0	
Neither inexperienced, neither experienced	38	8.1		13.2	
Experienced	137	16.2		15.4	
FP had training in palliative care			0.027		0.100
None	57	8.8		7.1	
In basic physician training	34	17.6		26.5	
In post-academic or postgraduate training	59	22.4		13.6	
Other or in-service training	36	2.9		13.9	

\* FP='Family Physician'; Missings ranged between 4 and 9 and were excluded from the analysis.

† %=row percentages of total.

‡ Chi-square or Fisher's Exact Test; for differences between 'appropriate' and 'potentially inappropriate'; and for differences between 'Unavoidable' and 'Potentially avoidable'; for the given patient or family physician factor.

§ Total number of contacts dichotomized at its median value (=3).

**Table 3 Inappropriateness and avoidability of terminal hospital admissions by admission factors (N=189)\***

	Total	Potentially inappropriate (n=25)		Potentially avoidable (n=26)	
		n	(%) <sup>†</sup>	p-value <sup>‡</sup>	(%) <sup>†</sup>
<i>Admission factors</i>					
Life expectancy at time of admission <sup>§</sup>					
Less than a day to a few weeks	84	23.5		22.2	
More than a few weeks	85	6.0		7.1	
Admission was out-of-hours			0.990		0.885
No	135	13.5		14.3	
Yes	54	13.5		13.5	
Admission was during weekend			0.545		0.927
No	143	12.7		14.2	
Yes	46	16.3		13.6	
Admission was planned			0.821		0.184
No	147	13.9		16.1	
Yes	40	12.5		7.7	
Person who took initiative for admission <sup>  </sup>			0.036		0.004
Family physician	67	4.5		10.6	
Patient	26	23.1		23.1	
Partner	19	22.2		36.8	
Family (not partner)	18	23.5		11.8	
Family physician out-of-hours	15	15.4		7.1	
Specialist	29	13.8		0.0	
Length of stay <sup>¶</sup>			0.028		0.020
≤9	91	19.3		20.2	
10+	98	8.2		8.3	
Medical reasons <sup>††</sup>					
Curative reasons			0.491		0.456
No	138	14.1		14.7	
Yes	49	10.2		10.4	
Palliative reasons			0.390		0.156
No	84	11.7		9.6	
Yes	103	14.0		16.8	
Diagnostic reasons			0.273		0.036
No	131	14.8		17.1	
Yes	56	8.9		5.5	
Other or social reasons			0.097		0.021
No	178	12.0		12.0	
Yes	9	33.3		44.4	

\*Missings ranged between 4 and 7 and were excluded from the analysis

† %=row percentages of total

‡Chi-square or Fisher's Exact Test; for differences between 'appropriate' and 'potentially inappropriate'; and for differences between 'Unavoidable' and 'Potentially avoidable'; for the given admission factor.

§ 'Don't know' was excluded from the analysis (n=20)

|| 'Other' (n=6), 'don't know' (n=5) and 'nurse' (n=1) were excluded from the analysis, given the low numbers

¶ Total number of days dichotomized at its median value (=9)

†† Multiple answers were possible



## INTERVENTIONS THAT COULD HAVE PREVENTED THE TERMINAL HOSPITAL ADMISSIONS

Of the 26 terminal hospital admissions that were considered to be potentially avoidable, FPs considered 12 could have been prevented by informing the patient earlier about their limited life expectancy and about palliative care (**Table 4**); and 12 by providing better support to the family caregivers. In eight cases, FPs considered that the admission could have been prevented by involving the FP in the decision to admit or by having consensus about this decision between all those involved.

**Table 4 Interventions that (in hindsight) could have prevented potentially avoidable terminal hospital admissions, according to the FPs (n=26)\***

	n (%)
<b><i>Aspects with regard to timely communication</i></b>	<b>16 (69.6)</b>
Specialist needed to inform the family physician in time about the patient's incurable illness	3 (13.0)
Earlier discussion with patient about stopping treatment or diagnostics	3 (13.0)
Inform patient earlier about limited life expectancy and palliative care	12 (52.2)
Discuss the patient's preferences regarding the end of life, in time (e.g. place of death)	7 (30.4)
<b><i>Aspects with regard to care that is present</i></b>	<b>16 (69.6)</b>
Use caregivers specialized in palliative care earlier	4 (17.4)
Provide better support to family caregiver(s)	12 (52.2)
Use more nurses or carers at the patient's residence	4 (17.4)
More involvement and guidance by family physician	4 (17.4)
<b><i>Aspects with regard to the circumstances during the decision to admit</i></b>	<b>19 (82.6)</b>
Clear transfer of information during out-of-hours services	0 (0.0)
Involve family physician in the decision whether to admit	8 (34.8)
Consensus about the decision not to admit between all who is involved	8 (34.8)
Availability of necessary caregivers during acute situations	5 (21.7)
<b><i>Aspects with regard to the necessary medical acts</i></b>	<b>12 (52.2)</b>
Use more technical resources for palliative care	5 (21.7)
Better competencies in palliative care of caregivers that were involved	4 (17.4)
Consider palliative sedation	5 (21.7)

\*Missings (n=3) and unavoidable admissions were excluded from the analysis; multiple answers were possible.

## DISCUSSION

Of all terminal hospital admissions to an acute care university hospital of patients for whom death could – at least to some extent – have been anticipated, 14% were considered to be potentially inappropriate and 14% potentially avoidable by the treating FP. According to family physicians, the terminal hospital admission was more likely to be considered potentially inappropriate and/or potentially avoidable for patients who died of cancer, by family physicians who had had palliative care training at basic, postgraduate or post-academic level, when the patient's life expectancy at the time of admission was limited and when the admission was initiated by the patient, partner or other family. Potentially avoidable admissions could have been prevented by providing better support to family caregivers or by timely communication with the patient about limited life expectancy and the possibilities of palliative care, according to the FPs.

To our knowledge, this study is one of the first to examine the appropriateness and avoidability of terminal hospital admissions and the associations with patient, FP and admission factors. All deaths in an eight-month period in a university hospital were identified in the hospital's medical record system. Information about the patient's terminal hospital admission was provided by their FP, whom they consult regularly (78% at least once a year),<sup>31</sup> and who is considered to be important in guiding or preventing such terminal hospital admissions, given they are likely to be best informed about the patient's medical and social situation.<sup>32</sup> The response rate was satisfying compared with other surveys among FPs,<sup>29;36-38</sup> and an additional nonresponse analysis indicated that there was no nonresponse bias. Questionnaires were sent two weeks after the patient's death, to limit recall bias. A certain post-hoc rationalisation cannot be excluded and could explain that FPs qualified a large majority of terminal hospital admissions to be appropriate and unavoidable in retrospect. As FPs in Belgium perceive their own role in preventing and guiding these admissions to be important,<sup>32</sup> and given that questionnaires were sent from and to the university hospital, there might have been a tendency towards providing answers that would be considered as good medical practice.<sup>39</sup> Only FPs' perspectives were reported in this study, while patients, relatives or other healthcare professionals might have reported different results.<sup>40</sup> The relatively small proportion of potentially avoidable or potentially inappropriate hospital admissions precluded the construction of multivariable statistical models simultaneously controlling for multiple covariates. Generalizability, eg to non-academic hospitals, may be limited and repetition of our study with the inclusion of all hospitals in the catchment area may be warranted.

According to FPs, the vast majority of the terminal hospital admissions in this study (86.3%) qualified as appropriate –‘the best option for the patient, considering the circumstances’. This could indicate that although the patient’s death might have been expected, in many cases a terminal hospital admission was considered justified; either due to the patient preferring the admission, the insufficient caring capacity to provide adequate end-of-life care at home, or because of an uncontrollable acute medical situation.<sup>35</sup> However, terminal hospital admissions were more likely to be considered potentially inappropriate for patients who died of cancer and for those with a very limited life expectancy (less than a few weeks). This indicates that in these cases, where death might be more expected, hospitalizations at the end of life are more likely to be regarded as undesirable. On the other hand, this might indicate that for most admissions, death might have been less expected – although it was non-sudden, in retrospect – and the admissions are therefore more likely to be considered appropriate by FPs.

The proportion of end-of-life hospital admissions considered to be potentially avoidable in this study (14.2%) differed from those found in England or the Netherlands.<sup>28;29</sup> As the proportion of all deaths occurring in hospital in England (58.1%) and in Belgium (52%) is similar, one might assume the proportion of potentially avoidable end-of-life hospital admissions to be similar.<sup>8</sup> However, it has been found to be lower (6.7%), although the methodology of the study was different: the subject was the admission of patients with palliative care needs as assessed by palliative medicine consultants, instead of admissions prior to hospital death, assessed by FPs, as in our study.<sup>28</sup> On the other hand, the proportion of deaths occurring in hospital is substantially lower in the Netherlands (34%) than in Belgium.<sup>8</sup> However, Dutch FPs considered a larger proportion of admissions as avoidable (24%), though the Dutch study focused on the final admission in the last three months of life, rather than admissions prior to hospital death, as in our study.<sup>29</sup> The differences between England, Belgium and the Netherlands indicate that the perception of what might be avoidable and what is not is largely country or population dependent and may be influenced by cultural values,<sup>41</sup> or by organizational differences in health care provision. However, considering that generalizability, eg to national figures, in these studies may be limited, repetition of our study on a larger, nation-wide scale, as well as cross-national research may be warranted to examine and understand differences in the proportions of potentially avoidable end-of-life hospital admissions and their cultural and health care organizational constituents.

FPs indicated that almost one third of the potentially avoidable admissions could have been prevented by involving an FP during decision-making about the admission. In addition, terminal hospital admissions initiated by patients, partners or other family members were more likely to be considered potentially inappropriate or potentially avoidable. This might indicate that a stronger

gatekeeper-role for Belgian FPs could possibly reduce the number of terminal hospital admissions. In Belgium, FPs have a more restricted gatekeeping role towards hospital care compared with in the Netherlands.<sup>32</sup> Adopting a system where the FP is consulted mandatorily prior to hospital admissions might be a good starting point to reduce the number of such terminal hospital admissions in Belgium.

FPs in our study indicated that a majority of potentially avoidable terminal hospital admissions could have been prevented by informing patients earlier about their limited life expectancy and about palliative care. This shows that a timely palliative approach might have been lacking and that this could be an important strategy to avoid patients going to hospital at the end of life. Therefore, it could be suggested that adequate advance care planning and pro-active, timely discussions with the patient about a palliative approach are needed to reduce the number of hospital deaths.<sup>42-44</sup> FPs with more formal palliative care training at basic, postgraduate or post-academic level were more likely to label a patient's admission as potentially inappropriate. This might indicate that such FPs are more critical of the usefulness of terminal hospital admissions, or have more knowledge of the possibilities for enabling patients to die at home. Considering that FPs' competencies in end-of-life care provision are crucial in preventing inappropriate terminal hospital admissions, we suggest that more palliative care training is needed in graduate, vocational and postgraduate education.<sup>32</sup> Furthermore, FPs also suggested that a majority of potentially avoidable terminal hospital admissions could have been prevented by providing more adequate support to family caregivers. This might indicate that the home care setting in particular needs to be improved in terms of continuous support and palliative care. However, it has to be noted that this should not mean that end-of-life care research and policy should exclude improving end-of-life care provision in the acute hospital setting, for as our results show, it is and will probably remain an important setting for end-of-life care.<sup>9</sup> Expanding initiatives such as specialised palliative care units therefore remains highly recommended.

## **CONCLUSION**

FPs in this study considered four out of five of their patients' terminal hospital admissions to be appropriate and unavoidable. Timely communication with the patient about their limited life expectancy and the provision of better support to family caregivers might be important strategies to reduce the number of hospital deaths, as suggested by the responding FPs.

## **ACKNOWLEDGEMENTS**

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## **CONFLICT OF INTEREST**

The authors declare that there is no conflict of interest.

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# PART V

Discussion



## CHAPTER 9

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### General Discussion and Conclusion

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## INTRODUCTION

The main objectives of this dissertation were to examine the proportion of older people with a dementia-related disease who died in hospital in Belgium; to explore family physicians' perceptions regarding their role in preventing and guiding hospital admissions at the end of life; and to gain insights into the reasons why patients are admitted to hospital at the end of life and the appropriateness and avoidability of such admissions. The main results of the studies undertaken to meet these objectives will be discussed in subsequent paragraphs of this part. First, the main findings will be summarised; next, the methodological considerations will be addressed; then, a general discussion of the most important findings will be provided; and several challenges for practice, policy and research will be suggested.

## SUMMARY OF MAIN FINDINGS

In the following paragraph, the main results of the previous chapters are summarised in three separate themes: the examination of the proportion of older people with a dementia-related disease who died in hospital in Belgium (Objective 1 of this dissertation); the exploration of family physicians' perspectives on their role in preventing and guiding hospital admissions (Objective 2 of this dissertation); and the gained insights into the reasons why patients are admitted to hospital at the end of life, and the appropriateness and avoidability of such an admission (objective 3 of this dissertation).

### HOSPITAL DEATH AMONG OLDER PEOPLE WITH DEMENTIA

#### *International variation in place of death among older persons who died from dementia in fourteen European and non-European countries*

In Chapter 2, we examined variations in place of death among older people who died from a dementia-related disease, across 14 different countries (Belgium, the Netherlands, England, Wales, France, Italy, Spain, Czech Republic, Hungary, New Zealand, USA, Canada, Mexico and South Korea), using death certificate data. In total, 4.8% of the older population died from a dementia-related disease. The proportion of hospital deaths among older people who died from dementia varied between 1.6% in the Netherlands and 73.6% in South Korea; for Belgium this proportion was 21.6%. The hospital was the most frequent place of death in South Korea, Hungary and France; home was the most frequent place of death in Italy, Spain and Mexico and most deaths occurred in a long-term

care setting in Belgium, the Netherlands, England, Wales, Czech Republic, New Zealand, USA and Canada. Healthcare system factors did statistically explain country variation in place of death and even after controlling for healthcare system factors, as well as sociodemographic factors and social support, notable differences remained. When compared with France, the odds of dying at home rather than in a hospital setting were significantly higher in the Netherlands, and lower in all other countries. The odds of dying in a long-term care setting, rather than in a hospital were higher in Belgium, England, the USA, Czech Republic, and particularly in the Netherlands, when compared with France.

### ***Dying in hospital with dementia and pneumonia: a nationwide study using death certificate data***

In chapter 3 we examined the incidence of and risk factors for hospital death in older people who died with pneumonia and dementia, using death certificate data. In Belgium (2008), 9.931 of all those dying (9.8%) died with a dementia-related disease. Of those, 14.3% were additionally certified with pneumonia as a cause of death or as a comorbidity. Older people who died with dementia and pneumonia were more likely to die in hospital (47%) than those with dementia who died without pneumonia (28%). This was an independent risk factor, even when controlling for other potential confounders (place of residence, type of dementia, age, gender, educational attainment, marital status, living arrangement, urbanization level and healthcare system factors). Older people who died with dementia and pneumonia, living in their own home, were more likely to die in hospital if they were single or living in strongly urbanized areas. For those living in a long-term care setting at the time of death, hospital death was more likely for those living in areas with higher availability of residential beds (without skilled nursing continuously available) in long-term care settings.

## **FAMILY PHYSICIANS' PERSPECTIVES ON THEIR ROLE IN END-OF-LIFE HOSPITAL ADMISSIONS**

### ***The family physician's perceived role in preventing and guiding hospital admission at the end of life: a focus group study***

In chapter 4, five key roles were identified that family physicians perceived for themselves in preventing and guiding hospital admissions at the end of life and the accompanying difficulties they experience in fulfilling these roles. As a first role, family physicians take on the role of care planner; care needs to be planned and re-planned throughout the dying phase to anticipate future scenarios and to prevent future end-of-life hospital admissions. However, participants explained that sometimes they feel excluded by hospital specialists and therefore lose sight of patients, which

hinders them in organizing adequate care. Furthermore, participants indicated that in acute situations, family physicians frequently take on the role of ‘initiator of decisions’; family physicians are sometimes considered to mediate the perspectives of those involved (patient, relatives and caregivers) in order to avoid conflicts, which would otherwise hinder the decision-making. Moreover, participants indicated that this role was merely advisory, as they cannot prevent patients from going to hospital. They also take on the role of ‘provider of end-of-life care’, in which competencies and attitudes were considered to be important. Those who are more skilled and have the right attitude towards end-of-life care were considered to be more effective in keeping a patient at home or in the nursing home. Participants also felt it was expected that a family physician, as a ‘provider of support’, needs to be able to support dying patients at all times and therefore to be available continuously, which could prevent patients from going to hospital. However, they also admitted that being available at all times is difficult, particularly during weekends, and that a hospital admission in these circumstances might be more comfortable. As a ‘decision maker’, family physicians are considered to take responsibility (e.g. for not sending a patient to hospital) and they do need to be prepared to take such decisions, participants indicated. However, they also acknowledged that in some situations, when they are not sure about the situation (e.g. when they question whether they would be able to provide adequate care or when on-duty out-of-hours and information is lacking), many family physicians might decide to hospitalize the patient.

## **REASONS FOR AND APPROPRIATENESS AND AVOIDABILITY OF HOSPITAL ADMISSIONS AT THE END OF LIFE**

### *The acute hospital setting as a place of death and final care: a qualitative study on perspectives of family physicians, nurses and family carers*

In Chapter 5, we explored how the acute hospital setting is perceived as a place for end-of-life care and as a place of death, according to family physicians, nurses and family carers whose relative had died in hospital. Three key themes were identified. First, it was found that participants perceived the acute hospital setting to be an inadequate setting for terminally ill patients, although it has to be noted that they also acknowledged that differences do exist between hospitals and/or wards regarding the quality of end-of-life care. The acute hospital setting was considered to be inadequate: it is not properly adjusted to the needs of dying patients; it is predominantly focused on curative care and life-prolongation; and communication in this setting is often poor or contradictory. On the other hand, the acute hospital setting was also perceived as a ‘safe haven’, a setting where people can be at ease because they feel safer there: because they fear death and hope to recover or prolong life; or

fear that they would not be able to receive the best possible care during the dying phase; or regard the acute hospital setting as a familiar care environment because along the end-of-life trajectory they have become used to the surroundings and have become more acquainted with the health care professionals over time; and in some situations, it is the only alternative, a last resort. A third key theme describes how participants acknowledged that some acute hospitals or wards have changed their attitude towards end-of-life care, indicating that there might have been an improvement in the provision of end-of-life in some hospitals or wards.

***What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses***

Family physicians' and nurses' perceptions were explored in Chapter 6, to gain insight into the circumstances that from their point of view could justify an end-of-life hospital admission – being the best option for the patient, considering the circumstances (i.e. appropriate). A hospital admission at the end of life was considered to be justified when this would reflect the patient's preferences because it benefits the patient's well-being. Participants also agreed that irrespective of the patient's preferences in terms of care setting, the priority is that the patient should be able to receive adequate care, continuously. When adequate care can no longer be ensured, participants also considered a hospital admission at the end of life justified. This was considered to be different for the home care setting (i.e. because of a higher burden of care for family caregivers, or because they might be unwilling or unable to provide care) than for nursing homes. Acute medical situations were also considered to justify an end-of-life hospitalisation because they cannot always be anticipated. However, there was no consensus about which specific medical problems would justify the admission and which would not.

***Reasons for terminal hospital admissions: results of a survey among family physicians***

In Chapter 7 a survey was conducted among family physicians concerning their patients who died in the acute hospital setting of a university hospital and concerned the reasons and additional aspects that had played a role in the decision-making leading to the terminal hospital admissions of those patients. We received 245 completed questionnaires (response rate 70%), of which 189 were considered to be non-sudden deaths according to the family physicians and which were included in the study analysis. Of those, according to family physicians, 55% were considered to be for palliative reasons, 30% for diagnostic purposes and 26% for curative or life-prolonging reasons. In one out of three terminal hospital admissions, family physicians indicated that the patient feeling safer in hospital had played a role in the decision to admit them and in more than half that family members perceived care to be better in hospital. In 85% of the admissions an inadequate care setting had played a role in the decision to admit the patient to hospital, family physicians reported. Family physicians

were more likely to report that the patient's preferences had played a role in the decision-making about the admission, when they reported that they had made more than three visits in the last month of life, when they considered themselves to be involved in their patient's end-of-life trajectory and when they were aware about their patient's preferred place of death. When patients were admitted with a limited anticipated life expectancy, family physicians were more likely to report that the admission had been for palliative reasons and that an inadequate care setting had played a role in the decision to admit the patient to hospital.

***Appropriateness and avoidability of terminal hospital admissions - results of a survey among family physicians.***

In Chapter 8 the same survey study among family physicians was used as in Chapter 7 and included 189 terminal hospital admissions of patients who died non-suddenly in the acute hospital setting of a university hospital. According to family physicians, 14% of the terminal hospital admissions were considered to be potentially avoidable and 14% potentially inappropriate; 8% were considered to be both potentially avoidable and potentially inappropriate. Family physicians were more likely to indicate an admission to be potentially inappropriate or potentially avoidable for patients who died of cancer, when the patient's anticipated life expectancy at the time of admission was less than a few weeks or when the admission was initiated by patients, partners or other family. They were more likely to indicate they were potentially inappropriate when they had had palliative care training at basic, postgraduate or post-academic level. The admissions were less likely to be considered potentially avoidable by family physicians when they were for diagnostic reasons. Family physicians indicated that most potentially avoidable terminal hospital admissions could have been prevented by providing more support to family caregivers or by more timely communication with the patient about the limited life expectancy and the possibilities of palliative care.



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## METHODOLOGICAL CONSIDERATIONS

In the following section an overview of the methodological considerations is provided: first the analysis of the death certificates is discussed; next, we provide some strengths and limitations of the qualitative studies (focus groups and interviews) that were used and of the survey study among family physicians. The use of such a mixed-method approach is considered to be one major strength of this dissertation, although it has to be noted that for practical reasons of design, we did not include hospital physicians' or patients' perspectives, which is an important limitation.

### ANALYSIS OF DEATH CERTIFICATES

Death certificate data were used to address research objective 1. In Chapter 2 the hospital death risk of older persons who died from a dementia-related disease was examined across 14 different countries; in Chapter 3 we examined the hospital death risk of older persons who died with a dementia-related disease in Belgium, and the likelihood of these patients of dying in hospital with pneumonia.

The use of death certificate data has proved to be useful in other studies and makes whole-country comparisons possible,<sup>1-4</sup> as was done in Chapter 2. Moreover, due to the large numbers they offer the opportunity to study relatively small subpopulations (such as patients who died from dementia) within or across different countries and to use a variety of variables to do so (such as sociodemographic characteristics, social support or healthcare system factors) and still allowing for sufficient statistical power.<sup>5</sup> However, it has to be noted that some information was not provided or available through the death certificates in several countries (even despite the individual linking with other databases), forcing us to exclude them in the multivariate analysis of Chapter 2. Furthermore, not all variables known to affect place of death could be included, as death certificates do not entail important information such as personal preferences or decision-making processes.<sup>5,6</sup> Moreover, it has to be noted that differences in diagnosing, reporting or death certification may exist between countries or between different health care settings within one country.<sup>7</sup>

In most countries only underlying cause of death was available in Chapter 2, therefore we selected patients with dementia as an underlying cause of death, i.e. those who died from dementia and thus were probably in an advanced stage of their dementia-related condition at the time of death. This may have limited bias related to death certification and may have ensured a more homogeneous study population. On the other hand, in Chapter 3 we used all cases in Belgium for which the death certificate contained dementia and pneumonia as cause of death or comorbidity, to counter the

underreporting of dementia in death certification. Dementia as cause of death is known to be underreported; mild dementia has a lower probability of being listed and dementia might not be recognized as a cause of death when other (immediate) causes of death are present.<sup>7</sup> Our findings may be biased because dementia might have been more likely to be reported in long-term care settings, and pneumonia as a cause of death might have been underestimated outside hospitals, because of the lack of diagnostic tools. Furthermore, that the pneumonia might be hospital-acquired after admission cannot be ruled out.<sup>8</sup>

### **QUALITATIVE RESEARCH: FOCUS GROUPS AND INTERVIEWS**

A qualitative research design was used in Chapter 4, 5 and 6, which was considered to be most suitable to explore the perspectives of family physicians, nurses and family carers.<sup>9</sup> Focus groups were used to explore family physicians' and nurses' perspectives and semi-structured interviews for those of bereaved family carers.

We chose focus group discussion as the best approach to explore the opinions and experiences of nurses and family physicians, given its meaningful process of sharing and comparing.<sup>10</sup> Given the explorative nature of the research questions, it has proved to be a useful methodology to gain insights into and understandings of a wide range of views.<sup>11</sup>

We organized nurse and family physician focus groups separately, in order to avoid issues concerning hierarchy, which was probably beneficial for the group discussions, considering there are more 'shared experiences'.<sup>12</sup> Family physician focus groups were organized among groups that regularly meet; using such pre-existing groups has proved to be beneficial, as group discussions are more 'naturally occurring'.<sup>13</sup> However, this might also have meant that some of the family physician participants restricted reporting their thoughts or opinions – they might have felt safer not questioning their own or others' competencies in front of their colleagues.

Participants for two nurse focus groups were purposely selected from different care settings (nursing home, hospital or home setting) in order to maximise variation.<sup>12</sup> However, this might have meant that these group discussions were more vibrant, as hospital nurses' perspectives regularly opposed those working out-of-hospital.<sup>14</sup> Moreover, given these participants did not know each other prior to the discussion, this might have meant they needed more time to explain themselves, which could have been beneficial in this regard.<sup>14</sup> One focus group was conducted with nursing home nurses only, to further explore their perspectives on this matter; these discussions appeared to be less vibrant and participants were able to elaborate on 'shared experiences' more often.<sup>14</sup>

The average age of family physician focus groups tended to be high. As there are no indications that our recruitment procedure selected for older physicians, and because the short questionnaires completed before discussions showed a great variety of expertise and experience, we believe this has not biased the results, though it should be taken into account. As a result of the recruitment procedure for nurse focus groups, these participants might have had an increased interest and even expertise in end-of-life care, which we believe was not the case for family physician focus groups.

We anticipated that discussing the perspectives of family carers whose relative had died in a hospital setting with them might provoke emotional reactions and therefore would most suitably be explored in-depth through face-to-face, semi-structured interviews.<sup>15</sup> As a result of the recruitment of the respondents, it cannot be ruled out that participants had a particular bad or positive experience or opinion about end-of-life care in hospitals. While it was considered important that the interviews took place three months to two years after the relative had died – in order to limit recall bias – this also meant that most interviews were emotion-laden, which might have restricted the interviewer at times in posing certain questions or to further in-depth questioning at that moment. The interview took place at the respondent's residence, and the interviewer made sure the respondent was at ease before starting the interview, making the situation more comfortable for the respondent. The interviews lasted about 45 minutes – not including small talk before, in between and after, to make sure that it was not too exhausting for the respondent, which otherwise might have impeded adequate data collection. Moreover, because the subject (the respondent's relative) had died in hospital, it cannot be ruled out that there were some effects of an a posteriori justification for the admission.

Data analysis was guided by a constant comparative approach,<sup>16</sup> which has proved to be useful in other end-of-life care research.<sup>17-21</sup> Such an approach, in which analysis is typically done in several stages of data coding and interpretation (open, axial and selective coding),<sup>16</sup> allowed the researchers to refine the results while focusing on a particular research question, and hence to improve data analysis. The analysis was mostly done by the researcher (T.R.) who conducted each focus group and interview, and coding was regularly discussed with the researcher (D.H.) who co-moderated the focus groups, which improved consistency and data-triangulation. Moreover, in each stage of data analysis, the results were regularly discussed within the research team, to further improve consistency and data-triangulation. The research team consisted of five medical sociologists and a family physician was added to this team in Chapter 4, all with experience in qualitative research and knowledge of the field. Furthermore, it has to be noted that generalising the results of study might prove to be difficult, due to the nature of the research methodology.

## **SURVEY AMONG FAMILY PHYSICIANS**

In Chapter 7 and Chapter 8 we used a cross-sectional survey among family physicians whose patients had died non-suddenly in the acute setting of a university hospital and which concerned their terminal hospital admission. We were able to identify all deaths in this setting during the study period (January to August 2014).

In Belgium, almost 95% of the population has a family physician whom they consult regularly (78% at least once a year).<sup>22</sup> Moreover, family physicians have a pivotal role in providing and coordinating out-of-hospital end-of-life care.<sup>23</sup> Consequently, family physicians were considered to be well informed about the patient's medical and social situation. However, it has to be noted that including patients, relatives or other healthcare professionals might have led to different results.<sup>24</sup>

The response rate was very satisfying (70%), when compared with other surveys among family physicians.<sup>25-28</sup> Such a high response rate might be attributed to the data collection procedure that was based on the Total Design Method.<sup>29</sup> As we were unable to provide the patient's name in the guiding letters of the mailing procedure due to privacy regulations, it cannot be ruled out that some family physicians were unable to identify the patient and therefore did not complete the questionnaire; however the nonresponse questionnaire results indicated that most of the reasons for nonresponse were due to time restraints. Three physicians indicated that they did not complete the questionnaire, because they objected the methods or objectives of this kind of research, which needs to be taken into account. The nonresponse analysis showed that there were no significant differences between cases for which the family physicians responded and for those for which they did not, regarding age and gender.

The use of a research assistant in the mailing procedure was a good guarantee of the privacy of the patients and their family physicians and was beneficial for the consistency of the data collection. Moreover, the use of such a research assistant enabled the researchers to obtain data that linked information provided by family physicians (survey data) to information from the electronic medical record system of the hospital (medical record data), that would otherwise have been impossible due to privacy regulations in Belgium.

Questionnaires were sent two weeks after the patient's death, to limit recall bias. However, as family physicians have a pivotal role in providing and coordinating out-of-hospital end-of-life care and given that questionnaires were sent to and from the university hospital, it cannot be ruled out that there was some kind of post-hoc rationalisation about the terminal hospital admission, and a tendency towards providing answers that would be considered good medical practice.<sup>30</sup> Moreover, this could

partially explain the particularly low proportion of potentially avoidable or potentially inappropriate terminal hospital admissions, as judged by the family physicians in this study.

One major strength of the survey was that the questionnaire was based on the results of the previous qualitative research of this dissertation (cfr. Chapter 4, 5 and 6), and surveys that have been used in the Netherlands and Belgium.<sup>25;31;32</sup> Moreover, it was developed within a research team, consisting of five sociologists (of whom one is also a nurse) and a family physician, all of them with experience in survey methodology and knowledge of the subject.

Generalizability of the results, e.g. to non-academic hospitals or to nationwide figures, might be limited, and that should be taken into account. Moreover, that the study sample comprised deaths in a university hospital might have meant that the proportion of terminal hospital admissions for palliative reasons might have been underestimated and that this proportion might be even higher in a general hospital.

## GENERAL DISCUSSION

In subsequent paragraphs some reflections on the main results are provided, structured according to the three main themes and objectives that have been handled in this dissertation. The first objective of this dissertation was to examine the proportion of older people with a dementia-related disease who died in hospital in Belgium. Belgium has a relatively low proportion of hospital deaths among older patients who died from dementia, although there are indications that there might be some room to further reduce this proportion. The second objective of this dissertation was related to the family physician's role in preventing and guiding hospital admissions at the end of life. Family physicians in Belgium have a pivotal role in providing out-of-hospital end-of-life care that could enable them to prevent end-of-life hospital admissions – and therefore to reduce the proportion of hospital deaths, although certain barriers may impede an adequate fulfilment of this role. The third objective of this dissertation was to gain insights into the reasons why patients are admitted to hospital at the end of life and the appropriateness and avoidability of such admissions. The acute hospital setting is considered to be a safe haven in a number of situations; patients or families might prefer to be admitted or an inadequate care setting might cause them to prefer an admission to an acute hospital setting at the end of life. Finally, we will provide some reflections on the avoidability of end-of-life hospital admissions in Belgium.

### HOSPITAL DEATHS AMONG OLDER PATIENTS WITH DEMENTIA

For patients with a dementia-related disease, the acute hospital setting is not considered to be an optimal setting for end-of-life care or as a suitable place of death.<sup>33;34</sup> Chapter 2 showed that the proportion of hospital deaths among older persons who died from dementia was lower in Belgium (22%) than in England (32%), Wales (43%), France (36%), Spain (34%), Hungary (62%), Czech Republic (28%), Canada (32%), Mexico (26%) and South Korea (74%); however it was higher when compared to New Zealand (14%), the USA (13%) and the Netherlands (2%). Moreover, the multivariate analysis showed that these differences remained statistically significant (New Zealand, Mexico and Hungary were excluded from the analysis) after controlling for sociodemographic factors, social support and health care system factors. This seems to be consistent with studies showing that the overall proportion of hospital deaths in New Zealand (34%), the Netherlands (34%) and the USA (36%) is substantially lower than in Belgium (52%).<sup>3;35-37</sup> Hence, our findings suggest that the proportion of hospital deaths in Belgium could be further reduced, in particular when compared with the Netherlands. The lower proportion of hospital deaths among older persons who died from dementia in the Netherlands could be attributed to the nursing homes being well-equipped to provide long-

term end-of-life care; with in-house specialist elderly care physicians and 24-hour nursing care as important factors in preventing end-of-life hospital admissions.<sup>4</sup> Another important factor could be that family physicians in the Netherlands have a stronger gatekeeper role towards the use of hospital services than in Belgium.<sup>38;39</sup> Belgian family physicians' perspectives on their ability to prevent end-of-life hospital admissions will be discussed further below.

It was found in Chapter 3 that older persons in Belgium have a higher likelihood of dying in hospital, when they died with dementia and pneumonia than those who died with dementia but without pneumonia, both for those living at home and those living in a nursing home. In Belgium these patients are at risk of being admitted in the event of an acute medical situation (such as pneumonia), with an increased possibility of hospital death as a result. The focus group discussions among family physicians and nurses (Chapter 6) also indicated that in these situations (in the event of an acute medical situation) an end-of-life hospital admission might be considered justified. Hence, although there are indications that the proportion of hospital deaths in Belgium could be further reduced, it might be questioned whether such a reduction would be appropriate, or possible, which is discussed further below.

### **THE FAMILY PHYSICIAN'S ROLE IN END-OF-LIFE HOSPITAL ADMISSIONS**

Belgian family physicians could have a pivotal role in preventing and guiding hospital admissions at the end of life, but this is not achieved, despite the relatively strong position of primary care in the Belgian health care system,<sup>22</sup> and the emphasis in Belgian end-of-life care policy on family physicians for providing and coordinating out-of-hospital palliative care.<sup>40</sup> Our results indicate that Belgian family physicians can experience several difficulties in preventing patients from going to hospital at the end of life, and therefore their ability to prevent such admissions might be limited.

During focus group discussions with family physicians (Chapter 4) it was found that family physicians in Belgium can differ in their competencies and attitudes towards end-of-life care and the prevention of end-of-life hospital admissions, in the sense that those who are more competent or have the right attitude, are more likely to prevent such admissions. They may be more likely to take responsibility for not sending their patient to hospital and to ensure support and care from their part, at all times. Moreover, in Chapter 8 it was shown that terminal hospital admissions were more likely to be considered potentially inappropriate by family physicians who had had training in palliative care at basic, postgraduate or post-academic physician level. Therefore, in order to optimally use family physicians' pivotal roles in preventing end-of-life hospital admissions, their competencies in

providing end-of-life care need to be further improved and their attitudes changed. Ideally this is done through adequate education and training in end-of-life care; either by ensuring such education in basic physician curricula or by stimulating further training.

Furthermore, we found that family physicians feel more competent and confident when supported by a multidisciplinary palliative home care team (Chapter 4). Stimulating family physicians to increase their use of such services and to further provide such readily accessible support and assistance to them, therefore, is also highly recommended and might lead to more patients dying at home or in the nursing home where they reside.

One particular barrier that family physicians experience in preventing end-of-life hospital admissions is their limited gatekeeper role towards the use of hospital services; it hinders their role as a care planner and diminishes the weight of their decisions in acute situations. During focus group discussions (Chapter 4) family physicians indicated that sometimes they lose sight of patients when they are in treatment in hospital, and then frequently need to plan care at the very end of their patient's life when hospital physicians feel they can no longer treat, i.e. cure, them. In our survey study (Chapter 7), concerning patients who died non-suddenly in a university hospital, only half of the family physicians indicated that they were involved in planning and decision-making in their patient's end-of-life trajectory. We have shown (Chapter 8) that when the terminal hospital admission was initiated by patients or their families, family physicians were more likely to consider the admission to be potentially inappropriate or potentially avoidable, and of those considered potentially avoidable, they indicated that one out of three could have been prevented by involving a family physician in the decision to admit. This might partially explain why countries where family physicians have a stronger gatekeeper role, e.g. the Netherlands or Denmark, have fewer patients hospitalized in the last three months of life,<sup>31;39;41</sup> or have a lower proportion of hospital deaths.<sup>3;35</sup>

In conclusion, considering the results of our studies, there are indications that family physicians in Belgium can have a pivotal role in preventing end-of-life hospital admissions, although it is not being used to its full extent. Moreover, it seems to be that in acute situations at the end of life there is a given number of patients and families in Belgium that do not turn to their family physicians – and therefore bypass them – and go directly to an acute hospital setting. This could suggest that there may be a preference or a need – or both – among patients and their families for an admission to an acute hospital setting at the end of a patient's life.



## REASONS AND JUSTIFICATIONS FOR END-OF-LIFE HOSPITAL ADMISSIONS

The acute hospital was not considered to be an adequate setting for end-of-life care and as a place of death, according to family physicians, nurses and family carers (Chapter 5). However, the vast majority of the terminal hospital admissions (86%) were considered to be appropriate according to family physicians (Chapter 8). It was shown that end-of-life hospital admissions were sometimes considered to be justified by family physicians and nurses in the event that patients and their families preferred such an admission (Chapter 6); or when the caring capacity of the care setting is insufficient and the acute hospital setting is considered to be a valid, or the only alternative. For the purpose of this section of the discussion, wanting to be admitted i.e. choosing an admission, is distinguished from needing to be admitted i.e. being in need of going somewhere else than the setting where the patient is currently residing, although it has to be noted that in reality these perceptions may coexist.

### *Justifications for end-of-life hospital admissions: preferring to be admitted*

It was found that according to family physicians, nurses and family carers, the acute hospital setting is sometimes perceived as a safe haven by patients and their families – a setting where they might prefer to go to and where they can be at ease (Chapter 5). Moreover, the results of our studies show that a hospital admission at the end of life is sometimes preferred by patients or families: where there is uncertainty that the patient is dying; when the patient prefers curative or life-prolonging treatment; when this setting has become a familiar setting to these patients; or when they perceive care to be better in this setting; and that it might be considered ‘justified’ or ‘appropriate’ in these situations.

The results of our studies show that sometimes it is possible that patients prefer to be admitted because patients, families or even health care providers do not know whether cure or life-prolonging is still possible or not. During focus group discussions with family physicians and nurses (Chapter 6) it was suggested that an admission to hospital in these cases was considered to be justified – that patients sometimes prefer to go to hospital, to be sure that ‘everything has been done’ and no other treatment is possible, and that this might be considered ‘justified’ i.e. appropriate. They considered that the patient would not be at ease, unless he/she is admitted to hospital, and therefore remaining at home or in the nursing home might not guarantee a good death. In our survey study among family physicians whose patients died in a university hospital (Chapter 7), it was found that 30% of the terminal hospital admissions were – according to family physicians – for diagnostic purposes, for further decision-making; and they were less likely to indicate that the admission was potentially avoidable i.e. medically unnecessary, in these instances (Chapter 8).

In our survey study among family physicians (Chapter 7), it was also found that almost one out of four terminal hospital admissions were for curative reasons or life-prolonging, although their deaths were not considered to be sudden or totally unexpected. Although this might be a post-hoc rationalisation from their part, this finding seems to be consistent with that of another study which assessed the proportion of palliative patients in 14 different hospitals throughout Belgium and found that 27% of the palliative population had a life-prolonging treatment according to the treating hospital physicians.<sup>42</sup> This indicates that for a given number of patients, death might not be sudden or totally unexpected, but some kind of hope to be cured or to prolong life remains.

Furthermore, it was found that patients who are aware that they are dying can sometimes choose to die in hospital; and perhaps the best example of this is one family carer in the interviews explaining that her husband had chosen to die in hospital with euthanasia, where he had been a patient for 30 years, rather than at home (Chapter 5). Patients – as some focus group participants explained – have sometimes been in a hospital or on a ward for a long time or have been there frequently. During that time they may have become more familiar with physicians, nurses, or other staff and with the hospital environment. Patients might therefore choose to die in this setting, although it has to be noted that situations where this would be the case may be very limited. It was found that in 6% of the terminal hospital admissions ‘the patient being able to die at his/her preferred place of death’ had played a role in the decision-making about that admission (Chapter 7). However, it also has to be noted that our study showed a much lower proportion of family physicians that were aware about their patients’ preferred place of death (25%), compared with the study of Meeussen and colleagues (46%) in the total population of patients who died non-suddenly, including those who died at home and in nursing homes.<sup>43</sup> In that study it was also found that the preferred place of death is particularly less often known by the family physician (and probably elicited or expressed) when someone died in hospital.

Another important finding (Chapter 5) was that according to family physicians, nurses and family caregivers, patients and families sometimes perceive care to be best in the acute hospital setting – or at least better than the setting where the patient is residing. Moreover, family physicians indicated (Chapter 7) that in almost half of the admissions, family members believing care to be better in hospital had played a role in the decision to admit the patient and in one third that the patient felt safer there. In Chapter 5, participants pointed out that whether care is actually better within the hospital setting or not, it is this perception that can be particularly persistent among patients and families.

On the other hand, these preferences for being admitted to hospital at the end of life – because of uncertainty about life expectancy; because of hope to prolong life or to cure; because it has become a familiar setting; or because they perceive care to be better there – might be considered to reflect a certain belief or attitude, or an intuition among patients and their families, that causes them to perceive the acute hospital setting as the right place to be in at the end of life. As a result, it might be suggested that such a desire to be admitted to hospital at the end of life is the result of “the ever-increasing medicalisation of society and related reluctance, both on part of health professionals and the wider public, to accept the limits of life-sustaining medical intervention” and the hospital offering “the possibility of, if not cure, temporary reprieve from death”, as Gott and colleagues have stated.<sup>44</sup> Moreover, in contemporary society, we are socialised into seeking medical treatment in response to a serious health event – even when death might be expected – and in these situations an easily-accessible setting, such as the hospital, might be regarded as a valid option;<sup>44;45</sup> which might partially explain the particularly high proportion of end-of-life hospital admissions considered as appropriate among the family physicians (Chapter 8).

We found (Chapter 7), that of those patients who died in the acute setting of a university hospital and whose death was not considered to be unexpected or sudden – according to family physicians – only 28% had used a specialised palliative care service (e.g. in-hospital palliative support team or a multidisciplinary palliative home care team). Moreover, family physicians were more likely to indicate the terminal hospital admission as potentially avoidable or potentially inappropriate when patients were admitted with an anticipated life expectancy of less than a few weeks and potentially inappropriate when patients died from cancer. This might indicate that for those patients, death might have been more expected and therefore hospital admissions at the end of life are more likely to be regarded as undesirable. On the other hand, this also indicates that for most patients, death might have been less expected – although it was non-sudden – and a palliative care approach might have been lacking, and therefore the admissions were more likely to be considered appropriate according to the family physicians.

It was found that according to family physicians and nurses an end-of-life hospital admission was considered justified when the patient preferred such an admission, although they also stressed the importance of the patient being adequately informed (Chapter 6). Moreover, during focus groups, family physicians indicated that they felt it was their role to (re)plan care continuously throughout the dying phase, based on a two-way process of providing information to the patient about their possibilities and options associated with end-of-life care and taking their preferences into account, and that this might prevent future end-of-life hospital admissions (Chapter 4). Furthermore, in Chapter 8, family physicians also indicated that most potentially avoidable admissions, could have

been prevented by adequately informing patients about their limited life expectancy and the possibilities of palliative care. Therefore, it is suggested that more adequate advance care planning and pro-active, timely discussions with the patient about a palliative approach is needed to reduce the number of terminal hospital admissions and hospital deaths.<sup>18;19;46-48</sup> This is further discussed in the 'Challenges for practice' section.

### ***Justifications for end-of-life hospital admissions: needing to be admitted***

According to family physicians, nurses and family carers (Chapter 5), the acute hospital setting is sometimes also considered to be a last resort, a setting where patients need to go to because there is no alternative. Moreover, during focus group discussions among family physicians and nurses (Chapter 6) there was a consensus that patients should be able to receive adequate care continuously, and if this were not possible at the setting where the patient is was residing, an end-of-life hospital admission was considered justified, i.e. appropriate. In our survey study among family physicians (Chapter 7), it was found that an inadequate care setting had played a role in the decision to admit the patient to hospital in 85% of the terminal hospital admissions. Therefore, these findings may suggest that for a large number of end-of-life hospital admissions, the preference or reason for being admitted to hospital might indeed be pragmatic in nature.<sup>49</sup> Moreover, this might support the idea that there is an important difference between a preference for not dying in hospital – in ideal circumstances – and such a preference changing in favour of dying in hospital as death approaches.<sup>50;51</sup>

In a study of Gott and colleagues it was found that an admission due to a family caregiver not being able to cope was considered inappropriate – as this contradicted generalist palliative care providers' perspectives of a good death.<sup>44</sup> However, in Chapter 6 it was found that an inadequate care setting was considered to be a justified reason for an end-of-life hospital admission – being the best option for the patient, considering the circumstances, i.e. an appropriate admission, as we explored the perspectives of family physicians and nurses from different care settings. This might in particular be due to the difference between both studies in how 'appropriateness' was defined; as a hospital death in the study of Gott and colleagues may not be a good death from their participants' point of view, it might still be considered the best option considering the circumstances, as our participants indicated. To enable future research to accumulate evidence about the appropriateness of end-of-life hospital admissions, we suggest that consensus about the definition of this concept is needed, as well as what is meant by 'avoidability' and the differences between these concepts.

Participants in Chapter 5 also indicated that patients or their families sometimes fear death or dying because they are no longer familiar with 'death and dying'; that death has become a taboo and

perhaps this might be one of the reasons why they fear death, and prefer to go to hospital. This seems to support the idea that the institutionalisation of death is a self-perpetuating process; as fewer people die at home, people might increasingly be unprepared for providing proper end-of-life care and as a result, patients are more frequently admitted to hospital, or another care setting such as a nursing home, at the end of life.<sup>44;52</sup> Given the reduced availability of family carers and the growing proportion of frail elderly patients in contemporary society,<sup>53;54</sup> this might be an important issue to consider.

Palliative care units in Belgium have predominantly been created to be able to care for patients with a limited life expectancy, for whom an admission to the acute hospital setting is considered unnecessary, and for whom care at the setting where the patient is residing is insufficient.<sup>23</sup> Therefore, it was most surprising that more than half of the terminal hospital admissions to the acute hospital setting (i.e. excluding the palliative care unit) of a university hospital in our study were for palliative reasons, according to family physicians (Chapter 7). Moreover, an additional analysis shows that in 91% of the terminal hospital admissions for which the family physician indicated that the patient needed to be admitted for a palliative reason, they also indicated that there was an inadequate care setting that had played a role in the decision to admit the patient to hospital ( $p=0.013$ ). As was shown, family physicians were more likely to indicate that an inadequate care setting had played a role in the decision to admit the patient to hospital, when the patient was admitted with an anticipated life expectancy of less than several weeks. Ideally these patients would have been cared for in a palliative care unit – as was also suggested by nurses and family physicians during focus group discussions (Chapter 6). However most of the time the number of palliative care unit beds in Belgium – 379 beds for the whole country – is insufficient.<sup>42</sup> Therefore, it might be suggested that the expansion of such initiatives is needed, i.e. more palliative care unit beds need to be provided or other initiatives should be developed e.g. hospices, to reduce the number of hospital deaths of those people for whom the caring capacity of the care setting is insufficient in ensuring proper end-of-life care.

Moreover, where the caring capacity of the care setting is insufficient in providing proper end-of-life care, palliative day care centres may also be considered as valuable alternatives.<sup>23</sup> They have the potential for avoiding hospital admission, whereas the family physician remains to have a pivotal role in coordinating palliative care and informal caregivers are temporary exempted from their duties to provide care continuously.<sup>55</sup> Their potential for avoiding end-of-life hospital admissions needs to be further explored.<sup>55</sup>

The results of our study seem to indicate that end-of-life care provision in Belgium is rather hospital-centric. Moreover, this seems to be in line with studies indicating that Belgium has a higher proportion of cancer patients dying in hospital,<sup>2;3</sup> a higher proportion of cancer patients being admitted to hospital in the last 30 days of life when compared to their counterparts in the Netherlands, Italy or Spain,<sup>56</sup> and a higher proportion of hospital-based specialist palliative care use in patients who died non-suddenly than their counterparts in these countries.<sup>57</sup>

Consequently, it might be concluded that many end-of-life hospital admissions in Belgium occur because of an inadequacy of the care setting where the patient is residing, or because the acute hospital setting is perceived as a valid option or the only alternative in these circumstances, i.e. the admission might be preferred. And as previously indicated, at the same time, the family physician can be bypassed in these circumstances. Therefore, it might be questioned whether these end-of-life hospital admissions in Belgium could be avoided – and the proportion of hospital deaths reduced accordingly.

### **AVOIDABILITY OF END-OF-LIFE HOSPITAL ADMISSIONS**

In our survey among family physicians whose patients had died in the acute hospital setting of a university hospital (Chapter 8), it was found that they considered 14% of these terminal hospital admissions to be potentially avoidable. This low proportion of potentially avoidable terminal hospital admissions was somewhat surprising, and needs some clarification. First, we would like to refer to the ‘methodological considerations’ section and to recall that there may have been a post-hoc rationalisation for the terminal hospital admissions by family physicians, and they may have provided answers that could be considered good medical practice, in particular because it concerned a hospital death in a university hospital setting, which might partially explain the particularly low proportion of potentially avoidable terminal hospital admissions.

Secondly, it has to be noted that the proportion of potentially avoidable terminal hospital admissions found in this study differed from the proportion found in similar studies in England, New Zealand and the Netherlands.<sup>25;58;59</sup> Given that England has a similar proportion of hospital deaths (58%) when compared to Belgium (52%),<sup>3;35</sup> one might assume a similar proportion of potentially avoidable end-of-life hospital admissions were to be found in England. A study of Gott and colleagues found a substantially lower proportion (7%),<sup>58</sup> although the methodology differed: admissions of patients with palliative care needs were assessed by palliative medicine consultants (hospital specialists), instead of admissions prior to hospital death as assessed by family physicians, as was done in our

study. As the proportion of hospital deaths is much lower in New Zealand (34%),<sup>35</sup> one might assume a lower proportion of end-of-life hospital admissions to be potentially avoidable. Robinson and colleagues, however, found a higher proportion (22%) of hospital admissions among patients with palliative care needs to be potentially avoidable.<sup>59</sup> In this study these hospital admissions were assessed by two palliative medicine physicians and admissions to the intensive care unit were excluded.<sup>59</sup> Similarly, one might assume a lower proportion of end-of-life hospital admissions to be avoidable in the Netherlands, given the proportion of hospital deaths is substantially lower (34%).<sup>35</sup> However, Dutch family physicians considered almost 24% of their last hospital admission in the last three months of their patient's life to be avoidable.<sup>25</sup> It has to be noted that it remains difficult to draw cross-national conclusions, considering that none of these studies allow for generalizability to national figures.

On the other hand – although it might be considered premature to do so – it could be concluded that these comparisons seem to indicate that the perception of what is avoidable could be attributed to certain beliefs or attitudes that exist within a given health care system. In the sense that patients, families and even health care professionals in the Netherlands or New Zealand might be less likely to perceive the acute hospital setting to be a safe haven at the end of life and might be less likely to perceive a necessity for patients to be admitted to hospital at the end of life. Moreover, this might partially explain the higher proportions of potentially avoidable end-of-life hospital admissions that were found in these countries,<sup>25;59</sup> and the lower proportion of hospital deaths at the same time.<sup>35</sup> Furthermore, it could be hypothesised that such differences in perceptions might also be the result of differences within a health care system (e.g. the provision of end-of-life care). This would mean that appropriate improvements within the health care system in Belgium could bring about different attitudes and beliefs towards the appropriateness or avoidability of end-of-life hospital admissions among patients, families and health care professionals. Hence, fewer patients would be admitted at the end of life, leading to a reduction in the proportion of hospital deaths in Belgium. However, again it has to be noted that such conclusions go beyond the scope of our studies, and therefore we suggest that future research should elucidate whether these differences in proportions of potentially avoidable end-of-life hospital admissions reflect differences in the health care system (e.g. the provision of end-of-life care) or reflect differences in health behaviours as a result of variations in beliefs and attitudes, or a combination of both.

On the other hand, some people may also question whether such changes within the Belgian health care system, to reduce the number of end-of-life hospital admissions, are actually needed. The acute hospital setting consistently remains a frequent place of death in many high-income countries,<sup>35;37</sup> and the results of our study show that it will probably continue to be a meaningful end-of-life care

setting in Belgium. Therefore it is also recommended that end-of-life care research and policy should not exclusively focus on out-of-hospital deaths and exclude improving end-of-life care provision within the acute hospital setting. We do, however, recommend that research and more public debate is needed about which setting would be most ideal or most suitable for patients to die in.

In conclusion, the acute hospital in Belgium is not considered to be an adequate setting for end-of-life care and as place of death. When comparing the proportion of hospital deaths among older persons who died from a dementia-related disease with other countries, this proportion in Belgium seems to be relatively low. However, when compared to countries such as the Netherlands, it could be suggested that this proportion might even be lowered. However, for other chronic illnesses, such as cancer, the proportion dying in hospital is, then again, relatively high compared with a number of countries and end-of-life care provision in Belgium might be rather hospital-centric. Furthermore, in some situations an admission to the acute hospital setting is considered appropriate or justified, as patients or families might perceive this setting as a safe haven and prefer to be admitted, or they might need to be admitted because the care setting where they are residing is perceived to be inadequate. In these situations, family physicians are often bypassed and their ability to prevent such end-of-life hospital admissions might be limited, although they could have a pivotal role in achieving this. In part, this might explain the relatively low proportion of terminal hospital admissions that family physicians perceived to be potentially avoidable (14%) or potentially inappropriate (14%). In other words, this might mean that within the current health care system in Belgium they perceive a large number of terminal hospital admissions to be appropriate and unavoidable. Appropriate improvements within the Belgian health care system might lead to different perceptions about the appropriateness or avoidability of end-of-life hospital admissions among patients, families and health care providers, which in turn could cause a reduction in the number of terminal hospital admissions. Important strategies and improvements within the health care system in Belgium that – according to the results of our studies – could avoid end-of-life hospital admissions and other challenges for practice, policy and research are discussed in subsequent paragraphs.



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## CHALLENGES FOR PRACTICE, POLICY AND FUTURE RESEARCH

Our results suggest a number of challenges for practice, policy and future research. For practice, our results show that more attention needs to be paid among health care providers to timely communication about end-of-life care and that more optimal support to caregivers in the home care setting needs to be guaranteed, as this might reduce the number of end-of-life hospital admissions. However, we also recommend that more attention is paid to the quality of end-of-life care within the acute hospital setting in Belgium. For policy we recommend the strengthening of family physicians' gatekeeper role, stimulation of their use of supportive services in end-of-life care and improvement of their competencies in end-of-life care through basic and post-graduate training. We also suggest that policy makers need to reflect on whether alternatives to the acute hospital setting, such as palliative care units, need to be expanded, or other initiatives – such as hospices – need to be developed. Challenges for future research are also provided: to explore differences in perceptions regarding the proportion of potentially inappropriate or potentially avoidable end-of-life hospital admissions among physicians, patients and family caregivers; to explore patients' perceptions regarding the adequacy of the acute hospital as a setting for end-of-life care and as a place of death; to explore intercultural differences regarding the adequacy of the acute hospital setting as a place of death; to explore cross-national differences regarding the avoidability of end-of-life hospital admissions.

### CHALLENGES FOR PRACTICE

#### *Focus more attention on timely communication about end-of-life care*

During focus group discussions, family physicians (Chapter 4) indicated that adequate care planning throughout the patient's end-of-life trajectory could prevent end-of-life hospital admissions, and it was their opinion that this is most adequately done in a two-way process of providing information to the patient and taking their preferences into account. Furthermore, in Chapter 8 family physicians reported that a majority of potentially avoidable terminal hospital admissions could have been prevented by timely communication with the patient about the patient's limited life expectancy and the possibilities of palliative care. Therefore, one particular challenge that remains important is to focus more attention on timely communication about end-of-life care.

The development of the Flemish guideline for family physicians for advance care planning as published in Pallialine,<sup>60</sup> or studies exploring the barriers and facilitators in initiating advance care planning,<sup>18;61</sup> therefore seem to be appropriate initiatives and are highly recommended. Moreover,

research has shown that family physicians sometimes fail to pro-actively initiate discussions about end-of-life care or wait for patients to do so, while patients tend to do the same.<sup>19;61</sup> Also, family physicians tend to admit a patient to hospital when there is uncertainty about whether the patient is dying or not (Chapter 4). Therefore, it is suggested that tools, guidelines or assessment methods that enable family physicians to identify patients for whom there would be little benefit in being admitted to hospital are needed, or more frequently need to be used as a guideline to initiate end-of-life care discussions with patients and their families.<sup>62-64</sup> This might be important to reduce the number of end-of-life hospital admissions.<sup>65</sup> Moreover, considering that patients are more likely to die at their preferred place of death when their family physician is aware of their preference,<sup>43</sup> it is suggested that such a preference more routinely needs to be assessed, and that such end-of-life care discussions with patients might be an ideal opportunity to do so.<sup>43;66-68</sup> Such timely and adequate end-of-life care discussions with patients and families are considered important for reducing the number of end-of-life hospital admissions.<sup>47;48</sup>

### ***Guarantee optimal support for caregivers in the home care setting***

Family physicians and nurses from different care settings (Chapter 6) considered the caring capacity of the home care setting to be different from that of nursing homes. According to the participants, caring for a dying patient at home can be particularly burdensome and when the burden becomes too high, an end-of-life hospital admission was considered justified. According to family physicians, in 85% of the terminal hospital admissions (Chapter 7) there was an inadequate care setting that had played a role in the decision to admit the patient to hospital and in the vast majority (93%) of the terminal hospital admissions, the patient was residing at home. Additionally, it was found that most family physicians indicated that providing better support to family caregivers could have prevented potentially avoidable terminal hospital admissions (Chapter 8). Therefore, to reduce the number of end-of-life hospital admissions, one major challenge remains – to guarantee optimal support in the home care setting.

In Belgium several measures have already been developed to support family caregivers and to facilitate palliative and end-of-life care to take place in the home setting, such as the palliative status, the palliative lump sum ('forfait') and multidisciplinary mobile home care teams.<sup>23</sup> However, considering that family physicians indicated (Chapter 7) that in only 28% of terminal hospital admissions the patient had used a specialised palliative care service e.g. hospital-based palliative support team or multidisciplinary palliative home care team, the uptake of these measures might be questioned. In a study of the Belgian sickness funds ('Intermutualistisch Agentschap') it was found that among cancer patients who had cancer between 2006 and 2008 and died before 2010, only 18% had used a multidisciplinary palliative home care team.<sup>69</sup> Among those who had had a hospital

admission in the last month of life, this was only 11%; whereas those who had used such a multidisciplinary palliative home care team were less likely to have been admitted to the acute hospital setting in the last month of life.<sup>69</sup> Moreover, we showed that according to family physicians (Chapter 7), most of the terminal hospital admissions were for palliative reasons, which might be in line with other studies showing that end-of-life care in Belgium is rather hospital-centric.<sup>2;56;57</sup> Therefore, it is recommended that the use of supportive measures for home-based end-of-life care needs to be further encouraged, as they might reduce the number of end-of-life hospital admissions.<sup>70;71</sup>

An inadequate care setting was more likely to be reported by family physicians as an aspect that influenced the decision-making about the terminal hospital admission when the admission was during weekends (Chapter 7). During focus group discussions (Chapter 4), they also indicated that supporting patients by being available at all times might prevent them from going to hospital at the end of life, although this was hard for them to achieve, particularly during weekends. Therefore, it is recommended that it is particularly during the weekends that the home care setting more adequately needs to be supported and that either family physicians need to be stimulated to do so, or that other health care providers should be stimulated to take over from family physicians when they are unable to do so. Initiatives such as respite care, palliative day care centres, or rapid response palliative care services, ensuring availability 24 hours a day, seven days a week, are recommended to reduce the number of end-of-life hospital admissions.<sup>23;55;72-77</sup>

Moreover, given the reduced availability of family carers and the growing proportion of frail elderly patients in contemporary society,<sup>53;54</sup> these recommendations might be important to consider.

### ***Improve end-of-life care provision in the acute hospital setting***

It was found that family physicians, nurses and family carers in our qualitative study considered the acute hospital setting to be inadequate for terminally ill patients (Chapter 5). However, the results of our studies also suggest that it will likely remain a frequent place of death and a meaningful end-of-life care setting in Belgium. Given family physicians' limited gatekeeper role to hospital services, the acute hospital setting in Belgium probably will continue to be an easily accessible setting and will sometimes remain to be perceived as a safe haven by patients and families. Therefore, one persisting major challenge is to ensure proper end-of-life care within the acute hospital setting for those patients that prefer to die there or are unable to die at the setting where they are residing.

In particular, the results indicate that there is still some work left to do in challenging the predominant discourse and culture of cure i.e. 'saving' lives, in the acute hospital setting, which is in line with previous research.<sup>78-81</sup> Changing such a predominant culture of cure into one that is more

sensitive to end-of-life care matters could be difficult, although it remains recommended, considering many patients in Belgium die in hospitals.<sup>37</sup> One part of the solution might be the integration of end-of-life care training into nurse and physician curricula.<sup>42;79</sup>

<sup>42;79</sup> Moreover, one particular item that needs to be considered in such trainings might be – as our results have suggested – communication skills in end-of-life care among hospital health care professionals. This was already suggested by Glaser & Strauss in 1966 in their influential qualitative research about dying in the hospital and,<sup>82</sup> hence, suggests that this is a persistent problem and further improvements in this regard may still be needed.<sup>81;83;84</sup>

As it is suggested that the acute hospital setting needs to be improved in terms of end-of-life care provision, initiatives such as the development of the Care Programme for the Last Days of Life in Belgium are highly encouraged.<sup>85</sup> This programme has been developed to improve the quality of end-of-life care in acute geriatric hospital wards and provides a comprehensive template of evidence-based multidisciplinary care for the last days and hours of life. Furthermore, given that only 17% of those in our study sample that died non-suddenly (Chapter 8) did so in a geriatric ward, it is suggested that such initiatives also need to be expanded to other wards, such as oncology or internal medicine.

It was suggested by several participants in focus group discussions among family physicians and nurses and interviews with family carers (Chapter 5), that in several wards or hospitals there already has been a shift towards better end-of-life care; which could indicate that in Belgium – limited as it may be – we are already on the right track. This points to the need for quality indicators about the provision of end-of-life care, that could enable health care providers to improve care where needed, should this be appropriate.<sup>81;86;87</sup>

## **CHALLENGES FOR POLICY**

### ***Improve the family physician's gatekeeping role regarding access to hospital services***

Family physicians in Belgium have a pivotal role in providing and coordinating out-of-hospital end-of-life care, although our studies also indicate that their limited gatekeeper role regarding access to hospital services impedes their ability to adequately prevent patients from going to hospital. Enhancing this gatekeeper role might be beneficial, as this could mean that they would be more involved during decision-making about admitting a patient to hospital at the end of life; as this might cause their opinion to carry more weight during such decision-making; and as this also might mean that they would be more (or earlier) involved in the patient's end-of-life trajectory and therefore

would be better able to plan adequate care that could prevent patients from going to hospital in the future (Chapter 4). Recently, four Flemish Family Physician professors pleaded for a more strengthened gatekeeper role for family physicians,<sup>88</sup> which shows that indeed this might be an important aspect to consider for Belgian health care policy. However, it has to be noted that adopting a system by which the family physician is consulted for every potential hospital admission would substantially increase Belgian family physicians' workload and therefore it could be questioned whether this would be feasible; further public debate regarding such a structural change in Belgium is recommended.

When combined with changing their attitudes and improving their competencies regarding end-of-life care provision and stimulating the use of supportive measures for family physicians in providing end-of-life care, a strengthened gatekeeper's role might have substantial effect on their ability to adequately prevent end-of-life hospital admissions.

#### ***Improve family physicians' competencies in providing end-of-life care***

Our results show that family physicians in Belgium can differ in their competencies and attitudes in end-of-life care and towards the prevention of end-of-life hospital admissions, in the sense that those who are more competent or have the right attitude are more likely to prevent such admissions. They may be more likely to take responsibility for not sending their patient to hospital and to ensure support and care on their part, at all times. Moreover, in the survey study (Chapter 8) it was indicated that terminal hospital admissions were more likely to be considered potentially inappropriate by family physicians who have had training in palliative care at basic, postgraduate or post-academic physician level. Therefore, to reduce the number of end-of-life hospital admissions, their competencies in providing end-of-life care need to be improved. Ideally this is done through adequate end-of-life care training; either by ensuring such training in basic physician curricula or by stimulating further postgraduate training.

One particular item that can be addressed in such training is communication about end-of-life care, and advance care planning in particular. More attention to improving skills, attitudes and knowledge concerning advance care planning and end-of-life care, in family practice curricula in particular, therefore, is highly recommended.<sup>18</sup>

#### ***Stimulate the use of supportive services in end-of-life care***

As the results of our studies show, family physicians face many different roles and difficulties in preventing and guiding hospital admissions at the end of life. During focus group discussions (Chapter 4) some indicated that they felt more competent and confident in providing end-of-life care when they were supported by a multidisciplinary palliative home care team. Therefore, it is

recommended that the use of such supportive services in their provision of end-of-life care is encouraged. This could help family physicians to acquire knowledge, practical help, and possibly emotional support in caring for their patients at home, and consequently to enable more of their patients to die there.<sup>89</sup>

In Belgium, Palliative day care centres were developed, in part, to avoid hospital admissions; as it may be a valuable alternative when the caring capacity of the care setting is insufficient in providing adequate end-of-life care.<sup>23</sup> However, as palliative day care centres are relatively unknown in Belgium, further awareness to use such services is highly recommended and could potentially lead to a reduction in end-of-life hospital admissions.<sup>55</sup>

### ***Increase the availability of out-of-hospital alternatives***

Palliative care units in Belgium have predominantly been created to be able to care for patients with a limited life expectancy for whom an admission to the acute hospital setting is considered unnecessary, and for whom care at the setting where the patient is residing is insufficient.<sup>23</sup> However, the results of our studies have shown that according to family physicians many patients are admitted to the acute hospital at the end of life in order to receive palliative care or treatments and that an inadequate care setting is more likely to play an important role in the decision to admit these patients. Ideally these patients would have been cared for in the palliative care unit, although the total number of such palliative care unit beds in Belgium (379 for the whole country) is insufficient.<sup>42</sup> The number of palliative care beds in Belgium therefore needs to be expanded, to be able to ensure proper end-of-life care for those patients for whom end-of-life care at the setting where they are residing is insufficient. It is also recommended that the development of other initiatives needs to be explored in Belgium, such as hospices.<sup>90</sup> As palliative care units usually are situated near or on the hospital campus, this could cause people to believe that the hospital is the best setting to go to at the end of life, which could lead to more end-of-life hospital admissions. Alternatives need to be available for patients for whom a good death is not possible at the setting where they are residing, and providing another valid option for patients and families next to the acute hospital setting might therefore substantially reduce the number of end-of-life hospital admissions. We suggest that Belgian policy needs to reflect on whether it would be feasible to expand existing initiatives (palliative care units) or new initiatives (such as hospices).

## CHALLENGES FOR RESEARCH

### *Explore differences in perceptions regarding the proportion of potentially inappropriate or potentially avoidable end-of-life hospital admissions*

We explored family physicians' perspectives regarding the proportion of potentially inappropriate or potentially avoidable terminal hospital admissions. However, to increase the generalizability of our findings we recommend that other perspectives are also examined, and that differences between them are explored among physicians, nurses, patients and family caregivers. For example, family physicians' assessments on the avoidability or appropriateness of a terminal hospital admission might be different from those of families or hospital physicians, or family caregivers. Taking such differences into account might bring about a more critical understanding of this concept and how it is perceived in contemporary society. Moreover, we advocate for such studies to also use a mixed method approach in studying such differences in perceptions and to focus on exploring why such differences in perceptions exist, should they occur.

### *Explore patients' perceptions regarding the adequacy of the acute hospital as a setting for end-of-life care and as a place of death*

We explored the perceptions of family physicians, nurses from different care settings and family caregivers whose relative had died in the acute hospital, regarding the acute hospital as a setting for end-of-life care and as a place of death. Moreover, many studies have explored patients' preferences regarding the setting in which they would want to be cared for at the end of life, or where they would want to die.<sup>49-51;66;91-98</sup> However, little is known about how patients perceive the acute hospital setting as a place of death or as a setting for end-of-life care. Therefore, we suggest that more research in this regard is needed and longitudinal studies that focus on changes in patients' perceptions regarding the appropriateness of the acute hospital as a setting for end-of-life care and as a place of death are recommended. Such studies could elicit patients' preferences and needs regarding proper end-of-life care provision in the acute hospital setting, hence enabling further improvements in provision that adequately addresses their needs.

### *Explore intercultural differences regarding the adequacy of the acute hospital setting as a place of death*

In Belgium and in metropolitan regions in particular, there is a diversity of cultures. Health care professionals will increasingly care for patients from cultural backgrounds other than their own and differences in beliefs and values might be of particular importance at the end of life.<sup>99-101</sup>

Little is known about differences between such cultures regarding their view on what is to be considered an appropriate place of death and why. Exploring whether, how and why such cultural differences exist regarding the appropriateness of certain places of death could lead to a better understanding of why patients prefer or would not prefer to go to hospital at the end of life in contemporary society. And most importantly, this could bring about an end-of-life care practice that is more sensitive to such different values and beliefs.

***Research on the differences between countries regarding avoidability of terminal hospital admissions.***

Our studies in Chapter 7 and 8 were more explorative in nature. Similar studies regarding the avoidability of end-of-life hospital admissions on a larger scale are warranted, as this could enable research that examines differences between geographical entities, such as countries. Cross-national studies on the avoidability of end-of-life hospital admissions could explain why differences in the proportions of hospital deaths exist between different countries,<sup>35</sup> and could highlight important system factors that could reduce the proportion of hospital deaths.

***Research on hospital physicians' perspectives regarding their role in providing end-of-life care and enabling patients to die out-of-hospital***

Little is known about how hospital physicians perceive their role in providing end-of-life care in the acute hospital setting. Either they need to be able to cope with their role in providing end-of-life care, as patients will continue to die in hospital wards, or hospital physicians will need to assist in facilitating home deaths or nursing home deaths – for example by making sure that patients know that further curative treatment or life-prolongation would be futile. Furthermore, as differences might exist between hospital disciplines regarding such perceptions, we suggest that such differences need to be explored, as do questions as to why they exist.



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## Samenvatting van de Belangrijkste Bevindingen

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## ACHTERGROND

De manier waarop we sterven is sterk veranderd sinds de tweede helft van de 19<sup>de</sup> eeuw. Als gevolg van epidemiologische en demografische trends, de ontwikkeling van de medische wetenschap en de verminderde beschikbaarheid van informele zorg binnen de familie, is de acute ziekenhuissetting een prominente plaats van overlijden geworden. In 2008 stierven ongeveer de helft van alle Belgen in een ziekenhuissetting; waarbij België geen uitzondering is tussen de andere landen met hoog inkomen. Reeds van het begin werd de gepastheid van dergelijke ziekenhuisoverlijdens in vraag gesteld.

Dergelijke ziekenhuisoverlijdens werden dan bekritiseerd door sociale wetenschappers als zijnde een ‘medicalisering van de sterfte’ of een ‘institutionalisering van de dood’. Door een toenemende ongerustheid bij zorgverleners ontwikkelde zich de palliatieve zorg, met een visie waarbij ‘de goede dood’ moeilijk overeen te stemmen was met een ziekenhuisoverlijden. Bijgevolg, was er dus een toegenomen interesse naar ‘plaats van overlijden’.

Onderzoek heeft inmiddels aangetoond dat de thuissetting de meest gewenste plaats van overlijden is en dat een meerderheid steeds verkiest om buiten het ziekenhuis te overlijden. Levensindesorg in de ziekenhuissetting is vaak suboptimaal, bijvoorbeeld door strikte regulering of door de dominante cultuur van genezing en levensverlenging die er heerst. Het is dan ook niet verwonderlijk dat een beleid er vaak op gericht is om zo veel mogelijk thuisoverlijdens – of overlijdens in een vertrouwde omgeving – mogelijk te maken.

Om deze – consistent hoge – proportie ziekenhuisoverlijdens te kunnen reduceren groeide er een interesse naar het verminderen van ziekenhuisopnames aan het levenseinde. Echter, dit blijkt niet zo voor de hand liggend te zijn: niet elke ziekenhuisopname aan het levenseinde is ongewenst of ongepast – de patiënt kan dergelijke opname verkiezen – en in een aantal gevallen is een opname mogelijks ook onvermijdbaar. Deze verhandeling is er dan op gericht meer inzichten te verwerven in de redenen, de gepastheid en de vermijdbaarheid van dergelijke ziekenhuisopnames aan het levenseinde.

Palliatieve zorgverlening in België berust voornamelijk op de gewoonlijke zorgverleners (vb. huisartsen, verpleegkundigen en mantelzorg), waarbij deze kunnen worden bijgestaan door zorgverleners gespecialiseerd in palliatieve zorg. Vooral huisartsen hebben een prominente rol in het coördineren en verlenen van palliatieve zorg buiten het ziekenhuis. Het is om die redenen dat deze verhandeling de nodige aandacht schenkt aan de perspectieven van deze gewoonlijke zorgverleners – en deze van de huisarts in het bijzonder.

Het aandeel oudere personen met een dementie-gerelateerde aandoening stijgt jaarlijks, wereldwijd. Dergelijke patiënten worden vaak opgenomen in het ziekenhuis aan het levenseinde, veelal vanwege een complicatie (vb. longontsteking, heupbreuk), terwijl dit nefast kan zijn voor hun levenskwaliteit. De plaats van overlijden – meer specifiek de proportie ziekenhuisoverlijdens – binnen deze patiëntengroep wordt ook om die redenen behandeld in dit proefschrift.

Op die manier beoogt deze verhandeling meer inzichten te geven in de complexiteit van de redenen en omstandigheden die een ziekenhuisopname aan het levenseinde voorgaan en een beter begrip te vormen van de gepastheid en de vermijdbaarheid van dergelijke ziekenhuisopnames, zodoende bij te kunnen dragen aan het debat omtrent ‘plaats van overlijden’ en implicaties voor beleid en praktijk te kunnen formuleren, met het oog op een verdere optimalisatie van levenseindezorg.

## **ONDERZOEKSDOELEN**

Binnen deze verhandeling onderscheiden we drie onderzoeksdoelen, elk met eigen onderzoeksvragen:

Onderzoeksdoel 1: Onderzoeken van de proportie ziekenhuisoverlijdens in België bij ouderen met een dementie-gerelateerde aandoening.

- a) Hoe varieert de proportie ziekenhuisoverlijdens bij oudere personen die overleden zijn aan een dementie-gerelateerde aandoening, tussen België en 13 andere Europese en niet-Europese landen; in welke mate zijn ziekenhuisoverlijdens geassocieerd met sociodemografische factoren, sociale steun, residentiële factoren en factoren gerelateerd aan het gezondheidszorgsysteem; en wat is de variatie tussen deze landen in het risico op een ziekenhuisoverlijden bij deze populatie wanneer gecontroleerd wordt voor deze factoren?
- b) Hebben personen overleden met dementie en pneumonie meer kans om in een ziekenhuis te overlijden dan deze zonder pneumonie? Wat is de incidentie van ziekenhuisoverlijdens bij personen overleden met dementie en een pneumonie en welke factoren zijn geassocieerd met dergelijke ziekenhuisoverlijdens?

Onderzoeksdoel 2: Verkennen van de perspectieven van huisartsen ten aanzien van hun rol in het vermijden en begeleiden van ziekenhuisopnames aan het levenseinde.

- c) Hoe percipiëren huisartsen hun rol ten aanzien van het vermijden en begeleiden van ziekenhuisopnames aan het levenseinde en welke moeilijkheden ervaren zij binnen hierbij?

Onderzoeksdoel 3: Inzichten verwerven in de redenen waarom patiënten worden opgenomen in het ziekenhuis aan het levenseinde, en de gepastheid en vermijdbaarheid van degelijke opnames.

- d) Hoe percipiëren huisartsen, verpleegkundigen en mantelzorgers de acute ziekenhuissetting als plaats voor levenseindezorg en als plaats van overlijden?
- e) In welke omstandigheden beschouwen huisartsen en verpleegkundigen een ziekenhuisopname aan het levenseinde als gerechtvaardigd?
- f) Welke redenen en aspecten ten aanzien van de wensen van de patiënt, preferenties van de familie en de zorgomgeving beschouwen huisartsen een belangrijke rol te hebben gespeeld in de terminale ziekenhuisopname van hun patiënt en in welke mate zijn deze redenen en aspecten gerelateerd aan karakteristieken van de patiënt, van de zorg die de patiënt kreeg voor de opname en van de omstandigheden van die opname?
- g) Welke proportie terminale ziekenhuisopnames beschouwen huisartsen van hun patiënten als ‘potentieel gepast’ of ‘potentieel vermijdbaar’; welke factoren gerelateerd aan de patiënt, de huisarts en de opname zijn geassocieerd met de ongepastheid of vermijdbaarheid van deze terminale ziekenhuisopnames en welke interventies zouden deze potentieel vermijdbare ziekenhuisopnames kunnen vermeden hebben, volgens deze huisartsen?

## **METHODES**

Om tegemoet te komen aan deze onderzoeksdoelen werd er gebruik gemaakt van data verzameld aan de hand van overlijdenscertificaten en een mixed method benadering, waarbij focusgroepen en interviews werden gecombineerd met vragenlijsten.

### **ANALYSE VAN OVERLIJDENSCERTIFICATEN**

Voor het eerste onderzoeksdoel werd gebruik gemaakt van data verzameld aan de hand van de overlijdenscertificaten van alle overlijdens in België in 2008 en een gelijkaardige dataverzameling van 13 andere landen: Canada (zonder Québec), Tsjechië, Engeland, Frankrijk, Hongarije, Italië, Mexico,

Nederland, Nieuw-Zeeland, Spanje (Andalusië, 2010), Zuid-Korea, de Verenigde Staten van Amerika (2007) en Wales.

### **KWALITATIEF ONDERZOEK: FOCUSGROEPEN EN INTERVIEWS**

Om tegemoet te komen aan het tweede en derde onderzoeksdoel werd er gebruik gemaakt van kwalitatieve onderzoeksmethoden: er werden 5 focusgroepen georganiseerd om de perspectieven van huisartsen te verkennen (39 huisartsen in totaal), voornamelijk gerekruteerd aan de hand van LOK-groepen; in 3 focusgroepen exploreerden we de perspectieven van verpleegkundigen uit de thuiszorg, woon-en-zorg centra en de ziekenhuissetting (23 verpleegkundigen in totaal) en er werden 17 semi-gestructureerde interviews met mantelzorgers afgenomen, wiens naasten overleden zijn in een acute ziekenhuissetting. Dataverzameling en –analyse gebeurden aan de hand van een constant-comparatieve methode; waarbij gebruik werd gemaakt van een onderzoeksteam (5 gezondheidssociologen, waaronder een verpleegkundige en een huisarts), om zo data-triangulatie te kunnen bevorderen.

### **VRAGENLIJSTEN BIJ HUISARTSEN**

Voor het derde onderzoeksdoel werd een cross-sectioneel vragenlijstenonderzoek gedaan bij huisartsen, wiens patiënten overleden waren in de acute ziekenhuissetting van een universitair ziekenhuis in België, tussen januari en augustus 2014. Deze vragenlijst werd ontwikkeld op basis van gelijkaardige onderzoeken en de resultaten van de kwalitatieve studies van deze verhandeling.

## **RESULTATEN**

### **INTERNATIONALE VARIATIE IN PLAATS VAN OVERLIJDEN BIJ OUDEREN MET EEN DEMENTIE-GERELATEERDE AANDOENING IN 14 EUROPESE EN NIET-EUROPESE LANDEN**

In het tweede hoofdstuk van deze verhandeling onderzochten we de variaties in plaats van overlijden bij ouderen die overleden zijn aan een dementie-gerelateerde aandoening tussen 14 verschillende landen (België, Nederland, Engeland, Wales, Frankrijk, Italië, Spanje, Tsjechië, Hongarije, Nieuw-Zeeland, de Verenigde Staten van Amerika, Canada, Mexico en Zuid-Korea). In totaal stierf ongeveer 5% van de oudere populatie aan een dementie-gerelateerde aandoening. De proportie

ziekenhuisoverlijdens varieerde tussen 2% in Nederland en 74% in Zuid-Korea; voor België was dit 22%. Het ziekenhuis was de meest frequente plaats van overlijden in Zuid-Korea, Hongarije en Frankrijk; thuisoverlijdens waren het meest frequent in Italië, Spanje en Mexico en de grootste proporties overlijdens in woon-en-zorg centra waren in België, Nederland, Engeland, Wales, Tsjechië, Nieuw-Zeeland, Verenigde Staten van Amerika en Canada. Factoren gerelateerd aan het gezondheidszorgsysteem verklaarden statistisch een groot aandeel van deze verschillen tussen landen inzake plaats van overlijden, en zelfs wanneer ook gecontroleerd werd voor socio-demografische factoren en sociale steun, bleven deze verschillen bestaan. Wanneer vergeleken met Frankrijk, blijken de odds om thuis te overlijden eerder dan in een ziekenhuis groter in Nederland en lager in alle andere landen. De odds om in een woon-en-zorg centrum te overlijden, eerder dan in een ziekenhuis, waren hoger in België, Engeland, de Verenigde Staten van Amerika, Tsjechië en veel hoger in Nederland, wanneer vergeleken met Frankrijk

### **ZIEKENHUISSTERFTE MET DEMENTIE EN PNEUMONIE: EEN NATIONALE STUDIE MET OVERLIJDENSCERTIFICATEN**

In hoofdstuk 3 van deze verhandeling onderzochten we de incidentie en risicofactoren van ziekenhuisoverlijdens bij ouderen die overleden zijn met een pneumonie en dementie, aan de hand van overlijdenscertificaten. In België (2008) stierven 9.931 ouderen (9.8% van alle overlijdens) met een dementie-gerelateerde aandoening. Daarvan stierf 14% bijkomend met een pneumonie volgens het overlijdenscertificaat. Ouderen die overleden met dementie én met een pneumonie hadden een grotere kans om te overlijden in een ziekenhuis (47%) dan deze die overleden met dementie zonder pneumonie (28%). Sterven met een pneumonie was een onafhankelijke risicofactor voor ziekenhuisoverlijden bij ouderen met een dementie-gerelateerde aandoening, zelfs wanneer gecontroleerd voor andere storende factoren. Ouderen, overleden met dementie én met pneumonie, die officieel thuis woonden op het moment van overlijden, hadden een grotere kans om te overlijden in het ziekenhuis wanneer zij alleen waren of in een sterk urbane omgeving woonden. Zij die in woon-en-zorg centra verbleven op het moment van overlijden hadden een grotere kans om in het ziekenhuis te overlijden met dementie én met pneumonie wanneer zij woonden in een gebied met een groter aantal residentiële (RVT-) bedden.

## **DE PERCEPTIES VAN HUISARTSEN TEN AANZIEN VAN HUN ROL IN HET VERMIJDEN EN BEGELEIDEN VAN ZIEKENHUISOPNAMEN AAN HET LEVENSEINDE: EEN FOCUSGROEPENSTUDIE**

In hoofdstuk 4 vonden we vijf verschillende rollen die de huisartsen zich toeschreven in het vermijden en begeleiden van ziekenhuisopnames aan het levenseinde. Een eerste rol is deze van zorgplanner; zorg dient aangepast en her-aangepast te worden tijdens de stervensfase, zodoende te kunnen anticiperen op toekomstige scenario's en ziekenhuisopnames aan het levenseinde te kunnen vermijden. Echter, sommige participanten gaven ook aan dat ze zich wel eens uitgesloten voelen door ziekenhuisartsen en daardoor patiënten uit het zicht verliezen, wat hun rol als zorgplanner bemoeilijkt. Bij de beslissing om een patiënt al dan niet op te nemen in acute situaties, zijn verschillende perspectieven aanwezig: de huisarts, patiënt, familieleden en andere zorgverleners. Als huisarts moet je daar rekening mee houden, vonden de deelnemers en treedt je soms op als 'onderhandelaar' om conflicten te voorkomen. Bovendien vonden de deelnemers dat dit slechts een adviserende rol was; je kan de patiënt niet tegenhouden naar het ziekenhuis te gaan en dus mag je hier ook geen conflict creëren. Een andere rol is deze van 'verlener van levenseindezorg'; zowel competenties als attitudes van de huisarts ten aanzien van levenseindezorg werden volgens sommige deelnemers belangrijk geacht in het al dan niet vermijden van een ziekenhuisopname aan het levenseinde. Huisartsen die competentier zijn of er een bepaalde attitude op na houden hebben dan een grotere kans om de patiënt thuis of in het woonzorgcentrum te houden tijdens het overlijden. Daarnaast werden de multidisciplinaire begeleidingsequipes gezien als een belangrijke hulp in het vervullen van deze rol. Een andere rol is deze van 'ondersteuner'; men vond dat er van zich wel eens verwacht werd dat men de patiënt ten allen tijde moet kunnen bijstaan en men dus ook continu beschikbaar moet zijn voor deze patiënten, en dat dit – indien geschikt – kan voorkomen dat men naar het ziekenhuis gaat of wenst te gaan. Echter, enkele deelnemers gaven ook toe dat het moeilijk is om steeds beschikbaar te zijn en dat het ook wel eens comfortabeler kan zijn om een patiënt op te nemen in het ziekenhuis, voornamelijk in het weekend. Als 'verantwoordelijke beslisser' moeten huisartsen soms verantwoordelijkheid durven nemen om de patiënt niet naar het ziekenhuis te sturen, en moeten zij bereid zijn deze verantwoordelijkheid te nemen, gaven enkele deelnemers aan. Maar ook hier gaven enkele huisartsen aan dat je in sommige situaties niet zeker bent (bijvoorbeeld tijdens een wachtdienst) en dat een ziekenhuisopname op dat ogenblik een uitweg kan bieden.

## **DE ACUTE ZIEKENHUISSETTING ALS PLAATS VOOR LEVENSEINDEZORG EN ALS PLAATS VAN OVERLIJDEN: EEN KWALITATIEVE STUDIE BIJ HUISARTSEN, VERPLEEGKUNDIGEN EN MANTELZORGERS**

In hoofdstuk 5 werden de perspectieven van huisartsen, verpleegkundigen en mantelzorgers verkend omtrent hun visie ten aanzien van de acute ziekenhuissetting als plaats voor levenseindezorg en als plaats van overlijden; we vonden drie thema's. In de eerste plaats werd de acute ziekenhuissetting beschouwd als een inadequate setting voor terminale patiënten, hoewel de nuance moet gemaakt worden dat er verschillen kunnen bestaan – volgens de participanten – tussen ziekenhuizen en/of ziekenhuisafdelingen inzake de kwaliteit van levenseindezorg. De acute ziekenhuissetting is inadequaat: het is niet goed aangepast aan de noden van terminale patiënten; er is een dominante cultuur van genezing in levensverlenging; en communicatie kan slecht of contradictorisch zijn. Anderzijds wordt de acute ziekenhuissetting ook wel beschouwd als een 'veilige haven', een setting waar men op zijn/haar gemak kan zijn, omdat men zich er veiliger voelt: omdat men angst heeft voor het overlijden; omdat men een hoop koestert om te kunnen blijven leven; omdat men er hoopt de beste zorgen te krijgen; omdat het een vertrouwde omgeving is geworden; of omdat dit het enige – laatste – alternatief is in bepaalde omstandigheden. Binnen een derde thema gaven de participanten aan dat de acute ziekenhuissetting in bepaalde ziekenhuizen of ziekenhuisafdelingen reeds veranderd is inzake de kwaliteit van levenseindezorg, wat kan duiden op mogelijke verbeteringen.

## **WAT RECTHVAARDIGT ZIEKENHUISOPNAMES AAN HET LEVENSEINDE? EEN FOCUSGROEPENSTUDIE BIJ HUISARTSEN EN VERPLEEGKUNDIGEN**

De perspectieven van huisartsen en verpleegkundigen werden verkend in hoofdstuk 6, zodoende inzichten te verwerven in de omstandigheden waarin – volgens hun perspectieven – een ziekenhuisopname aan het levenseinde als gerechtvaardigd (gepast; gedefinieerd als de beste optie voor de patiënt, gezien de omstandigheden) kan beschouwd worden. Een ziekenhuisopname aan het levenseinde is dan gerechtvaardigd wanneer dit de wens van de patiënt reflecteert, omdat dit het welzijn van de patiënt kan verbeteren. De participanten waren er ook van overtuigd dat – ongeacht de wensen van de patiënt – deze patiënt ook adequate en continue zorg moet kunnen krijgen. Wanneer dergelijke zorgen niet meer verzekerd kunnen worden op de plaats waar de patiënt verblijft, is een ziekenhuisopname aan het levenseinde volgens deze deelnemers gerechtvaardigd. Dit blijkt ook verschillend te zijn voor woon-en-zorg centra en de thuisomgeving (vb. omdat de last voor de mantelzorg zeer hoog kan zijn). Acute medische situaties (vb. een obstructie of massief bloedverlies) beschouwde men ook als een gerechtvaardigde reden om de patiënt naar het



ziekenhuis te brengen aan het levenseinde, gezien men hier niet altijd op voorbereid is. Er was echter geen consensus over welke specifieke medische problemen dan wel of niet een ziekenhuisopname aan het levenseinde rechtvaardigde.

### **REDENEN VOOR TERMINALE HOSPITALISATIES: RESULTATEN VAN EEN VRAGENLIJSTENSTUDIE BIJ HUISARTSEN**

In hoofdstuk 7 werd een vragenlijstenstudie behandeld die werd uitgevoerd bij huisartsen wiens patiënten overleden zijn in de acute ziekenhuissetting van een universitair ziekenhuis en waarbij gevraagd werd naar de redenen en aspecten die een rol speelden in de beslissing die leidde tot de terminale hospitalisatie van deze patiënten. We kregen 245 vragenlijsten (responsegraad 70%), waarvan er 189 cases niet-plotse en niet-onverwachtse overlijdens waren volgens deze huisartsen en deze werden dan geïnccludeerd in de analyses van de studie. Daarvan werd er – volgens de huisartsen – 55% opgenomen voor palliatieve redenen, 30% voor diagnostische redenen en 26% voor curatieve of levensverlengende redenen. In één op de drie terminale hospitalisaties gaven de huisartsen aan dat de patiënt zich veiliger voelde in het ziekenhuis en dat dit een rol heeft gespeeld in de beslissing tot opname; evenals dat in één van de twee opnames de familie de zorgen in het ziekenhuis beter achtten. In 85% van de terminale hospitalisaties was er volgens de huisarts een inadequate zorgomgeving die een rol heeft gespeeld in de beslissing tot opname. Huisartsen gaven vaker aan dat de wensen van de patiënt een rol speelde in de beslissing tot opname, wanneer deze huisartsen aangaven dat zij meer dan drie bezoeken hadden gedaan in de laatste maand voor het overlijden van de patiënt, wanneer zij vonden dat ze betrokken waren in het levenseindetraject van de patiënt en wanneer zij op de hoogte waren van de gewenste plaats van overlijden van deze patiënt. Wanneer patiënten opgenomen werden met een beperkte levensverwachting, gaven huisartsen meer aan dat de opname voor palliatieve redenen was en dat een inadequate zorgomgeving een rol heeft gespeeld in de beslissing tot opname.

### **GASTHEID EN VERMIJDBAARHEID VAN TERMINALE HOSPITALISATIES: RESULTATEN VAN EEN VRAGENLIJSTENSTUDIE BIJ HUISARTSEN**

In hoofdstuk 8 hanteerden we dezelfde vragenlijstenstudie als in hoofdstuk 7, waarbij we 189 terminale hospitalisaties includeerden van patiënten die niet-plots overleden zijn in de acute ziekenhuissetting van een universitair ziekenhuis. Volgens de huisartsen van deze patiënten was 14% van deze terminale hospitalisaties potentieel ongepast; 14% was potentieel vermijdbaar en 8% was

potentieel vermijdbaar en potentieel ongepast. Huisartsen gaven meer aan dat het een potentieel ongepaste of potentieel vermijdbare terminale hospitalisatie was wanneer patiënten gestorven waren aan kanker, wanneer de patiënt op de moment van opname een beperkte levensverwachting had (minder dan enkele weken) en wanneer de opname werd geïnitieerd door de patiënt, partner of andere familie. Huisartsen gaven meer aan dat deze terminale hospitalisaties potentieel ongepast waren wanneer zij een formele training in palliatieve zorg hadden gekregen in de basis artsopleiding, of op postgraduaat of postacademisch niveau. De terminale hospitalisaties werden minder potentieel vermijdbaar bevonden door de huisartsen wanneer ze voor diagnostische redenen waren. De huisartsen van deze studie gaven ook aan dat van alle potentieel vermijdbare terminale hospitalisaties de meeste opnames vermeden hadden kunnen worden door eerder met de patiënt te communiceren over zijn/haar beperkte levensverwachting en de mogelijkheden van palliatieve zorg; evenals een betere ondersteuning te bieden aan de mantelzorg.

## **DISCUSSIE**

### **ZIEKENHUISOVERLIJDENS BIJ PATIËNTEN MET DEMENTIE IN BELGIË**

Wanneer we België vergelijken met andere landen inzake de plaats van overlijden bij patiënten overleden aan dementie, dan blijkt dat België een relatief laag cijfer ziekenhuisoverlijdens heeft bij deze patiëntengroep. Dit komt dan ook overeen met cijfers inzake 'plaats van overlijden' in andere studies. Echter, wanneer we vergelijken met Nederland of Nieuw-Zeeland, dan blijkt dat er toch ook nog ruimte is voor verbetering.

Meer nog, zo blijkt dat oudere personen met dementie in België een verhoogde kans hebben om in het ziekenhuis te overlijden wanneer zij overlijden met een pneumonie. Ook in de focusgroepen zagen we dat huisartsen en verpleegkundigen een medische complicatie een gepaste reden vonden voor een ziekenhuisopname aan het levenseinde.

### **DE ROL VAN DE HUISARTS INZAKE ZIEKENHUISOPNAMES AAN HET LEVENSEINDE**

Belgische huisartsen zouden een belangrijke rol kunnen spelen in het vermijden van ziekenhuisopnames aan het levenseinde, maar dit potentieel wordt niet ten volle benut; desondanks hun voorname rol in het verlenen en coördineren van levenseindezorg buiten het ziekenhuis.

Huisartsen in België geven aan moeilijkheden te ervaren in het vermijden dat patiënten naar het ziekenhuis gaan aan het levenseinde, en dat hun vermogen hierin dan ook gelimiteerd is.

Een van de mogelijkheden om dit te verhelpen is dan – volgens onze resultaten – om de competenties van huisartsen inzake levenseindezorg te verbeteren en te zorgen dat zij er een attitude op nahouden die hen toelaat de patiënt thuis of in het woon- en zorgcentrum te houden, indien gepast. Dit kan dan verwezenlijkt worden door adequate opleidingen in levenseindezorg te voorzien in de basisartsenopleiding, of door bijkomende opleidingen te stimuleren. Ook het gebruik van multidisciplinaire begeleidingsequipes door huisartsen zou gestimuleerd kunnen worden.

Een belangrijke barrière die huisartsen ook ervaren in het vermijden van ziekenhuisopnames aan het levenseinde is hun eerder gelimiteerde poortwachtersrol ten aanzien van ziekenhuisservices; het verhindert hun rol als zorgplanner en vermindert het gewicht van hun mening tijdens acute situaties. Mogelijkheden tot versterking van deze rol zouden dan verkend kunnen worden in België.

## **REDENEN EN RECHTVAARDIGINGEN VOOR ZIEKENHUISOPNAMEN AAN HET LEVENSEINDE**

De acute ziekenhuissetting werd beschouwd als een setting die niet optimaal is voor levenseindezorg of als plaats van overlijden. Echter, een groot aantal terminale hospitalisaties (85%) werd als ‘gepast’ beschouwd volgens de survey bij huisartsen. Volgens de participanten van de focusgroepen (huisartsen en verpleegkundigen) waren ziekenhuisopnames aan het levenseinde dan wel gepast (ook wel: gerechtvaardigd) wanneer de patiënt en familie dit prefereerde of wanneer de zorgomgeving ontoereikend zou zijn. We maken dan een onderscheid tussen ‘wensen opgenomen te worden’ – een ziekenhuisopname prefereren – en ‘een opname nodig hebben’ – ergens anders naartoe moeten dan de setting waar de patiënt verblijft; hoewel deze samen kunnen voorkomen.

### ***Rechtvaardigingen voor ziekenhuisopnames aan het levenseinde: een ziekenhuisopname wensen***

De acute ziekenhuissetting wordt ook wel eens een ‘veilige haven’ beschouwd door patiënten en familie. Volgens de resultaten van onze studies komt het voor dat patiënten en familie een ziekenhuisopname aan het levenseinde prefereren: wanneer er een onzekerheid is dat de patiënt zou sterven; wanneer de patiënt wenst genezen te worden of levensverlengende behandelingen wenst; wanneer dit een vertrouwde omgeving is geworden; of wanneer men er de zorgen beter acht. Een ziekenhuisopname kan in deze omstandigheden als ‘gepast’ beschouwd worden.

Anderzijds reflecteren deze preferenties mogelijks een zekere attitude, een geloof, een intuïtie die patiënten en familie doet geloven dat de acute ziekenhuissetting de juiste plaats is om naartoe e

gaan aan het levenseinde. Dergelijke wens om opgenomen te worden in het ziekenhuis aan het levenseinde kan dan beschouwd worden als een resultaat van de verregaande medicalisering in de hedendaagse samenleving en een geloof in de mogelijkheden van geneeskunde en het ziekenhuis om genezen te kunnen worden, zo niet de dood tijdelijk uit te kunnen stellen. We worden gesocialiseerd in het zoeken van medische hulp wanneer er zich een gezondheidsprobleem voordoet – zelfs wanneer overlijden niet onverwacht zou zijn – en in dergelijke situaties is een gemakkelijk bereikbare setting zoals het ziekenhuis een valide optie.

Dergelijke preferenties – en dus ook ziekenhuisopnames aan het levenseinde – zouden dan volgens de resultaten van onze studies verminderd kunnen worden door een adequate zorgplanning aan het levenseinde en proactieve, tijdige gesprekken met de patiënt over een beperkte levensverwachting en de mogelijkheden van palliatieve zorg.

### ***Rechtvaardigingen voor ziekenhuisopnames aan het levenseinde: een ziekenhuisopname nodig hebben***

In de focusgroepen was er consensus over dat de patiënt ten allen tijde, adequate zorg moet kunnen krijgen op de plaats waar deze verblijft. Indien dit niet mogelijk is, wordt een ziekenhuisopname aan het levenseinde ook wel gerechtvaardigd (gepast) beschouwd. Van deze patiënten die niet-plots overleden zijn in de acute ziekenhuissetting van een universitair ziekenhuis, vond 85% van de huisartsen dat een ontoereikende zorgomgeving een rol heeft gespeeld in de beslissing tot opname. Gezien een overgrote meerderheid van deze sample uit de thuisomgeving kwam, kan gesteld worden dat het mogelijks de thuisomgeving is die adequaat dient ondersteund te worden. Ook gaven huisartsen aan dat van deze terminale hospitalisaties die ‘potentieel vermijdbaar’ waren (14%), ongeveer de helft vermeden had kunnen worden door de mantelzorg beter te ondersteunen. Meer nog, de resultaten van onze studies wijzen er ook op dat dergelijke ondersteuning vooral nodig kan zijn in het weekend. Daarom lijkt het aangewezen om initiatieven zoals respijtzorg of palliatieve dagcentra uit te breiden en/of het gebruik ervan te stimuleren.

Het ziekenhuis kan ook in een bepaald aantal omstandigheden, de enige optie zijn, gezien het aantal alternatieven gelimiteerd is. Dit wijst dus mogelijks op het gebrek aan alternatieven, naast de acute ziekenhuissetting, als plaats van overlijden. Om die redenen lijkt het dan ook aangeraden om het aantal bedden voor palliatieve eenheden – momenteel 379 in totaal voor België – uit te breiden; of nieuwere initiatieven (zoals een ‘hospice’) dienen verkend te worden. Ook de rol die een palliatief dagcentrum kan spelen in het vermijden van dergelijke terminale hospitalisaties dient verkend te worden en zo nodig het gebruik ervan gestimuleerd.

## VERMIJDBAARHEID VAN ZIEKENHUISOPNAMES AAN HET LEVENSEINDE

Huisartsen wiens patiënten niet-plots overleden zijn in de acute ziekenhuissetting van een universitair ziekenhuis beschouwden 14% van deze terminale hospitalisaties ‘potentieel vermijdbaar’ te zijn. Dergelijke laag cijfer was eerder verrassend en verdient daarom enige verduidelijking. In de eerste plaats zouden we dan willen wijzen op de gehanteerde methodologie die hiertoe zou kunnen bijgedragen hebben: het betrof een survey bij huisartsen die mogelijks antwoordden in overeenstemming met ‘goede medische praktijk’ en een post-hoc rationalisatie van de opname door deze huisartsen kan ook niet worden uitgesloten.

Daarnaast blijkt deze proportie ook te verschillen met gelijkaardige studies in Nieuw-Zeeland, Engeland en Nederland. Meer nog, gezien Engeland een gelijkaardige proportie ziekenhuisoverlijdens heeft, verwachten we hier een gelijkaardige proportie ‘potentieel vermijdbare’ ziekenhuisopnames aan het levenseinde; terwijl deze lager bevonden werd. Op dezelfde manier verwachten we – door een lagere proportie ziekenhuisoverlijdens – een lagere proportie ‘potentieel vermijdbare’ ziekenhuisopnames aan het levenseinde in Nederland en Nieuw-Zeeland; terwijl deze in beide landen hoger werden bevonden. Gezien deze studies niet identiek uitgevoerd werden, noch de nodige generaliseerbaarheid ontbreken, lijkt het nog voorbarig om hier conclusies uit te trekken. Toch kunnen we hier enige hypothesen over vormen – hoewel dus enige voorzichtigheid is geboden. Deze verschillen zouden er op kunnen wijzen dat de perceptie aangaande welke ziekenhuisopnames vermijdbaar zijn en welke niet, toegeschreven zouden kunnen worden aan bepaalde attitudes of overtuigingen binnen een gezondheidssysteem. In die zin dat patiënten en familie, en zelfs zorgverleners, in Nederland en Nieuw-Zeeland minder geneigd zouden zijn om de acute ziekenhuissetting te beschouwen als een ‘veilige haven’ aan het levenseinde en minder baat zien bij een ziekenhuisopname aan het levenseinde. Dergelijke verschillen in percepties zouden dan op hun beurt het gevolg kunnen zijn van verschillen in de organisatie van zorg (zoals levenseindezorg) tussen deze landen. Dit zou kunnen aantonen dat het aantal ziekenhuisopnames aan het levenseinde in België gereduceerd zou kunnen worden, en bijgevolg de proportie ziekenhuisoverlijdens, door deze percepties van patiënten, familie en zorgverleners te wijzigen, door de nodige verbeteringen te treffen binnen het Belgisch gezondheidszorgsysteem. Gezien dergelijke conclusie eerder buiten het bereik valt van dit proefschrift, wordt dit een uiterst geschikt knooppunt beschouwd voor toekomstig onderzoek.

Anderzijds dient het ook gesteld dat dit niet mag betekenen dat beleid en onderzoek omtrent levenseindezorg niet uitsluitend gericht mag zijn op het faciliteren van overlijdens buiten het ziekenhuis en een verbetering van de levenseindezorg binnen de acute ziekenhuissetting kan

negeren. Ook is het aangeraden om meer publiek debat aan te vatten over welke setting meest ideaal kan worden beschouwd als 'plaats van overlijden'.

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## CV & List of Publications

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## **CURRICULUM VITAE**

Thijs Reyniers was born on the 12th of February 1987 in Turnhout, Belgium. He studied Sociology (major in Sociology of Health) at Ghent University and obtained his Master's degree in 2009. One year after, he finished the Teacher Program at Ghent University. After that Thijs quickly found his way back to science and started working as a junior researcher at the End-of-Life Care Research Group, Vrije Universiteit Brussel (VUB) & Ghent University. Supported by a grant from the Flemish government agency for Innovation by Science and Technology (IWT), Thijs conducted research on end-of-life hospital admissions, supervised by Prof. Dr. Luc Deliens and Prof. Dr. Dirk Houttekier, and co-supervised by Prof. Dr. Joachim Cohen and Prof. Dr. Robert Vander Stichele.

Thijs Reyniers now works at the Institute of Tropical Medicine in Antwerp, as a social science coordinator on a project that focuses on HIV prevention among MSM.



## LIST OF PUBLICATIONS

### ARTICLES IN INTERNATIONAL PEER-REVIEWED JOURNALS

Reyniers T., Deliens L., Pasman R., Morin L., Addington-Hall J., Miccinesi G., Cardenas-Turanzas M., Onwuteaka-Philipsen B., Naylor W., Ruiz-Ramos M., Wilson D., Loucka M, Csikos A., Rhee J.; Teno J., Cohen J., Houttekier D.; *International variation in place of death of older persons who died from dementia in fourteen European and non-European countries*; Journal of the American Medical Directors Association. 2015; 16(2):165-71 (IF 4.781, 2013)

Houttekier D., Reyniers T., Deliens L., Van Den Noortgate N., Cohen J.; *Dying in hospital with dementia and pneumonia: a nationwide study using death certificate data*; Gerontology. 2014; 60: 31-7 (IF 2.681, 2013)

Reyniers T., Houttekier D., Cohen J., Pasman R., Vander Stichele B., Deliens L.; *The family physicians's perceived role in preventing and guiding hospital admissions at the end of life – a focus group study*; Annals of Family Medicine. 2014 Sep-Oct; 12(5):441-6 (IF 4.613, 2013)

Reyniers T., Houttekier D., Cohen J., Pasman R., Deliens L.; *The acute hospital setting as a place of death and final care: a qualitative study on perspectives of family physicians, nurses and family carers*; Health & Place. 2014 May;277:77-83 (IF 2.435, 2013)

Reyniers T., Houttekier D., Cohen J., Pasman R., Deliens L.; *What justifies a hospital admission at the end of life? A focus group study on perspectives of family physicians and nurses*; Palliative Medicine. 2014 Feb 17;28(7):941-948 (IF 2.845, 2013)

Reyniers T., Houttekier D., Cohen J., Pasman R., Vander Stichele B., Sijnave B., Deliens L.; *appropriateness and avoidability of terminal hospital admissions – results of a survey among family physicians*; Submitted

Reyniers T., Houttekier D., Cohen J., Pasman R., Vander Stichele B., Sijnave B., Deliens L.; *Reasons for terminal hospital admissions: results of a survey among family physicians*; Submitted

### ARTICLES IN NATIONAL JOURNALS

Reyniers T., Margot H.; *Thuis sterven of in het ziekenhuis*; Nursing, April 2014

Reyniers T., Margot H.; *Sterven in het ziekenhuis, liever niet*; Nursing, January 2015

Reyniers T., Houttekier D., Pasman R., Vander Stichele R., Cohen J., Deliens L.; *Ziekenhuisopnames aan het levenseinde: begeleiden en vermijden*; Huisarts Nu (Domus Medica), April 2015

Reyniers T., Houttekier D., Pasman R., Cohen J., Deliens L.; Ziekenhuis als plaats van overlijden; Hospitals.be, April 2015

## **BOOKS**

Chapter in: *Palliatieve Zorg, Meer dan Stervensbegeleiding (2015)*; Cohen J., Smets T., Pardon P., Deliens L.; Lannoo, Leuven

## **PRESENTATIONS - INTERNATIONAL**

Reyniers T., Deliens L., Pasman H.R., Cohen J., Houttekier D., on behalf of the co-authors of the International Study on Place of Death (IPOD); *International Variation in Place of death of older persons who died from dementia in fourteen European and non-European countries.*; EAPC Congress Copenhagen, May 2015 (oral presentation)

Reyniers T., Houttekier D., Cohen J., Pasman R., Vander Stichele B., Deliens L.; *Reasons for, appropriateness and avoidability of End-of-Life hospital admissions: Results of a Survey among Family Physicians*; EAPC Congress Copenhagen; May 2015 (poster presentation)

Reyniers T., Houttekier D., Cohen J., Pasman R., Vander Stichele B., Deliens L.; *The acute hospital setting as a place of death and final care: a qualitative study on perspectives of family physicians, nurses and family carers*; EAPC Congress Lleida, Spain; June 2014 (poster presentation)

Reyniers T., Houttekier D., Cohen J., Pasman R., Vander Stichele B., Deliens L.; *The family physician's perceived role in preventing and guiding hospital admissions at the end of life – a focus group study*; EAPC Congress Lleida, Spain; June 2014 (poster presentation)

Reyniers T., Houttekier D., Cohen J., Pasman R., Deliens L.; *What justifies a hospital admission at the end of life? Perspectives of family physicians and nurses*; EAPC Congress, Prague, Czech Republic; May 2013 (poster presentation)

Reyniers T., Houttekier D., Cohen J., Pasman R., Deliens L.; *What justifies a hospital admission at the end of life? Perspectives of family physicians and nurses*; First Care Congress of the FLIECE Consortium; Leuven, Belgium; April 2013 (poster presentation)

Reyniers T., Houttekier D., Cohen J, Pasman R., Deliëns L.; measuring avoidable and inappropriate hospital admissions at the end of life – a research protocol; 2<sup>nd</sup> International Seminar of the PRC & EAPC RN; Ghent, Belgium, October 2012 (poster presentation)

Reyniers T., Houttekier D., Cohen J, Pasman R., Deliëns L.; *Measuring avoidable and inappropriate hospital admissions at the end of life – a research protocol*; EAPC Congress, Trondheim, Norway; June 2012 (poster presentation)

Reyniers T., Houttekier D., Cohen J, Pasman R., Deliëns L.; *Ongepaste en vermijdbare hospitalisaties aan het levenseinde – een onderzoeksprotocol*; Vlaams-Nederlands Onderzoeksforum Palliatieve Zorg, Amsterdam, The Netherlands ; March 2012 (oral presentation)