

**IMPROVING END-OF-LIFE CARE IN  
ACUTE GERIATRIC HOSPITAL WARDS IN FLANDERS:  
A PHASE 0-2 STUDY OF  
THE CARE PROGRAMME FOR THE LAST DAYS OF LIFE**

**Doctoral dissertation**

Dissertation submitted in the fulfilment of the requirements to obtain the joint PhD-degree in:

Social Health Sciences

Faculty of Medicine and Pharmacy

Vrije Universiteit Brussel

&

Health Sciences

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Vrije Universiteit Brussel (VUB) & Ghent University

June, 2015

**Rebecca Verhofstede**



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Vrije  
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### **Chapter 2**

Smets T, Verhofstede R, Cohen J, Van Den Noortgate N, Deliens L: Factors associated with the goal of treatment in the last week of life in old compared to very old patients: a population-based death certificate survey.

- *BMC Geriatrics* 2014, 14:61 -

### **Chapter 3**

Verhofstede R, Smets T, Cohen J, Eecloo K, Costantini M, Van Den Noortgate N, Deliens L. End-of-life care and quality of dying in twenty-three acute geriatric hospital wards.

- *Submitted* -

### **Chapter 4**

Van Den Noortgate N, Verhofstede R, Smets T, Cohen J, Piers R, Deliens L. Prescription and deprescription of medication during the last 48 hours of life: multi-centre study in 23 geriatric wards

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### **Chapter 5**

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### **Chapter 6**

Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, Deliens L. Implementing the Care Programme for the Last Days of Life in an acute geriatric hospital ward: a phase 2 mixed method study.

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### **Chapter 7**

Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, Deliens L. Improving end-of-life care in acute geriatric hospital wards using the care programme for the last days of life: study protocol for a phase 3 cluster randomized controlled trial.

- *BMC Geriatrics* 2015, 15:13 -

# **PART I**

## **INTRODUCTION**



# **CHAPTER 1: GENERAL INTRODUCTION**

# **1. General introduction**

## **1.1. Background**

### **1.1.1. Ageing and chronic illness among the older population**

An increase in life expectancy along with a dramatic drop in the fertility rate contribute to the ageing of our Western population<sup>1</sup>. It is expected that the number and proportion of older people will increase sharply in the years ahead; by 2050, more than one quarter of the population of the European region will be 65 or older<sup>2</sup>. The fastest growing age group in most European countries is the group of people aged 85 and older. This group is even predicted to double in size in the next 20 years<sup>2</sup>. As a result of the population ageing, the number of deaths has also begun to increase with a majority of deaths occurring after the age of 65 years<sup>3</sup>. The population of older people thus comprises a substantial proportion of those patients who are approaching the end of life.

As more people live to older ages, the pattern of disease at the end of life is changing and more people are living with frailty and serious chronic and degenerative diseases such as chronic heart disease, cerebrovascular disease, respiratory disease, dementia and cancer<sup>2,4,5</sup>. In addition, increased longevity is associated with the increased prevalence of co-morbidity, ie people living with two or more diseases at the same time. An increasing number of older people will therefore live with the consequences of one or more of these diseases. Moreover, older people often experience medical problems towards the end of life (e.g. pneumonia or hip fracture), that may result in hospital admission<sup>6,7</sup>.

These demographic and epidemiological changes increasingly confront societies with challenges regarding the organization of end-of-life care. As a consequence, the World Health Organization (WHO) has identified palliative care and end-of-life care as one of the public health priorities for older people<sup>2,7,8</sup>.

### **1.1.2. End-of-life care for older people**

#### Definition

End-of-life care is the clinical approach to the patient at the end of his/her life, which includes the months, days or hours before death<sup>9</sup>. In contrast to conventional medical care, in which the focus is on curation or on life-prolongation, palliative and end-of-life care put emphasis on improving and sustaining the quality of life.

End-of-life care for older people encompasses more than the mainstream palliative medicine principles and has therefore been defined as “the medical care and management of older patients with health-related problems and progressive, advanced disease for which the prognosis is limited and the focus of care is quality of life<sup>10</sup>. Therefore Geriatric Palliative Medicine<sup>10</sup>:

- combines the principles and practice of geriatric medicine and palliative care;
- focuses on comprehensive geriatric assessment; relief from pain and other symptoms; and management of physical and psychological problems, integrating social, spiritual, and environmental aspects;
- recognizes the unique features of symptom and disease presentation, the interaction between diseases, the need for safe drug prescribing, and the importance of a tailored multidisciplinary approach for older patients receiving palliative care and their family;
- emphasizes the importance of autonomy, the involvement in decision-making, and the existence of ethical dilemmas;
- calls for good communication skills when discussing and giving information to older patients and their families;
- addresses the needs of older patients and their families across all settings - home, long-term care, hospices, and hospital;
- pays special attention to transitions within and between settings of care; and
- offers a support system to help families cope during the patient’s terminal phase of care.”

### End-of-life care and quality of dying

The ultimate goal of end-of-life care is to pursue a good and dignified death for every person<sup>4</sup>. Hence it is increasingly accepted that end-of-life care should focus on symptom management, dignity and quality of life rather than on prolonging life itself<sup>2,7</sup>.

As older people may have specific and challenging needs towards the end of life, they may respond well to the expertise offered by specialist palliative care providers across all settings<sup>7</sup>. It is for instance known that the role of a palliative care consultation supports the optimization of the medication profile, tailoring each decision to the individual's preferences, comorbidities and prognosis<sup>11</sup>, though, end-of-life care should not be something that only specialized palliative care teams, palliative care services or hospices offer when other treatments have been withdrawn. It should be an integral part of care, be provided by any health professional and take place in any setting<sup>7</sup>.

According to older people, adequate pain and symptom management, appropriate social, spiritual and emotional support, avoiding inappropriate prolongation of dying and providing best quality of life for their families are important aspects of optimal end-of-life care which may contribute to a 'good death'<sup>4,12</sup>. Adequate care during the last days of life may also include an appropriate pharmacological management such as medication reviews, anticipatory prescription of medication for optimal symptom control and deprescription of potentially inappropriate medication<sup>11,13,14</sup>. A medication review aims to optimize pharmacologic treatments, reduce polypharmacy and minimize medication-induced adverse effects and acute complications, which are particularly common in frail individuals<sup>11</sup>. It is also recognised that appropriate care for the dying consists of symptom management, performing mouth care and avoiding inappropriate treatments and interventions<sup>4,15</sup>.

In perfect conditions, end-of-life care is in accordance with the patient's individual needs and wishes. Exploring and acknowledging individual needs at the end-of-life and appropriately addressing them is therefore crucial when striving for optimal end-of-life care.

However, delivering optimal end-of-life care in older people is challenging since older people often have complex and multifaceted needs due to the multiple chronic health problems they are experiencing. In addition, an increasing proportion of this older population is cognitively impaired which may also contribute to the challenging nature of end-of-life care provision<sup>2,4,16-19</sup>. Moreover, delivering appropriate end-of-life care for older people implies that health care professionals recognize the dying phase, which is particularly challenging in

the care of older people suffering from slowly progressive or fluctuating long term conditions<sup>12,20</sup>.

### Main goal of treatment

An important indicator for the quality of end-of-life care is the main goal of treatment at the end-of-life<sup>21</sup>. The absence of a palliative or comfort care goal at the time of death in patients suffering from chronic life-limiting diseases is generally associated with poor quality end-of-life care. A main goal of treatment aimed at comfort or quality of life may thus become more appropriate when death approaches<sup>21</sup>.

Although a number of studies have been performed to investigate the quality of end-of-life care for older people, among others in hospitals<sup>22,23</sup>, little is known about the main goal of treatment in older dying people as well as the type of care that older people of different ages receive at the end of life.

### **1.1.3. Acute geriatric hospital wards**

#### An important place of end-of-life care and death

Another important principle of achieving a good death is having choice and control over where death occurs<sup>24,25</sup>. Unfortunately, these choices and wishes are not always met.

The proportion of older people dying in a hospital setting remains persistently high in many high-income countries while most people prefer to be cared for and die at home<sup>26-29</sup>.

Although a more recent study of trends in place of death in Belgium has found a slight decrease in hospital deaths, still a majority of older patients die in hospital<sup>30</sup> and it is estimated that deaths in institutions will increase substantially in the next decades<sup>31</sup>.

#### Patients on acute geriatric wards

In Flanders (Belgium), specialized acute care units for older people, i.e. acute geriatric wards, are an important place within the acute hospital setting where older patients are hospitalized and end-of-life care may be provided. These wards were installed since 1984 for specialized acute geriatric care, with a multidisciplinary approach and supervised by a geriatrician, i.e. a specialist with a three year training in internal medicine and a supplementary three year training in geriatric medicine<sup>32</sup>. Geriatric patients, generally 75 years or older, are often admitted to these wards as a result of acute events such as falls, infections, acute cardiovascular problems, drug interactions. However, the geriatric patient is not defined on the

basis of age; the geriatric profile is rather determined by age-related vulnerability with associated co-morbidities. This geriatric profile associated with acute events poses various challenges to health care staff on acute geriatric wards; complex and multifaceted needs have to be addressed<sup>33,34</sup>. In line with a recently published resolution by the World Health Organization, geriatric medicine will particularly focus on improving the quality of life of older people and simultaneously centre on the improvement and rehabilitation of a patient's functional status<sup>8</sup>. However, some patients admitted to acute geriatric hospital wards may die in this specific setting and should thus benefit from appropriate end-of-life care where cure or life-prolongation is no longer a priority.

### *End-of-life care and quality of dying*

While we are aware of a substantial proportion of older people dying in acute geriatric hospital wards, we lack reliable data on what care they receive at the end-of-life and what the quality of the dying process is.

What we actually do know is that acute hospital care in general is considered to be inadequate to the needs of dying patients. Care in hospitals is mainly focused on cure or life-prolongation and studies have indicated that communication between health care professionals and patients and their families is often poor or contradictory in hospitals<sup>22,23,35</sup>. Moreover, studies show that many hospitalized patients often do not die a peaceful death<sup>36-38</sup>. Key findings of a study evaluating the dying experience at home and in institutional settings found that bereaved family members whose relatives died in a hospital, reported higher rates of concerns around dying in comparison to family members whose relatives died at home. For example, higher rates were found for unmet needs for symptom management, for concerns with physician communication about medical decision making, for the lack of emotional support for family members, and for the belief that their dying relative was not always treated with respect<sup>39</sup>.

Moreover, studies are showing that care at the end of life for the older person in the acute hospital ward is often suboptimal, resulting in poor symptom control during the last days of life and poor quality of dying<sup>22,23,39,40</sup>. For older patients in the hospital, pain control at the end-of-life seems to be less intensive than for younger patients<sup>5,41</sup>, the chance to receive optimal end-of-life care is lower compared to younger patients<sup>41</sup> and burdensome interventions aimed at prolonging life instead of interventions to promote their comfort are more often started or continued<sup>8</sup>. Furthermore, the patient population with dementia is especially prone to poor symptom control and quality of life during the last week of life<sup>42-44</sup>.

### 1.1.4. Barriers to providing optimal end-of-life care in older hospitalized patients

Several studies have already been carried out in order to identify barriers to providing optimal end-of-life care in older people<sup>4,45,46</sup>. Although the evidence is limited regarding barriers to optimal end-of-life care for older people in acute hospitals<sup>47</sup>, the findings are consistent with other study results not restricted to the hospital setting.

Three types of barriers can be identified from the literature to providing optimal end-of-life care for older hospitalized patients<sup>4,45-47</sup> (Table 1). These barriers are related to the patient/family, to the clinicians and to the institution.

Table 1 Three types of barriers to providing optimal end-of-life care

Patient/family related barriers	Clinician related barriers	Institution related barriers
Unrealistic patient/family expectations	Differing understandings of whose responsibility it was to provide palliative care	Suboptimal space for family meetings
Inability of patients to participate in discussions	Failure to implement a timely end-of-life plan of care	Inadequate staffing levels Lack of a palliative care service
Lack of advance directives	Reluctance to acknowledge treatment failure or to relinquish end-of-life patient care to other specialists	A focus on interventionist care with curative intent
Difficulty of survival prediction in non-malignant disease		Discontinuity of care
Older age	Lack of generic palliative care skills and knowledge amongst healthcare professionals  Reluctance to engage in and difficulties with conversations about death and dying with patients and their families  Possible reluctance in prescribing opioids to the oldest old people	

An essential finding is that older age in itself can be a barrier to providing optimal end-of-life care<sup>4,47</sup>. It was for instance found in a study that health professionals sometimes believe that older patients less often require palliative care than younger people, because death is more expected in an older persons, and the perception that older people find it easier to come to terms with a terminal diagnosis<sup>47</sup>. This thinking may influence the allocation of scarce resources to the care of older dying people and may also lead to a weak emphasis on quality of dying and a consequent failure to personalize end-of-life care<sup>4,48,49</sup>.

### **1.1.5. Initiatives to improve end-of-life care in older hospitalized patients**

Dealing with the abovementioned barriers is an important but challenging step when striving to improve end-of-life care in older hospitalized patients. Various initiatives have been developed and introduced worldwide in order to address and surpass these barriers<sup>2,50,51</sup>. Most of the initiatives such as educational programmes, symptom-specific interventions, advance care planning, and integrated care pathways aim to improve the provision of general palliative care for all and to prompt referral to specialist palliative care services when needed<sup>2,4</sup>. With respect to improving end-of-life care for older patients in hospitals, education of the staff members, identifying and assessing the people who need end-of-life care, good collaboration between all involved parties, e.g. geriatricians, oncologists, cardiologists, palliative care clinicians, pharmacists, psychologists, social workers, dieticians, nursing staff and chaplains, implementing care pathways and ensuring access to specialist palliative care teams are strongly recommended<sup>2,52</sup>. To our knowledge, no care pathways have been developed or implemented mainly aimed at improving end-of-life care in acute geriatric hospital wards.

Over many years several end-of-life care pathways have been developed to improve the quality of end-of-life care of which the Liverpool Care Pathway (LCP) for the Dying Patient is the most well-known<sup>13,50,53,54</sup>. The LCP was developed in 1997 in the United Kingdom (UK) as a multi-professional document that provides a template of care for the final days and hours of life and aims to transfer the hospice model of care to mainstream hospital services<sup>53,13</sup>.

Although the LCP as developed in the UK was meant to be implemented in every health care setting and population, individual patient characteristics and needs may differ as well as the health care setting in which they are cared for<sup>7</sup>. It is for instance known that the recognition of the dying phase is more challenging in older non-cancer patients<sup>53</sup> and that around half of older patients in hospital are cognitively impaired<sup>55</sup>. Furthermore, although studies suggest that the LCP can improve the quality of end-of-life care in a cancer population<sup>56-59</sup>, its effectiveness in people dying of causes other than cancer, especially older people, has not yet been investigated. Therefore, if we want to introduce and use such a care programme in acute geriatric hospital wards, we should be careful that the context is taken into account, especially during the process of implementation. Moreover, as the LCP has been widely criticized since June 2012 for leading to physicians and nurses not providing appropriate care, the development of an adapted care programme for the last days of life should also take into account the concerns that have been raised in the UK. Raised concerns regarding the LCP arise mainly from inappropriate implementation and use and not the principles of the LCP

itself. This was also recently highlighted in an independent review which recommended phasing out the LCP in the UK by July 2014<sup>60</sup>.

## **1.2. Research aims, methodology and outline of this dissertation**

### **1.2.1. Research aims**

The aims of our research project are threefold: (1) to evaluate the main goal of treatment at the end of life in older patients, (2) to describe end-of-life care for patients in acute geriatric hospital wards and (3) to develop and evaluate the effectiveness of the Care Programme for the Last Days of Life in improving end-of-life care in acute geriatric hospital wards.

#### **Research aim 1: To evaluate the main goal of treatment at the end of life in older patients**

The research objectives are:

- 1) To provide a population-based evaluation of the main goal of treatment that older people of different ages receive at the end of life (chapter 2)

#### **Research aim 2: To describe end-of-life care for patients in acute geriatric hospital wards**

The research objectives are:

- 2) To describe end-of-life care in terms of performed nursing and medical interventions in the last 48 hours of life and quality of dying of patients in acute geriatric hospital wards (chapter 3)
- 3) To describe the policy of prescription and deprescription of medication in the last 48 hours of life of patients in acute geriatric hospital wards (chapter 4)

#### **Research aim 3: To develop and evaluate the effectiveness of the Care Programme for the Last Days of Life in improving end-of-life care in acute geriatric hospital wards**

The research objectives are:

- 4) To develop the Care Programme for the Last Days of Life for older patients in acute geriatric hospital wards (chapter 5)
- 5) To test the feasibility of the implementation of the Care Programme for the Last Days of Life in an acute geriatric hospital ward and explore its preliminary effects (chapter 6)
- 6) To describe the research protocol of a cluster Randomized Controlled Trial (RCT) to evaluate the effectiveness of the Care Programme for the Last Days of Life in acute geriatric hospital wards (chapter 7)

## **1.2.2. Methodology**

### **I. Death certificate study in Flanders**

In order to compare the main goal of treatment in the last week of life of people aged 86 and older with those between 75 and 85 years, and thus address the first research objective, a secondary analysis of a previously published death certificate study was performed.

This death certificate study was conducted in the Flemish speaking part of Belgium in 2007. A random sample (N = 6927) of all death certificates of people aged one year or older and dying between June 1 and November 30, 2007 was received by the Flemish Agency for Care and Health. For each sampled death certificate the certifying physician was sent an anonymous structured questionnaire, identifying non-sudden deaths and medical end-of-life decisions that preceded death.

Prior to the analysis, cases were weighted to be representative of all deaths in Flanders in 2007. In the questionnaire, the treating physician was asked whether the death was sudden and unexpected (yes/no). The questionnaire included the question: ‘What was the main goal of treatment in the last week of life?’ with answer categories ‘cure’, ‘life-prolonging’ or ‘comfort’. All non-sudden deaths of persons aged 75 years and older were selected as being in principle eligible for comfort care in the final week of life.

More details on the methodology of this study are described in the published study protocol<sup>61</sup>. Positive recommendations for the anonymity procedure and study protocol were obtained from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Ethics Committee of the University Hospital of Ghent University, the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

### **II. Retrospective cross-sectional descriptive study**

To address research objectives 2 and 3, namely describing end-of-life care in terms of performed nursing and medical interventions, quality of dying and the policy of prescription and deprescription of medication in the last 48 hours of life of patients in acute geriatric hospital wards, we analyzed data collected through a retrospective cross-sectional descriptive study.

This cross-sectional study is the baseline assessment as part of the cluster RCT to evaluate the effectiveness of the Care Programme for the Last Days of Life. The cross-sectional study or baseline assessment was conducted from October 1<sup>st</sup> 2012 to September 30<sup>th</sup> 2013 in 23 acute

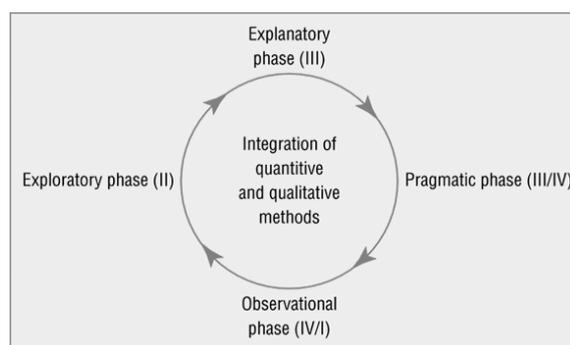
geriatric wards in 13 Flemish hospitals. For each deceased patient who has been hospitalized for more than 48 hours and has given informed consent at admission for the use of their personal information from medical or nursing records, the following characteristics were collected by the researcher via administrative files of the participating hospitals: age, sex and length of hospital stay. Structured after-death questionnaires were filled out by the nurse, the physician and the family carer most involved in end-of-life care for the patient who died on the geriatric ward. After-death questionnaires surveyed socio-demographic characteristics, clinical characteristics, end-of-life care in terms of the performed nursing and medical interventions in the last 48 hours of life, the physician's policy of prescribing and deprescribing medication in the last 48 hours of life and quality of dying.

More details on the methodology of this study as part of the cluster RCT are described in chapter 7 or the published study protocol of the cluster RCT<sup>62</sup>. The study was approved by the Central Ethics Committee of the Vrije Universiteit Brussel (VUB) (Belgium) and by the Local Ethics Committees of the participating hospitals in Flanders.

### **III. Medical Research Council (MRC) Framework for developing and evaluating complex interventions**

In order to address the third research aim with research objectives 4 to 6, the development and evaluation of the Care Programme for the Last Days of Life was conducted using the Medical Research Council (MRC) Framework for the Evaluation of Complex Interventions<sup>63</sup>. The MRC Framework follows a five phase iterative approach, i.e. pre-clinical phase (phase 0), modeling phase (phase I), exploratory phase (phase II), explanatory phase (phase III) and large-scale implementation (phase IV), and has proved to be valuable in guiding the development, modelling and evaluation of complex interventions (Figure 1)<sup>63-65</sup>. Each phase suggests the use of appropriate quantitative and/or qualitative methodologies depending on the specific objectives of the phase, and requires a specific study design taking into account the theoretical basis, any evidence on the issue and the context's specificity<sup>63</sup>. In this thesis we aimed to complete the first four phases, from pre-clinical phase to phase III.

Figure 1 Medical Research Council Framework for complex interventions<sup>63</sup>



First, phases 0-I according with the MRC Framework were completed in order to accomplish research objective 4. Phase 0 consisted of a review of existing LCP programmes from the UK, Italy and the Netherlands, a literature review to identify key factors for a successful LCP implementation and an analysis of the concerns raised in the UK regarding the LCP. In phase I, we developed the Care Programme for the Last Days of Life for older patients dying in acute geriatric wards based on the results of phase 0. The Care Programme was reviewed and refined by two nurses and two physicians working in an acute geriatric ward and by two experts from Italy and the Netherlands. More information about the phase 0-I study can be found in chapter 5.

Phase II of the MRC Framework was completed in order to accomplish research objective 5, i.e. testing if the implementation of the Care Programme for the Last Days of Life is feasible and exploring which preliminary effects may be achieved. This phase II encompassed a mixed methods study including participant observation and the use of a quantitative evaluation tool measuring the success of implementation. More information about the phase 2 study can be found in chapter 6.

According to the MRC Framework, a thorough evaluation of a complex intervention is needed before implementing it in practice<sup>63</sup>. We developed a study protocol for a cluster RCT (phase III of the MRC Framework) to evaluate the effectiveness of the Care Programme for the Last Days of Life<sup>62</sup>. The study protocol can be found in chapter 7. The development of this phase III study protocol addressed our last research objective.

With respect to phase II and III, we received approval of the Central Ethics Committee of the University Hospital of the Vrije Universiteit Brussel and by the Local Ethics Committees of the hospitals that participated in the study.

### **1.2.3. Outline of this dissertation**

In chapter 2 of this first part the results of a secondary analysis of a population-based survey in Belgium are presented (addressing research objective 1).

In part II of this dissertation end-of-life care for older patients in acute geriatric hospital wards is described. In chapter 3 end-of-life care in terms of nursing and medical interventions in the last 48 hours of life and the quality of dying of patients in acute geriatric hospital wards are described (addressing research objective 2). Chapter 4 describes the policy of prescription and deprescription of medication in the last 48 hours of life in acute geriatric hospital wards (addressing research objective 3).

Part III of this dissertation deals with the development and testing of the Care Programme for the Last Days of Life to improve end-of-life care in acute geriatric hospital wards. The development of the Care Programme for the Last Days of Life for the acute geriatric hospital setting is described in chapter 5 (addressing research objective 4). Chapter 6 describes the testing of the Care Programme for the Last Days of Life (addressing research objective 5). The research protocol of a cluster RCT to evaluate the effectiveness of the Care Programme for the Last Days of Life in acute geriatric wards, is outlined in chapter 7 (addressing research objective 6).

Finally chapter 8 in part IV presents a general discussion of the major findings in this thesis with recommendations for practice, policy and future research.

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**CHAPTER 2:**

**FACTORS ASSOCIATED WITH THE  
GOAL OF TREATMENT IN THE LAST  
WEEK OF LIFE IN OLD COMPARED TO  
VERY OLD PATIENTS: A  
POPULATION-BASED DEATH  
CERTIFICATE SURVEY**

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## **ABSTRACT**

### **BACKGROUND**

Little is known about the type of care older people of different ages receive at the end of life. The goal of treatment is an important parameter of the quality of end-of-life care. This study aims to provide an evaluation of the main goal of treatment in the last week of life of people aged 85 and older compared with those between 75 and 85 and to examine how treatment goals are associated with age.

### **METHODS**

Population- based cross sectional survey in Flanders, Belgium. A stratified random sample of death certificates was drawn of people who died between 1 June and 30 November 2007.

The effective study sample included 3,623 deaths (response rate: 58.4%). Non-sudden deaths of patients aged 75 years and older were selected (N=1681).

Main outcome was the main goal of treatment in the last week of life (palliative care or life-prolonging/curative treatment).

### **RESULTS**

In patients older than 75, the main goal of treatment in the last week was in the majority of cases palliative care (77.9%). Patients between 75 and 85 more often received life-prolonging/curative treatment than older patients (26.6% vs. 15.8%). Most patient and health care characteristics are similarly related to the main goal of treatment in both age groups. The patient's age was independently related to having comfort care as the main goal of treatment. The main goal of treatment was also independently associated with the patient's sex, cause and place of death and the time already in treatment.

### **CONCLUSION**

Age is independently related to the main goal of treatment in the last week of life with people over 85 being more likely to receive palliative care and less likely to receive curative/life-prolonging treatment compared with those aged 75-85. This difference could be due to the patient's wishes but could also be the result of the attitudes of care givers towards the treatment of older people.

## **BACKGROUND**

People aged 85 and older form the fastest growing age group in most European countries and their number is predicted to double in the next 20 years [1]. To date, little is known about the type of care that older people of different ages receive at the end of life. Palliative care has been identified as a public health priority worldwide for older people [2,3]. The WHO promotes palliative care as the preferred approach to end-of-life care, irrespective of age. The absence of a palliative or comfort care goal at the time of death in patients suffering from chronic life-limiting diseases is generally associated with poor quality end-of-life care [4].

Palliative care is aimed at improving the quality of life of patients and their families by providing relief from physical, psychological and spiritual problems, while curative treatment is focused on cure or management of a chronic disease and on prolonging life [2-4]. Many chronically ill older people need a mix of both palliative and life-prolonging or curative treatment [5]. However, life-prolonging and curative treatment decreases as the illness progresses and at the end of life the main goal of treatment should be palliative-oriented for most people [4].

Previous studies in Belgium have shown that for approximately 20% of patients a palliative treatment goal is lacking in the last week of life [6]. Recognizing that death is imminent is particularly challenging in the care of older people suffering from slowly progressive or fluctuating long term conditions [5,7]. Studies have shown that the quality of end-of-life care for older people is often suboptimal, especially in hospitals where burdensome interventions aimed at cure or prolonging life are sometimes continued until death [8-10]. Furthermore, a growing body of scientific literature shows that provision of end-of-life care also varies between patients of different ages [11-13].

The objective of this study is to provide a population-based evaluation of the main goals of treatment in the last week of life of people older than 85 compared with those between 75 and 85.

## **METHODS**

This is a secondary analysis of a survey with the primary aim of studying end-of-life practices in Flanders, Belgium. The survey was conducted with the use of data from death certificates in the Flemish speaking part of Belgium. In 2007, we performed a large-scale death certificate study in Flanders, Belgium (approximately 55,000 deaths per year). Questionnaires were sent to the reporting physicians on a representative sample of death certificates received by the Flemish Agency for Care and Health between June 1 and November 30, 2007. We received questionnaires for 3,623 of the 6927 initial cases. From non-response analyses, we found that for 725 cases response was not possible owing to issues of access to the medical file or to patient identification; these cases were removed from the sample. Cases were weighted to be representative of all deaths in Flanders in 2007.

In the questionnaire, the treating physician was asked whether the death was sudden and unexpected (yes/no). The questionnaire included the question: ‘What was the main goal of treatment in the last week of life?’ with answer categories ‘cure’, ‘life-prolonging’ or ‘comfort’. For this paper, ‘life-prolonging’ and ‘cure’ were concatenated. All non-sudden deaths of persons aged 75 years and older were selected as being in principle eligible for comfort care in the final week of life.

The study protocol has been published elsewhere [14]. Positive recommendations for the anonymity procedure and study protocol were obtained from the Ethical Review Board of the University Hospital of the Vrije Universiteit Brussel, the Ethics Committee of the University Hospital of Ghent University, the Belgian National Disciplinary Board of Physicians and the Belgian Federal Privacy Commission.

## **ANALYSES**

Bivariate differences between age groups were tested by Chi-square test. P-values that were less than or equal to 0.05 were considered to indicate statistical significance.

A binary multivariable logistic regression analysis was performed for both age groups to estimate the factors associated with palliative care as the main goal of treatment in the last week of life. SPSS version 20.0 was used for all statistical computations.

## RESULTS

### *Characteristics of non-sudden deaths by age groups*

The study sample included 6202 deaths. The response rate was 58.4%. Of all deaths of patients over 75 years old, 1681 were deemed non-sudden. Of those 57.3% were between the ages of 75 and 85 and 42.7% were older than 85 (Table 1). The older group differed in characteristics from the younger group. They were more often female (70.2 vs. 48.9%), widowed (72.1 vs. 38.9%) and of lower education (47.4 vs. 39.5%). Also they more often died from cardiovascular diseases (31.3 vs. 21.3%) and in care homes (54.0 vs. 21.1%).

**Table 1. Characteristics of non-sudden deaths of patients aged 75 - 85 compared with patients older than 85\***

	<b>75-85 years</b> N=964 (57.3)	<b>&gt;85 years</b> N=717 (42.7)	<b>p-value†</b>
<b>Sex</b>			<b>&lt;0.001</b>
Female	471 (48.9)	503 (70.2)	
Male	493 (51.1)	214 (29.8)	
<b>Marital status</b>			<b>&lt;0.001</b>
Widowed	375 (38.9)	517 (72.1)	
Married	473 (49.0)	133 (18.5)	
Single	90 (9.3)	57 (7.9)	
Divorced	27 (2.8)	10 (1.4)	
<b>Education</b>			<b>&lt;0.001</b>
Primary school	381 (39.5)	340 (47.4)	
High school (not graduated)	182 (18.9)	89 (12.4)	
High school/college	123 (12.7)	73 (10.2)	
Unknown	279 (28.9)	216 (30.1)	
<b>Cause of death</b>			<b>&lt;0.001</b>
Cardiovascular disease	205 (21.3)	224 (31.3)	
Malignant disease	314 (32.6)	103 (14.4)	
Respiratory disease	136 (14.1)	100 (14.0)	
CVA/stroke	102 (10.6)	62 (8.7)	
Disease of the nervous system	42 (4.4)	29 (4.1)	
Other disease	165 (17.1)	198 (27.7)	
<b>Place of death</b>			<b>&lt;0.001</b>
Hospital	537 (55.7)	229 (31.9)	
Care home	204 (21.1)	387 (54.0)	
Home	203 (21.1)	85 (11.9)	
Other/unknown/missing	20 (2.1)	16 (2.2)	

\*Number of cases (weighted percentages)

† Chi-square test for differences between age group

### ***Patient and health care characteristics by age groups and goal of treatment in the last week of life***

Patients between 75 and 85 years more often received life-prolonging or curative treatment than those over 85 years (26.6% vs. 15.8%,  $p < 0.001$ ). In both age groups, comfort care was more often the main goal of treatment for people in care homes or at home compared with those in hospitals. Other disease characteristics related to receiving comfort care are dying from a malignant disease and being in treatment for a longer period of time (table 2).

In the older group, female patients more often had a comfort care goal in the last week of life than did their male counterparts, as had patients without a partner. In the younger group those lacking capacity were more likely to receive life-prolonging or curative treatment at the end of life than were those of that age group with capacity, a difference not found in the older group.

**Table 2. Patient and health care characteristics by age groups and goal of treatment in the last week of life\***

	75-85 years N= 964 (57.3)		p-value	>85 years N= 717 (42.7)		p-value
	Comfort care N= 683 (73.4)	Life-prolonging or curative treatment N= 248 (26.6)		Comfort care N= 574 (84.2)	Life-prolonging or curative treatment N= 108 (15.8)	
<b>Sex</b>			0.540			<b>0.005</b>
Female	337 (72.5)	128 (27.5)		418 (86.7)	64 (13.3)	
Male	346 (74.2)	120 (25.8)		156 (78.0)	44 (22.0)	
<b>Marital status</b>			0.505			<b>0.004</b>
Widowed	258 (70.9)	106 (29.1)		425 (85.9)	70 (14.1)	
Married	347 (75.6)	112 (24.4)		94 (74.0)	33 (26.0)	
Single	59 (72.8)	22 (27.2)		45 (88.2)	6 (11.8)	
Divorced	19 (73.1)	7 (26.9)		10 (100)	0 (0.0)	
<b>Education</b>			0.131			0.141
Primary school	262 (69.7)	114 (30.3)		284 (85.3)	49 (14.7)	
High school (not graduated)	126 (75.4)	41 (24.6)		77 (90.6)	8 (9.4)	
High school/college	86 (72.3)	33 (27.7)		50 (79.4)	13 (20.6)	
Unknown	209 (77.7)	60 (22.3)		163 (81.1)	38 (18.9)	
<b>Place of death</b>			<0.001			<0.001
Hospital	292 (57.1)	219 (42.9)		148 (70.5)	62 (29.5)	
Care home	180 (90.5)	19 (9.5)		338 (89.7)	39 (10.3)	
Home	191 (95.5)	9 (4.5)		74 (91.4)	7 (8.6)	
<b>Cause of death</b>			<0.001			<0.001
Cardiovascular disease	116 (60.4)	76 (39.6)		174 (84.9)	31 (15.1)	
Malignant disease	276 (89.9)	31 (10.1)		93 (93.9)	6 (6.1)	
Respiratory disease	86 (65.6)	45 (34.4)		61 (65.6)	32 (34.4)	
CVA/stroke	65 (65.7)	34 (34.3)		53 (88.3)	7 (11.7)	
Disease of the nervous system	34 (81.0)	8 (19.0)		25 (86.2)	4 (13.8)	
Other disease	106 (66.2)	54 (33.8)		168 (86.2)	27 (13.8)	
<b>Capacity to make decisions†</b>			<0.001			1.000
Capable	153 (92.7)	12 (7.3)		62 (89.9)	7 (10.1)	
Incapacitated	264 (71.9)	103 (28.1)		269 (89.1)	33 (10.9)	
<b>Time in treatment for disease that caused death</b>			<0.001			<0.001
1-7 days	67 (39.4)	103 (60.6)		90 (65.7)	47 (34.3)	
7 days – 1 month	102 (63.4)	59 (36.6)		103 (80.5)	25 (19.5)	
1 month – 1 year	132 (76.7)	40 (23.3)		98 (90.7)	10 (9.3)	
More than 1 year	69 (94.5)	4 (5.5)		34 (97.1)	1 (2.9)	

\*Number of cases (weighted percentages)

† 1242 missing cases

### ***Factors associated with goal of treatment in the last week of life***

After controlling for the confounders sex, cause of death, place of death and time in treatment for the disease, age was independently related to the main goal of treatment in the last week of life. Those in the older group had a 1.61 higher chance (95% confidence interval: 1.20-2.17) of having a comfort care goal in the last week of life as compared with the younger group (not in tables). Other factors associated with comfort care as the main goal of treatment in the last week of life were similar in both age groups (Table 3). The chances of receiving comfort care in the last week of life rather than life-prolonging or curative treatment were in both age groups lower for those dying from non-malignant diseases, for those having been in treatment for the disease for a shorter period of time and for those dying in hospital.

**Table 3. Differences in age and other factors associated with having a comfort care goal as main goal of treatment\***

<b>Factors related to goal of treatment</b>	<b>75-85 years</b>	<b>&gt;85 years</b>
	<b>OR (95% CI)</b>	<b>OR (95% CI)</b>
<b>Sex</b>		
Male	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Female	1.37 (0.90-2.07)	<b>1.82 (1.03-3.23)</b>
<b>Cause of death</b>		
Cardiovascular disease	<b>0.25 (0.13-0.48)</b>	<b>0.28 (0.09-0.91)</b>
Malignant disease	1.00 (1.00-1.00)	1.00 (1.00-1.00)
Respiratory disease	<b>0.28 (0.14-0.55)</b>	<b>0.14 (0.04-0.43)</b>
CVA/stroke	<b>0.47 (0.23-0.96)</b>	0.59 (0.16-2.21)
Disease of the nervous system	<b>0.21 (0.07-0.68)</b>	0.48 (0.08-2.95)
Other disease	<b>0.28 (0.14-0.56)</b>	<b>0.27 (0.08-0.85)</b>
<b>Time in treatment for disease that caused death</b>		
<1 week	1.00 (1.00-1.00)	1.00 (1.00-1.00)
1 week-1 month	<b>2.42 (1.48-3.96)</b>	<b>2.14 (1.17-3.93)</b>
1 month-1 year	<b>2.97 (1.73-5.08)</b>	<b>4.23 (1.90-9.43)</b>
>1 year	<b>7.43 (2.27-24.35)</b>	<b>11.12 (1.07-115.57)</b>
<b>Place of death</b>		
Care home	<b>8.67 (4.07-18.48)</b>	<b>2.91 (1.65-5.15)</b>
Home	<b>16.17 (3.13-83.62)</b>	<b>7.41 (1.25-44.07)</b>
Hospital	1.00 (1.00-1.00)	1.00 (1.00-1.00)

\*Multivariable logistic regression. Presented figures are odds ratios and 95% confidence intervals. Significant results are indicated in bold. Independent variables which have no significant relationships are not presented in the table.

## DISCUSSION

This study indicates that for patients aged 75 and above, the main goal of treatment in the last week of life was in a large majority of cases comfort care (77.9%). However, those aged between 75 and 85 were more likely to receive mainly life-prolonging or curative treatment than those older than 85 (26.6% vs. 15.8%) at the expense of comfort care (73.4% vs 84.2%). This age difference persists even after controlling for relevant confounders of sex, cause of death, place of death and time in treatment for the disease. In both age groups, the chances of receiving comfort care in the last week of life were lower for people dying from non-malignant diseases, for those having been in treatment for their disease for a shorter period of time and for those dying in hospital.

Our study used a robust design also pursued in previous studies [15,16], including a large representative sample of death certificates and applying a mailing procedure guaranteeing total anonymity for patients and physicians. Although a non-response bias cannot be completely excluded, our non-response survey did not point in that direction. Consequently, we believe our results to be representative for all non-sudden deaths of those older than 75 in 2007 in Flanders, Belgium. As this is a secondary analysis of a survey primarily intended to study end-of-life practices, certain aspects that would have provided a more complete insight, such as the severity of the patient's condition and their functional status, the content of care in the last week of life, the patient's wishes for end-of-life care or the existence of an advance care plan were not studied. Nevertheless, our study is the first to provide robust epidemiological information about the extent to which older people predominantly receive comfort care at the end of life and which factors influence these patients receiving such care.

Although all deaths in this study were deemed non-sudden and expected by the treating physician, cure or life-prolonging treatment was the main goal of treatment in a substantial number of cases. Controlling for other factors, those above 85 are more likely to have a comfort care goal in the last week of life than are those between 75 and 85. A similar result was found in the Netherlands [17]. There are several possible explanations for this finding: it may suggest a palliative care ethos in the care of those above 85 or, alternatively, it may point to a form of ageism in the sense that age may be used as a criterion for rationing health care [13]. This would imply that the medical system will use more potentially life-saving options, appropriately or not, for those 75-85 than for those older than 85. It may also be that physicians believe that above 85, people are less likely to respond to life-prolonging treatments than are younger old patients or that they feel obliged to 'do everything' for

younger patients, even though they may find life-prolonging treatments futile for seriously ill patients of any age [12]. The fact that the lack of capacity to participate in decision-making leads to more aggressive treatment in the 75-85 age-group but not in those above 85 corroborates this hypothesis. It suggests that, in the absence of patient directives, there is an inclination to pursue life-prolonging treatments as long as the patient is not deemed 'too old'.

Irrespective of age group, the chance of receiving comfort care in the last week of life is much lower for older patients who die in a hospital than for those who die in a care home or at home. It is likely that these are older patients sent to hospital precisely for life-saving or curative efforts, for instance in situations where acute care is required. Previous research has indicated that a high number of hospital admissions in older people can, however, be avoided and may be inappropriate [18,19]. A series of complex reasons, including factors relative to the physician, the patient and the family, are usually given for this, the main underlying reason often being the failure to recognize approaching death at the appropriate time and thus to shift treatment towards maintaining comfort [18,19]. Once a patient is referred to a hospital for curative or life-prolonging reasons, the chance to change the focus to palliation may be missed as it can be challenging for hospital staff to distinguish people who can still be treated and recover from their acute situations from those who have reached a point where a shift in focus to palliative or end-of-life care would be more appropriate [20]. Additionally, as reported in previous studies [21,22], acute care hospitals often lack a palliative care ethos. It is likely that in those cases where comfort is not the main goal of treatment in the last week of life, an opportunity for a transition to palliative care has been missed, even though most older people may be in need of some kind of palliative care [2,3,5].

The likelihood of older people with cancer, compared with those with other chronic diseases, receiving care primarily aimed at comfort is striking. This may be related to the fact that palliative care has historically been focused on cancer patients [23], who generally have a clearer prognosis than those with non-malignant diseases such as organ failure, stroke or dementia for whom the timing of death often remains unpredictable until it is very close or who may die unexpectedly before palliative care can be started [5,7,24].

## **CONCLUSIONS**

Although improving the accessibility of palliative care for older people has been identified as an international public health priority [2,3], our findings show that even in the last week of life comfort care is not the main goal of care for a substantial proportion of older people, even among those over 85. These findings warrant more attention to the palliative care needs of older patients, perhaps particularly those between 75 and 85 who seem to be at a higher risk of receiving burdensome curative or life-prolonging interventions, possibly at the cost of their comfort, than those over 85. Further research is needed to better understand the needs of patients of different ages at the end of life and how age influences end-of-life care.

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## **PART II**

# **END-OF-LIFE CARE IN ACUTE GERIATRIC HOSPITAL WARDS**



**CHAPTER 3:**  
**END-OF-LIFE CARE AND QUALITY OF**  
**DYING IN TWENTY-THREE ACUTE**  
**GERIATRIC HOSPITAL WARDS**

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Submitted

# **ABSTRACT**

## **BACKGROUND**

Understanding the current quality of end-of-life care delivered to patients in acute geriatric hospital wards and their quality of dying can have a positive impact on improving practice. This study addresses the following main research questions: (1) which nursing and medical interventions are performed in the last 48 hours of life of patients dying in acute geriatric hospital wards, and (2) what is the quality of dying of these patients?

## **METHODS**

We conducted a retrospective cross-sectional descriptive study in 23 acute geriatric wards in 13 hospitals in Flanders. This sample was obtained after we had invited all acute geriatric Flemish wards to participate in the study. Patients who died between October 1<sup>st</sup> 2012 and September 30<sup>th</sup> 2013 were included in the study. For each included patient, structured after-death questionnaires were filled out by the nurse, the physician and the family carer most involved in end-of-life care. Main outcome measures were the percentages of performed nursing and medical interventions in the last 48 hours of life and the quality of dying.

## **RESULTS**

We included 338 patients (mean age 85.7 years; 173 female). Almost 58% had dementia (mild, moderate or severe) and nearly half were not able to communicate in the last 48 hours of their life. The most frequently continued or begun nursing and medical interventions in the last 48 hours of life were measuring temperature (91.6%), repositioning (83.3%), washing (89.5%), oxygen therapy (49.7%), intravenous fluids and nutrition (30%), antibiotics (22.8%) and routine blood tests (19.2%). In the same time span, shortness of breath, lack of serenity, lack of peace and lack of calm were reported most frequently by both nurses and family carers.

## **CONCLUSION**

Many nursing and medical interventions are continued or even begun in the last hours of a patient's life, which may not always be in their best interests. Furthermore, patients dying in acute geriatric wards are often affected by several symptoms which poses challenges to the provision of optimal end-of-life care, especially with respect to the patient's wellbeing.

## BACKGROUND

Populations worldwide are ageing, leading to a major increase in the proportion of those aged 65 years and older<sup>1</sup>. Patterns of disease in the last years of life are also changing with more people dying from chronic debilitating conditions, such as cardiovascular disease, chronic obstructive pulmonary disease, diabetes, cancer and dementia<sup>1</sup>. Since many of these illnesses are more common among older people, this group frequently experiences multiple and complex health problems and disabilities until death, and will therefore have special care needs at the end of life<sup>1,2</sup>.

Despite the fact that many people prefer to die at home<sup>3</sup>, a substantial proportion of these older people will die in a hospital setting<sup>4</sup>, e.g. in acute geriatric hospital wards, where ensuring appropriate end-of-life care is complex and challenging due to a focus on cure and life-prolonging treatment<sup>5-8</sup>, a lack of palliative care knowledge in hospital staff and difficulties in predicting the time of death in older people<sup>5-7,9-11</sup>. However, delivering optimal end-of-life care is a necessity for every patient, regardless of age, setting and diagnosis<sup>1</sup>. It is known for instance that appropriate care for the dying consists of the prevention of symptoms such as pain and distress, urinary retention, constipation and pressure ulcers, performing mouth care, carefully considering the need for rehydration and avoiding over-intervention with inappropriately aggressive treatments<sup>12,13</sup>. International research suggests that older people have reported that adequate pain and symptom management, spiritual and/or psychological well-being, avoiding inappropriate prolongation of dying, and providing best quality of life for their families are important aspects of optimal care which may contribute to a 'good death'<sup>13</sup>.

If we want to ensure and improve the quality of end-of-life care for people hospitalized in acute geriatric wards, we must first understand how end-of-life care is currently delivered and how people are presently dying. Knowledge regarding the nature and quality of end-of-life care in older people is increasing<sup>7,13-27</sup>, both in nursing homes and in the acute hospital setting. However, published research about end-of-life care for older patients in the acute hospital setting is from the United Kingdom<sup>13,20-23</sup>, Singapore<sup>24</sup> and Norway<sup>25,26</sup>, with no research published for the Belgian context where hospital care might be differently organized and care processes may be delivered differently. Additionally, the research that has been performed in the hospital setting is characterized by low sample sizes, an investigation of either the perspectives of nurses, physicians or family carers but no combination of these and a retrospective case note review methodology. Nevertheless, due to the limitations of incomplete documentation, difficulty in interpreting information found in the documents and variance in

the quality of information recorded by medical professionals<sup>25,28,29</sup> adopting this methodology is discouraged and other methodologies such as a questionnaire study are preferable. None of these studies were performed solely in specialized acute care units for older people, e.g. acute geriatric wards, indicating that research regarding end-of-life care for patients hospitalized in such wards is lacking. It is therefore beneficial to investigate end-of-life care delivered to patients hospitalized in acute geriatric wards, and how such patients die, by using a questionnaire methodology.

Hence, the general aim of this multicentre study was to examine end-of-life care and quality of dying by answering the following main research questions: (1) which nursing and medical interventions are performed in the last 48 hours of life of patients dying in acute geriatric hospital wards, and (2) what is the quality of dying of these patients?

## **METHODS**

### **DESIGN**

A retrospective cross-sectional descriptive study was conducted in Flanders, Belgium. Structured after-death questionnaires were filled out by the nurse, the physician and the family carer most involved in the care for the patient who died on the geriatric ward.

### **SETTING AND STUDY POPULATION**

After we had invited all hospitals situated in East and West Flanders and five hospitals from Antwerp and Limburg to participate in the study, we obtained a sample consisting of 23 acute geriatric wards in 13 Flemish hospitals. Deceased patients were included in the study and thus eligible for evaluation if they (a) had given their informed consent at the time of admission for the use of their personal information from medical or nursing records for the purposes of the study and (b) were hospitalized on the geriatric ward for more than 48 hours.

### **DATA COLLECTION**

From October 1<sup>st</sup> 2012 to September 30<sup>th</sup> 2013 all participating geriatric wards included patients who died on the ward. For each eligible patient, the following characteristics were collected by the researcher via the administrative files of the participating hospitals: age, gender and length of hospital stay (Figure 1). The nurse and the physician who had been most closely involved in the end-of-life care of the patient were asked to fill out a questionnaire within one week after death in order to minimize recall bias (Figure 1). Six weeks after death a questionnaire was sent to the patient's family carer who had been most closely involved in the end-of-life care and had given informed consent to be contacted by the researcher (Figure 1).

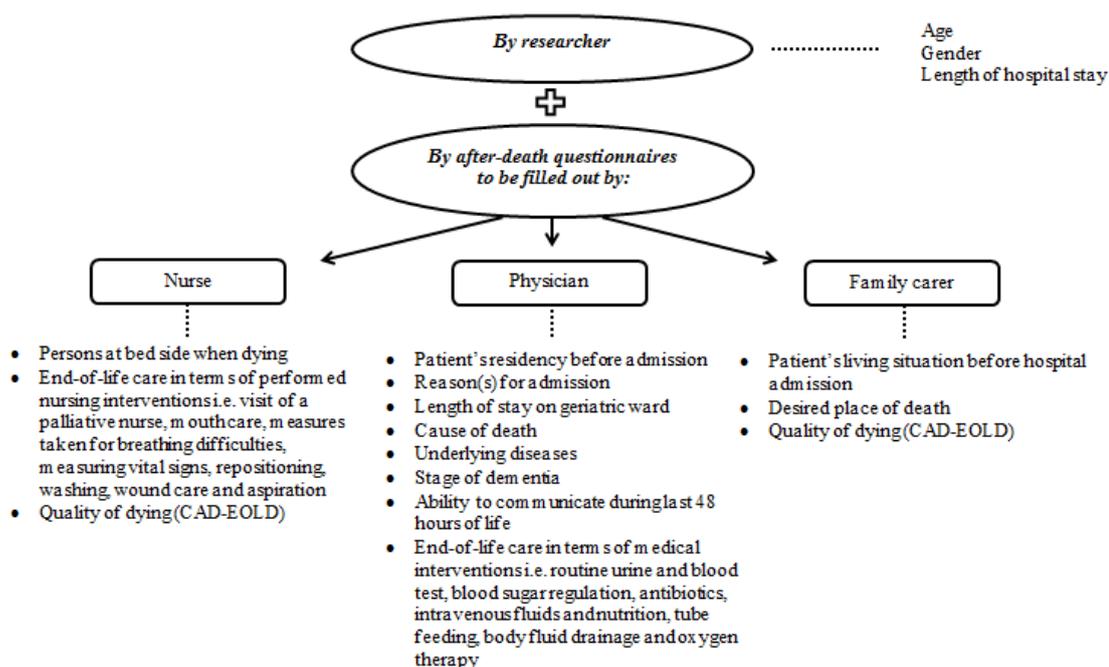
In cases where the family carer did not respond to the original questionnaire up to two reminders were sent, two weeks after the initial sending of the questionnaire and two weeks after that.

## MEASUREMENTS

After-death questionnaires filled out by the nurse, the physician and the family carer surveyed socio-demographic characteristics, clinical characteristics, the performed nursing and medical interventions in the last 48 hours of life and the quality of dying (Figure 1).

Performed nursing and medical interventions in the last 48 hours of life were measured by asking about visits from a palliative care nurse, the performance of nursing interventions at three points (48 to 24 hours before death, 24 to 12 hours before death and in the last 12 hours before death) and the performance of medical interventions in the last 48 hours of life (Figure 1). To measure the quality of dying, the nurse and family caregiver questionnaire contained the validated Comfort Assessment in Dying End-of-Life in Dementia Scale (CAD-EOLD)<sup>30</sup> (Figure 1). The original scale aims to measure the perceptions of symptom intensity and conditions common during the last week of life and contains 14 items each with a possible range from 1 (worst) to 3 (best). The total score is a summation of the 14 items and ranges from 14–42, with a higher score indicating a higher level of comfort for the patient<sup>31,32</sup>. In order to assess the comfort in the last 48 hours of life instead of the last week of life, wordings with respect to recall periods were modified.

Figure 1 Data collection of the study population



## **STATISTICAL ANALYSIS**

Descriptive statistics were used to describe the characteristics of the study population, the performed nursing and medical interventions in the last 48 hours of life and the quality of dying (CAD-EOLD). Results are reported as means and standard deviations (SD) or percentages. The Friedman Test was used to compare performed nursing interventions between the three different periods (48 to 24 hours before death, 24 to 12 hours before death and in the last 12 hours before death). All analyses were performed with SPSS statistical software, version 20 (SPSS Inc., IBM, USA).

## **ETHICAL APPROVAL**

Approval was obtained from the Central Ethics Committee of the Vrije Universiteit Brussel (VUB) (Belgium) and by the Local Ethics Committees of the participating hospitals in Flanders (B.U.N. 143201213985).

## **RESULTS**

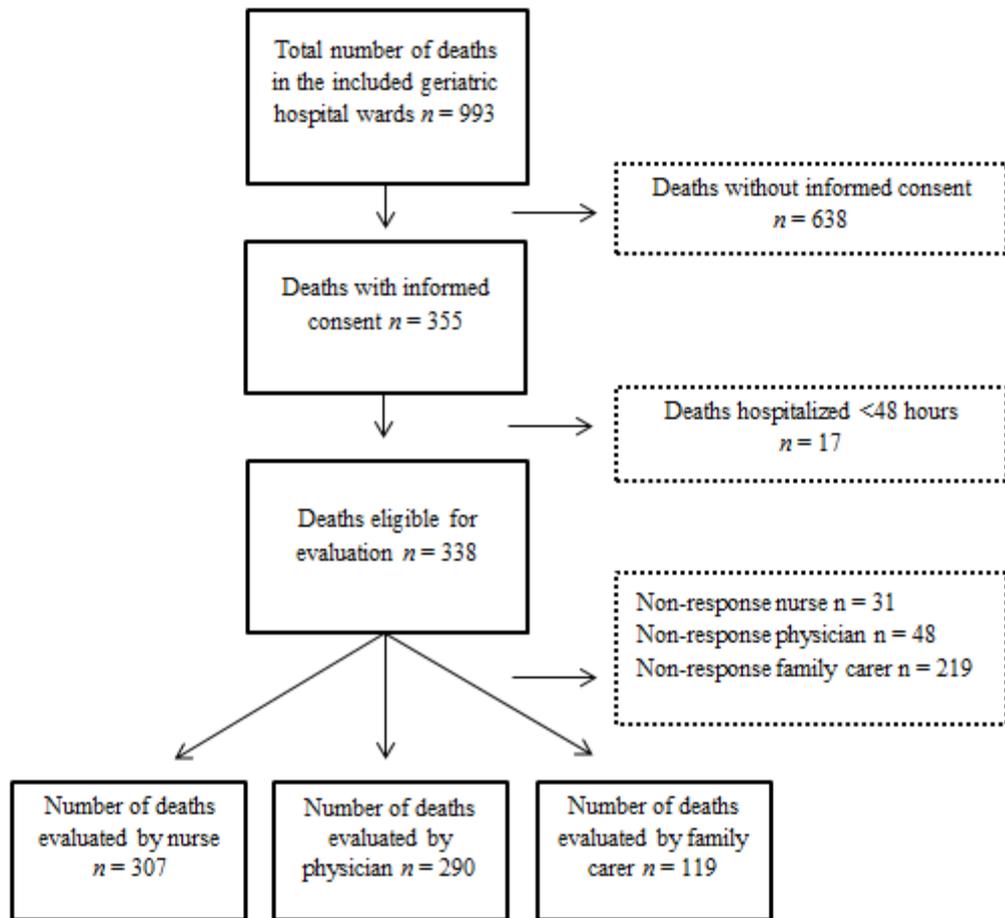
### ***Included patients who died on the acute geriatric wards***

From October 1<sup>st</sup> 2012 to September 30<sup>th</sup> 2013 a total of 993 patients died on the wards. Of these, 655 could not be included in the study because they had not given informed consent at admission for their personal data to be used for research purposes (n = 638) or because they were hospitalized for less than 48 hours (n = 17); 338 patients could thus be included in the study (Figure 2). There were no differences between included patients (n=338) and non-included patients (n=655) in terms of age (p=0.370) and gender (p=0.531). However, the mean length of hospital stay of non-included patients (16.4 days) was significantly shorter than that of included patients (23.7 days) (p <0.001).

### ***Responses of nurses, physicians and family carers***

Response rates for questionnaires of nurses was 91%, for physicians 85% and for family carers 35% (Figure 2). Since we obtained high response rates for the nurse and physician questionnaires, we were able to perform a thorough non-response analysis to assess a possible response bias for family carers. Results from a multivariate analysis showed that age and dying alone were independently related to the response of the family carer. Older patients were more likely to be evaluated by a family carer than younger patients (OR 1.05; p=0.020) and it was less likely in patients who died alone that a family carer questionnaire was filled out (OR 0.52; p=0.019).

Figure 2 Flow chart of the inclusion and evaluation of deceased geriatric hospital patients



### ***Characteristics of included patients***

Of the 338 included patients, the mean age was 85.7 (SD 6.52) years and 52% were female (Table 1). Mean length of stay in the hospital was 24.8 (SD 23.28) days (Table 1). Almost 20% of the included patients stayed longer than four weeks on the acute geriatric ward whereas the other 80% died after a shorter period (Table 1). According to the family carers approximately 48% of the patients wished to die at home and nearly 22% in a nursing home, service flat or hospital (Table 1). Nurses reported that 37% of the patients died alone on the ward (Table 1). Almost 58% of the patients had dementia (mild, moderate or severe) and nearly half were not able to communicate in the last 48 hours of life due to dementia, decreased consciousness, unconsciousness or an acute confusional state (Table 1). Acute organ failure (43.5%) and acute infectious diseases (39.9%) were the most important immediate causes of death (Table 1).

**Table 1 Characteristics of included patients died in acute geriatric wards**

Patient characteristics	N = 338 n (%)
<b>Age at death, mean number of years (SD)* [Observed range]</b>	85.7 (6.52) [63-103]
<b>Gender*</b>	
Female	173 (52.0)
Male	160 (48.0)
<b>Residency before admission to hospital†</b>	
Home	213 (74)
Nursing home	60 (20.8)
Service flat	10 (3.5)
Other hospital	3 (1.0)
Rehabilitation institute	2 (0.7)
<b>Reason(s) for admission to acute geriatric ward †   </b>	
A medical intervention was necessary	261 (90.6)
The care burden was too high for family carers	28 (9.7)
The care burden was too high for health care staff of the NH	8 (2.8)
The patient desired a hospital admission	5 (1.7)
There was no place in a nursing home	5 (1.7)
Other	6 (2.1)
<b>Length of hospital stay, mean number of days (SD)*</b>	24.8 (23.28)
<b>Length of stay on acute geriatric ward †</b>	
>4 weeks	56 (19.7)
2-4 weeks	95 (33.5)
1-2 weeks	73 (25.7)
72 hours-1 week	51 (18.0)
<72 hours	9 (3.2)
<b>Living situation before hospital admission ‡</b>	
Home, alone	45 (38.1)
Home with partner/children/other	50 (42.4)
Nursing home, alone	21 (17.8)
Nursing home with partner	2 (1.7)
<b>Desired place of death ‡</b>	
Home	55 (47.8)
Nursing home	7 (6.1)
Service flat	2 (1.7)
Hospital	16 (13.9)
Unknown	35 (30.4)
<b>Persons at bed side when dying §   </b>	
Died alone	112 (37.1)
Family	151 (50.0)
Nurse	195 (64.6)
General practitioner	1 (0.3)
Hospital physician	5 (1.7)
Other (nursing student, pastoral assistant)	6 (2.0)
<b>Immediate cause of death †</b>	
Acute oncologic	32 (11.5)
Acute infectious	111 (39.9)
Acute organ failure	121 (43.5)
Frailty/dementia	14 (5.0)
<b>Underlying diseases †</b>	
Metastatic cancer	40 (14.3)
Neurodegenerative disorder	4 (1.4)
Frailty	13 (4.6)
Organ failure	88 (31.4)
Frailty and organ failure	71 (25.4)
Neurodegenerative disorder and frailty	15 (5.4)
Neurodegenerative disorder and organ failure	17 (6.1)
Neurodegenerative disorder, frailty and organ failure	32 (11.4)
<b>Stage of dementia †</b>	
No dementia	111 (41.9)
Mild	57 (21.5)
Moderate	47 (17.7)
Severe	50 (18.9)
<b>Able to communicate during the last 48 hours †</b>	
Yes	152 (53)
No, because of	
Dementia	55 (19.2)
Decreased consciousness	58 (20.2)
Unconsciousness	12 (4.2)
Acute confusional state	34 (11.8)
Other	11 (3.8)

Missing values: age at death: n=11/338 (3.3%), gender: n=5/338 (1.5%), residency before admission: n=2/290 (0.7%), reason(s) for admission: n=2/290 (0.7%), length of hospital stay: n=7/338 (2.1%), length of stay on acute geriatric ward: n=6/290 (2.1%), living situation before admission: n=1/119 (0.8%), desired place of death: n= 4/119 (3.4%), persons at bed side when dying: n=5/307 (1.6%), cause of death: n=12/290 (4.1%), underlying diseases: n=10/290 (3.4%), stage of dementia: n=25/290 (8.6%), able to communicate during last 48 hours: n=3/290 (1.0%). \* Collected by the researcher; † Reported by the physician; ‡ Reported by the family carer; § Reported by the nurse; || More than one response was possible; Abbreviations: NH = nursing home

## ***End-of-life care in terms of performed nursing and medical interventions***

### *Nursing interventions*

Forty-six and a half percent of the deceased patients received one or more visits from a palliative care nurse. Mouth care in the last 48 hours of life was performed for 98%. For at least 75% of the patients who experienced breathing difficulties due to mucus production, measures were taken. However, for 21% the nurse did not know if any measures were taken. The three most frequently performed nursing interventions in the last 48 hours of life were measuring temperature, repositioning and washing (Table 2). As death approached the patient's vital signs were taken significantly less often and washing and wound care were performed significantly less often (Table 2).

### *Medical interventions*

During the last 48 hours of life, 49.7% of the patients received oxygen therapy, 30% intravenous fluids and nutrition, 22.8% antibiotics and in 19.2% a routine blood test was performed (Table 2). Antibiotics, intravenous fluids and nutrition and blood sugar regulation were stopped in the last 48 hours of life for 17.2%, 15.7% and 12.5% of the patients respectively (Table 2).

**Table 2 Nursing and medical interventions in the last 48 hours of life**

	%			p-value*
<b>Nursing interventions</b> N = 307	48 to 24 hours before death	24 to 12 hours before death	last 12 hours before death	
Blood pressure measurement	81.5	71.7	51.7	<0.001
Pulse measurement	81.9	74.6	57.4	<0.001
Temperature measurement	91.6	84.8	70.3	<0.001
Repositioning	83.3	80.9	80.7	0.070
Washing	89.5	85.5	69.3	<0.001
Wound care	31.7	27.9	19.9	<0.001
Aspiration	15.7	17.3	17.6	0.559
<b>Medical interventions</b> N = 290	Not carried out	Stopped	Continued	Started
Routine urine test	86.8	8.5	3.2	1.4
Routine blood test	69.2	11.5	17.1	2.1
Blood sugar regulation	81.4	12.5	6.1	0.0
Antibiotics	60.0	17.2	18.2	4.6
Intravenous fluids and nutrition	54.2	15.7	27.6	2.4
Tube feeding	94.0	4.2	1.4	0.4
Body fluid drainage	97.9	1.0	0.3	0.7
Oxygen therapy	39.4	11.0	44.7	5.0

Missing values are for nursing interventions 48 to 24 hours before death n= 20/307 (6.5%), nursing interventions 24 to 12 hours before death n=24/307 (7.8%) and nursing interventions last 12 hours before death n=11/307 (3.6%).

\*Differences between the frequency of performed nursing interventions 48 to 24 hours before death, 24 to 12 hours before death and the last 12 hours before death are tested using Friedman Test, significance level at 0.05.

Missing values are for routine urine test n=9/290 (3.1%), routine blood test n=4/290 (1.4%), blood sugar regulation n=10/290 (3.4%), antibiotics n=5/290 (1.7%), intravenous fluids and nutrition n=4/290 (1.4%), tube feeding n=7/290 (2.4%), body fluid drainage n=4/290 (1.4%) and oxygen therapy n=8/290 (2.8%).

## Quality of dying

### Comfort Assessment in Dying - End-of-Life in Dementia (CAD-EOLD)

In the last 48 hours of life, highest levels of comfort were reported by both nurses and family carers for crying (mean for nurse 2.9; mean for family carer 2.6) and moaning (2.5; 2.4). The reported level of the pain item was 2.2 according to nurses and 2.1 according to family carers (Table 3). More exactly, according to nurses and family carers, 59% and 69% of the patients respectively experienced a lot of pain or some pain.

Both proxies reported lowest levels of comfort around dying for shortness of breath (2.0; 1.8), serenity (2.0; 2.0), peace (2.1; 2.0), and calm (2.1; 2.0) (Table 3). More specifically, according to nurses and family carers, 69% and 72% of patients respectively were moderately to highly affected by shortness of breath and the majority experienced a lack of serenity (76% and 80% respectively).

According to family carers, low levels of comfort were also reported for difficulty with swallowing (1.8) and restlessness (1.9) (Table 3).

**Table 3 Quality of dying measured by CAD-EOLD\*: mean scores and distribution**

CAD-EOLD item scores	Reported by nurse N = 307					Reported by family carer N = 119			
	Mean scores (SD)† [Observed range]	%			Mean scores (SD)† [Observed range]	%			
		A lot	Sometimes	Not at all		A lot	Sometimes	Not at all	
1. Discomfort	2.3 (0.72)	15.1	38.9	46.0	2.1 (0.67)	19.6	54.6	25.8	
2. Pain	2.2 (0.73)	17.4	41.8	40.8	2.1 (0.74)	23.7	45.4	30.9	
3. Restlessness	2.2 (0.75)	21.7	41.7	36.7	1.9 (0.72)	34.3	46.5	19.2	
4. Shortness of breath	2.0 (0.79)	30.8	38.0	31.2	1.8 (0.85)	45.1	26.5	28.4	
5. Choking	2.5 (0.71)	12.4	26.8	60.8	2.2 (0.83)	27.4	28.4	44.2	
6. Gurgling	2.3 (0.77)	19.7	33.7	46.6	2.1 (0.81)	30.3	34.3	35.4	
7. Difficulty swallowing	2.2 (0.82)	26.0	28.4	45.7	1.8 (0.75)	39.2	40.2	20.6	
8. Fear	2.3 (0.74)	17.5	38.5	44.0	2.2 (0.74)	20.8	42.7	36.5	
9. Anxiety	2.3 (0.72)	15.5	39.0	45.5	2.0 (0.74)	25.8	46.4	27.8	
10. Crying	2.9 (0.39)	2.1	8.7	89.3	2.6 (0.61)	6.4	26.6	67.0	
11. Moaning	2.5 (0.70)	11.9	30.4	57.7	2.4 (0.74)	15.8	33.7	50.5	
12. Serenity	2.0 (0.68)	22.0	54.2	23.8	2.0 (0.66)	22.9	57.3	19.8	
13. Peace	2.1 (0.67)	18.4	54.4	27.2	2.0 (0.61)	18.8	63.5	17.7	
14. Calm	2.1 (0.62)	13.1	60.3	26.6	2.0 (0.64)	18.6	59.8	21.6	
<b>CAD-EOLD total score</b>	<b>31.9 (5.73) [16-42]</b>				<b>29.1 (5.85) [15-42]</b>				

\*The CAD-EOLD consists of 14 items with each a possible range from 1 (worst) to 3 (best). All items were (re)coded so that higher scores means better symptom management. The 14 items can be separated into four subscales. The CAD-EOLD total score is constructed by summing the value of 14 items. It ranges from 14 to 42 with higher scores indicating better symptom control; missing CAD-EOLD items were imputed with patients' means in case there were four or fewer missing scores on the scale.

Missing values for CAD-EOLD item scores varied between 2.3% and 7.8% for reports by nurses and varied between 14.3% and 21.0% for reports by family carers. Total scores (imputed with subject means for a maximum of four items missing) refer to reports by nurses (9.1% missing) and reports by family carers (23.5% missing).

†SD = standard deviation.

## DISCUSSION

This cross-sectional study examined end-of-life care provided for patients hospitalized in acute geriatric hospital wards in Flanders and their quality of dying. The study showed that several nursing and medical interventions, ie measuring temperature, repositioning, washing, oxygen therapy, intravenous fluids and nutrition, antibiotics and routine blood tests, are continued or even begun in the last 48 hours of life. Nurses and family carers reported that the quality of dying of these older patients is reasonably good although there is some room for improvement regarding shortness of breath and items related to the patient's well-being, such as serenity, peace and calm.

Our study was large-scale and multicentric with 338 patients recruited from 23 acute geriatric wards in 13 Flemish hospitals. As we included hospitals from different regions and of different sizes, this may have increased the generalizability of the study findings<sup>26</sup>. Unlike earlier conducted studies, we did not use a retrospective case note review methodology to examine end-of-life care and quality of dying. Due to incomplete documentation and lack of standardized structure, case note review methodology may lead to underreported variables and thus the validity of the findings may be questioned<sup>25,29</sup>. In contrast, our study adopted a more valid methodology by retrospectively completing questionnaires. Furthermore, three different questionnaires were developed to be filled out by a nurse, a physician and a family carer, which permitted us to investigate the perspectives of different proxies and to assess different constructs within end-of-life<sup>33</sup>. Finally, in this study we obtained a high response rate for both nurses (91%) and physicians (85%).

A number of limitations have to be considered. First, we cannot preclude selection bias as the study wards participated in the study on a voluntary basis and may have had a prior interest in end-of-life care. Furthermore, selection bias may have been introduced because of our inclusion criteria and the low response rate for family carers. This could have biased our results with regard to the quality of end-of-life care and the quality of dying. Although no differences were found between included and non-included patients within our sample in terms of age and gender, the mean length of hospital stay of the included patients was significantly longer. Regarding the low response rate for family carers (35%), a non-response analysis detected few significant differences between characteristics of patients for whom a family carer questionnaire was received and those for whom no family carer questionnaire was received. Only age and dying alone were independently associated with evaluation by a family carer and it may thus be that younger patients and those who died without being

surrounded by family members or friends had a different quality of dying as reported by the family carer. Second, our results may have been affected by assessment bias. Due to the vulnerability and poor health conditions of dying patients, we were not able to interview the patients themselves. Our data are based on proxy measures and not on what the patients themselves experienced. However, the reliability of proxy assessments in older patients with and without dementia for various aspects of quality of end-of-life are well described<sup>34</sup>. Assessments made by health care staff and family carers are reasonably accurate and nurses may be the most suitable source of proxy information, though proxy assessments should always be interpreted with caution<sup>35</sup>. Finally, for practical reasons, we did not compare the performance of medical and nursing interventions and quality of dying between the different participating geriatric wards, which could have added value to the study by providing insight into the extent to which variations in end-of-life care exist between settings.

For about half of the patients, a palliative care nurse visited at the end-of-life, which is more often than what was found in other studies performed in acute hospital in the United Kingdom and Singapore, where palliative care advisory support was sought for only two out of the 25 patients and 31% of patients respectively<sup>22,24</sup>. This may suggest that health care staff more willingly adopt a palliative care approach in an acute geriatric ward than in the average acute hospital ward and consequently more often contact a member of the palliative care team. Alternatively, it could also be that health care staff on the ward have more and easier access to palliative care services or that the palliative care team is more integrated into the acute geriatric ward than into other wards.

We also found that nursing interventions, such as mouth care and the management of breathing difficulties due to mucus production, were appropriately performed in the last 48 hours of life, which are important in contributing to a comfortable death<sup>12,13</sup>. Although some nursing interventions were significantly less often performed as death approached, several interventions such as measuring temperature, repositioning and washing were continued until death in a substantial number of cases. The influence of these interventions on the patient's comfort is questionable. It is for instance known that preventing and treating pressure ulcers by repositioning the patient may relieve discomfort and pain and thus contribute to a pain free death<sup>36,37</sup>. In contrast, other studies show that regularly repositioning or turning the patient may disturb or tire them, or induce pain<sup>38,39</sup>. Also a number of medical interventions, such as oxygen therapy, intravenous fluids and nutrition, antibiotics and routine blood test are continued until death and their appropriateness is also controversial. The choice to continue or

start these interventions should thus be well considered and must be tailored to the individual needs of patients and their family<sup>40-45</sup>.

Comparison of the CAD-EOLD scores with those from other studies is difficult because of important differences in setting and population, although the current study results seem to support previous research that used the same tool<sup>14,17,27,31</sup>. It was for instance found that both nursing home residents with dementia and older patients living with advanced dementia in the community died with a lack of serenity, peace and calm<sup>14,17,27,31</sup>. Results of both the present study and these earlier studies stress the magnitude of unmet psychosocial and existential needs at the end-of-life and the need to address these needs. One possible explanation for these findings could be that in the acute hospital less attention is given to psychosocial and existential aspects of end-of-life care compared with the medical aspects of care. It might also be that addressing these needs in our study population is challenging, knowing that nearly half of patients are not able to communicate in the last 48 hours of their life.

The present study also showed that nurses and family carers reported that a substantial portion of patients hospitalized in acute geriatric wards die with shortness of breath. As measured by the CAD-EOLD, the mean score on this item is similar to what was found in previous research performed in nursing homes<sup>14,17,27,31</sup>. According to research in the acute hospital setting, shortness of breath is a common symptom associated with end-of-life care in older patients<sup>24</sup>. Also pain appears to be an important symptom during the dying process of older people in acute hospital<sup>24</sup>. Previous research has shown that older people, particularly those suffering from non-malignant diseases, are less likely to receive appropriate pain control at the end of life compared with their younger counterparts<sup>46</sup>. However, in this study we cannot convincingly consider pain as a concern as we obtained a better mean score on the pain item in comparison with earlier performed studies in nursing homes<sup>14,17,27,31</sup> although the majority of patients experienced between some and a lot of pain, which cannot be neglected.

## CONCLUSIONS

This study provides important insights into the challenges of providing quality end-of-life care for older people dying in acute geriatric hospital wards. A number of interventions are continued or even begun in the last 48 hours of life which are at the least controversial and may not be in the patient's best interest. Further research should focus on the appropriateness of these interventions in the last days of life. Using the CAD-EOLD, we found that breathing problems and items related to the psychosocial and existential domain of wellbeing were common for patients dying in acute geriatric wards. The priorities for considering the appropriateness of nursing and medical interventions and for improving comfort around dying for this population should include structuring care processes in the last days of life, with specific attention to the identified problems. Second, health care staff should be educated regarding palliative care principles, including symptom management and comfort in the last days of life, so that they are able to address the identified problems and ensure better quality of care around dying. Third, health care staff could be encouraged to seek the support of the palliative care team for dealing with the psychosocial and existential needs of dying patients. In short, structuring care processes in the last days of life by using end-of-life care plans based on best practices for care in the last days of life may strongly contribute to the management of unfavourable symptoms in the terminally ill older patient, especially in acute geriatric wards, where approximately half of the patients are no longer able to communicate about their wishes and preferences.

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**CHAPTER 4:**  
**PRESCRIPTION AND**  
**DEPRESCRIPTION OF MEDICATION**  
**DURING THE LAST 48 HOURS OF LIFE:**  
**MULTI-CENTRE STUDY IN 23**  
**GERIATRIC WARDS**

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Submitted

## **ABSTRACT**

### **OBJECTIVES**

To describe the anticipatory prescription of medication for symptomatic treatment and the deprescription of potentially inappropriate medication (PIM) during the last days of life.

### **DESIGN**

Cross-sectional descriptive study between October 1st 2012 and September 30th 2013.

### **SETTING**

Twenty-three acute geriatric wards in 13 hospitals in Flanders, Belgium.

### **PARTICIPANTS**

Patients hospitalized for more than 48 hours before dying in the participating wards.

### **MEASUREMENTS**

Structured after-death questionnaires, filled out by the treating geriatrician. Main outcome measures were the anticipatory prescription and deprescription of medication during the last 48 hours of life.

### **RESULTS**

Anticipatory prescription of medication for symptomatic treatment was present in 65.4% of cases, 45.5% of these prescriptions being for morphine, 15.5% for benzodiazepine and 13.8% for scopolamine hydrobromide. A deprescription of PIM was noted in 67.9% of cases. Where death was expected by the physician, anticipatory prescription was present in 83% and deprescription of PIM took place 86% of cases. The likelihood of anticipatory prescription was significantly higher in cases where death was expected (OR 19; 95%CI [9-40];  $p<0.0001$ ) and significantly lower where dementia was present (OR 0.35; 95% CI [0.16-0.74];  $p<0.006$ ). The likelihood of deprescription was higher in cases where death was expected (OR 20; 95% CI [10 – 43];  $p<0.0001$ ) and in cases of patients dying from an oncological disease compared with those dying from frailty or dementia (OR 7.0; 95% CI [1.1-45.6],  $p=0.042$ ).

### **CONCLUSION**

Anticipatory prescription of medication and deprescription of PIM at the end of life in acute geriatric wards could be further improved. A well-developed evidence-based intervention to guide health care staff in developing a medication policy for older patients in the last days of life seems to be needed.

## INTRODUCTION

As a result of increasing life expectancy, nearly 50% of the population of Western Europe die aged 80 years and older (1). Depending on the country, from about 30% to over 60% of those die in acute hospital wards (2). Studies show that palliative care for the older person is often limited, resulting in poor symptom control and poor quality of dying (3,4). The population with dementia is particularly prone to poor symptom control during the last week of life (5,6).

One of the core principles of palliative care is the relief of suffering and improvement of quality of life through the impeccable treatment of pain and symptoms (7). Therefore, appropriate pharmacological management is increasingly highlighted as a quality indicator of palliative care (8). Two important aspects should be considered in appropriate pharmacological management at the end of life. First, there should be anticipatory prescribing of symptomatic medication to respond to fluctuations in symptom levels (8). Anticipatory prescribing of opioids has been studied in randomized control trials in cancer patients (9), but there are few data regarding anticipatory prescribing for other illnesses at the end of life (10,11). Secondly, because of the high incidence of multiple diseases and the consequential high intake of multiple medications, some authors highlight the necessity of a medication review and the deprescription of potentially inappropriate medication (PIM) at the end of life in frail older patients and in those with dementia (12-16). However, recent meta-analysis shows that little rigorous research has been conducted in this area (17). Moreover, the criteria for discontinuance of medication are heterogeneous, ranging from well-standardized appropriateness criteria like Beers, START/STOPP and the Medication Appropriateness Index to more implicit criteria taking into account the overall health condition like the Good Palliative-Geriatric Practice algorithm (17).

Un to now there have been few epidemiologic studies describing pharmacological management in nursing homes (18) and among cancer patients at the end of life (19-23), none of which address the subject of pharmacological management during the last days of life of frail older people on a specialized acute geriatric ward. Therefore, this study aims to describe (1) the anticipatory prescription of symptomatic medication and (2) the deprescription of PIM during the last 48 hours of life in acute geriatric wards; the relationship between medication practice and patient characteristics such as dementia will also be investigated.

## **METHODOLOGY**

### **DESIGN**

A cross-sectional descriptive study was conducted in Flanders, Belgium. Structured after-death questionnaires were filled out by the treating geriatricians.

### **SETTING AND STUDY POPULATION**

Twenty-three acute geriatric wards in 13 Flemish hospitals participated in the study. Deceased patients were included in the study if they met the following criteria: (a) being hospitalized on the geriatric ward for more than 48 hours and (b) having given informed consent at the time of admission for the use of their medical or nursing records. Approval for the study was obtained from the Central Ethics Committee of the Vrije Universiteit Brussel (VUB) and by the Local Ethics Committees of the participating hospitals (B.U.N. 143201213985).

### **DATA COLLECTION**

Data collection took place between October 1st 2012 and September 30th 2013. For each patient who died on the ward, administrative data such as age, sex and length of hospital stay were collected by the researcher. The treating geriatrician was asked to fill out a questionnaire within one week of death in order to minimize recall bias. Detailed information on the study methodology is described elsewhere (24).

### **MEASUREMENTS**

After-death questionnaires surveyed, among other variables, underlying diseases, cause of death, the main goal of treatment, ability to communicate, whether the death was expected by the geriatrician, anticipatory prescription of medication and deprescription of PIM during the last 48 hours of life. The anticipatory prescription was measured by questioning whether, during the last 48 hours of life, medication for symptom control had been prescribed and, if so, what that medication was. A list of PIM was developed using the Good Palliative-Geriatric Practice algorithm (16) and reviewed through pilot testing by two geriatricians with experience in palliative medicine. Out of this list of PIM, the geriatrician indicated which medications were started, stopped or continued during the last 48 hours of life.

### **STATISTICAL ANALYSIS**

Values are reported as absolute numbers and percentages. Chi-square tests were used for analyzing differences in characteristics between patients dying with or without dementia, and between patients in the different stages of dementia (beginning, mild, severe). Associations between patient characteristics, anticipatory prescribing and deprescribing were analyzed

using chi-square-tests (univariate analysis). Multivariable logistic regression models were built to detect key factors associated with having an anticipatory prescription or deprescription during the last 48 hours of life. All analyses were performed with SPSS statistical software, version 20 (SPSS Inc., IBM, USA).

## RESULTS

A total of 993 patients died on the participating wards during the study period; 338 met the inclusion criteria and a questionnaire was filled out by a geriatrician for 290 of those (response rate 85%).

The mean age of the patients was 85.7 years (not in tables); 53% were women and 73.4% were admitted from home (Table 1). In 70.6% the geriatrician had expected the patient's death. Fifty three percent were diagnosed with dementia. Those with and without dementia differed for the immediate cause of death ( $p=0.001$ ), the patient's ability to communicate ( $p<0.001$ ) and whether or not death had been expected by the geriatrician ( $p=0.046$ ).

**Table 1 Demographic and clinical characteristics of patients in the study**

	Total population n=290	People with dementia n=154 (53.1%)	People without dementia n=136 (46.9%)	p-value
<b>Age</b>				
< 75	6.8%	6.1%	7.7%	0.431
75-84	33.8%	37.8%	29.2%	
85-94	55.8%	52%	60%	
≥ 95	3.6%	4.1%	3.1%	
<b>Sex (% women)</b>	53.1%	53.9%	52.2%	0.925
<b>Underlying diseases</b>				
Metastatic cancer	14.3%	10.2%	18.8%	
Neurodegenerative disorder	1.4%	2.7%	0.0%	
Frailty	4.6%	4.1%	5.3%	
Organ failure	31.4%	26.5%	36.8%	
Frailty and organ failure	25.4%	17.7%	33.8%	
Neurodegenerative disorder and frailty	5.4%	10.2%	0.0%	
and organ failure	6.1%	8.8%	3.0%	
and frailty and organ failure	11.4%	19.7%	2.3%	<0.001
<b>Immediate cause of death</b>				
Oncological	11.5%	8.2%	15.3%	
Infectious	39.9%	43.5%	35.9%	
Organ failure	43.5%	39.5%	48.1%	
Frailty or dementia	5.1%	8.8%	0.8%	0.003
<b>Residency before admission</b>				
Long term care facility	20.7%	26%	14.7%	
Home	73.4%	68.8%	78.8%	
Data not available	5.9%	5.2%	6.5%	0.315
<b>Reason for admission</b>				
Medical intervention needed	90.0%	87.7%	92.6%	0.333
<b>Length of stay</b>				
> 4 weeks	19.3%	18.2%	20.6%	
2-4 weeks	32.8%	35.1%	30.1%	
< 2 weeks	25.2%	27.3%	22.8%	
< 1 week	20.7%	18.2%	23.5%	0.326
<b>Ability to communicate</b>	53.0%	35.1%	73.3%	<0.001
<b>% expected death by geriatrician</b>	70.6%	66%	75.7%	0.046

A total of 185 patients (65.4%) had an anticipatory prescription of medication during the last 48 hours of life (Table 2), 45.5% for morphine, 15.5% for a benzodiazepine and 13.8% for scopolamine hydrobromide (not in tables). No significant association between the class of drug medication prescribed and the immediate cause of death was found (not in tables).

**Table 2 Relation between the anticipatory prescription of medication and patient characteristics in 23 acute geriatric wards (n=290)**

	Anticipatory prescription of medication* N=185/283 (65.4%)	p-value
<b>Age (n=271)</b>		
< 75	12 /19 (63%)	
75-84	54/90 (60%)	
85-94	103/152 (68%)	
> ≥ 95	8/10 (80%)	0.473
<b>Immediate cause of death (n=272)</b>		
Oncological	20/32 (63%)	
Infectious	80/110 (73%)	
Organ failure	70/116 (60%)	
Frailty or dementia	9/14(64%)	0.256
<b>Underlying diseases (n=274)</b>		
Metastatic cancer	25/40 (63%)	
Neurodegenerative disorder	3/4 (75%)	
Frailty	11/13 (85%)	
Organ failure	50/85 (%)	
Frailty and organ failure	47/68 (59%)	
Neurodegenerative disorder and frailty	9/15 (60%)	
and organ failure	12/17(71%)	
and frailty and organ failure	24/32 (75%)	0.519
<b>Ability to communicate (n=280)</b>		
No	95/134 (71%)	
Yes	88/146 (60%)	0.078
<b>Death expected by physician (n=282)</b>		
Yes	165/198 (83%)	< <b>0.001</b>
No	19/84 (23%)	
<b>Dementia (n=283)</b>		
Yes	90/152 (59%)	
No	95/131 (73%)	<b>0.013</b>

\*Missing value: 7 out of 290 included patients; % calculated on included patients  
Numbers in rows are different due to missing values

The geriatrician expecting the patient to die ( $p < 0.001$ ) was significantly related to a higher prescription rate of anticipatory medication (Table 2). In 83% of those patients expected to die an anticipatory prescription was present (not in tables). Further, the anticipatory prescription of morphine was significantly lower in patients with dementia (Table 2;  $p = 0.013$ ) and especially in those with early stage dementia ( $p = 0.034$ ) (not in tables). For the anticipatory prescription of other medication no significant correlation with the stage of dementia was found. After multivariable adjustment for age, sex, cause of death and ability to communicate during the last 48 hours of life, the likelihood of having anticipatory medication was significantly higher in patients where death was expected by the physician OR 19; 95% CI [9-40];  $p < 0.0001$ ) and significantly lower in patients with dementia (OR 0.35; 95% CI [0.16-0.74];  $p < 0.006$ ) (Supplementary table online).

Supplementary tables online

Anticipatory prescription: Logistic Regression									
	B	S.E.	Wald	Df	Sig.	Exp(B)	95% C.I.for EXP(B)		
							Lower	Upper	
Step 1 <sup>a</sup>									
Dementia (yes versus no)	-1,060	,389	7,445	1	,006	,346	,162	,742	
Age patient (versus ≥ 95)			,187	3	,980				
(<75)	-.067	1,107	,004	1	,951	,935	,107	8,189	
(75-84)	-.124	,938	,017	1	,895	,883	,141	5,550	
(85-94)	,036	,911	,002	1	,969	1,036	,174	6,179	
Cause of death (versus frailty)			5,749	3	,124				
(oncological)	-.791	,897	,776	1	,378	,454	,078	2,633	
(infectious)	,200	,783	,065	1	,799	1,221	,263	5,671	
(organ failure)	-.655	,788	,690	1	,406	,520	,111	2,435	
Expected death (yes versus no)	2,960	,369	64,252	1	,000	19,294	9,357	39,786	
Ability to communicate (no vs. yes)	,520	,383	1,844	1	,175	1,682	,794	3,563	
Gender patient (male vs. female)	-.587	,356	2,719	1	,099	,556	,277	1,117	
Constant	-.328	1,199	,075	1	,784	,720			

a. Variable(s) entered on step 1: dementiayesorno, leeftijdscategorie\_patiënt, doodsoorzaak\_nieuw, verwacht\_overlijden, arts\_A7gesprek, Geslacht\_patiënt.

Deprescription: Logistic Regression									
	B	S.E.	Wald	Df	Sig.	Exp(B)	95% C.I.for EXP(B)		
							Lower	Upper	
Step 1 <sup>a</sup>									
Dementia (yes versus no)	,073	,394	,035	1	,852	1,076	,497	2,328	
Age patient (versus ≥ 95)			,580	3	,901				
(<75)	,259	1,239	,044	1	,834	1,296	,114	14,688	
(75-84)	-.118	1,016	,014	1	,907	,888	,121	6,503	
(85-94)	-.273	,983	,077	1	,781	,761	,111	5,232	
Cause of death (versus frailty)			11,479	3	,009				
(oncological)	1,946	,956	4,146	1	,042	7,002	1,076	45,586	
(infectious)	,813	,758	1,151	1	,283	2,255	,511	9,958	
(organ failure)	-.076	,755	,010	1	,920	,927	,211	4,070	
Expected death (yes versus no)	3,032	,371	66,803	1	,000	20,739	10,023	42,908	
Ability to communicate (no vs. yes)	-.148	,389	,144	1	,704	,863	,402	1,849	
Gender patient (male vs. female)	-.199	,354	,316	1	,574	,820	,410	1,639	
Constant	-1,251	1,253	,997	1	,318	,286			

a. Variable(s) entered on step 1: dementiayesorno, Age\_categorical, cause\_of\_death, expected\_death, ability\_to\_communicate, Gender\_patient.

The potentially inappropriate medications at the end of life with which patients were most often being treated on admission to the geriatric ward were antihypertensives (71.5 %), antibiotics (63.6%), diuretics (61.3%), anti-ulcer drugs (59.2%) and inhalation betamimetics and/or steroids (58.4%) (Table 3). In 67.9% of patients, and in 86% of those whose death was expected by the physician, one of the medications prescribed at admission was deprescribed during the last 48 hours of life (not in tables). Those most often withdrawn during the last 48 hours of life were antihypertensives (in 44.8% of all patients) and antibiotics (in 42.4% of all patients) (Table 3).

**Table 3 Deprescription of potentially inappropriate medication during the last 48 hours of life in 23 acute geriatric wards (N=290)**

	% patients treated at admission	% patients treated until death
Inhalation betamimetics and/or steroids (n=262)	58.4	32.1
Antihypertensive (n=270)	71.5	26.7
Anti-ulcer drugs (n=260)	59.2	26.5
Diuretics (n=266)	61.3	23.3
Antibiotics (n=264)	63.6	21.2
Laxatives (n=256)	44.5	15.2
Anticoagulants (n=250)	33.6	14.8
Aspirin (n=264)	45.5	13.3
Corticosteroids (n=247)	30.8	13.0
Bisphosphonates (n=256)	23.4	8.6
Lipid Lowering Drugs (Statins) (n=251)	21.5	8.8
Acetyl cholinesterase inhibitors (n=244)	14.0	5.7
Anti-diabetics		
Oral (n=244)	13.1	4.5
Subcutaneously (n=245)	12.2	2.9

Numbers in row are different due to missing values

A multivariable logistic regression analysis simultaneously controlling for various possible confounders showed that the likelihood of medication being deprescribed was higher in patients where the death was expected by the geriatrician compared with those where the death was not expected (OR 21; 95% CI [10–43];  $p < 0.0001$ ) and higher in patients dying from an oncological disease than in those dying from frailty or dementia (OR 7.0; 95% CI [1.1–45.6],  $p = 0.042$ ) (Supplementary table online).

## DISCUSSION

This multicentre cross-sectional study investigated the policy of anticipatory prescription of symptomatic medication and the deprescription of potentially inappropriate medication during the last 48 hours of life in Flemish acute geriatric wards. Firstly, we found a clear positive correlation between anticipatory prescription and the recognition of the dying phase by the geriatrician, while lower anticipatory prescription rates for morphine were found in patients with dementia, especially in those in the early stages. Secondly, only half of the medications prescribed at admission were withdrawn indicating that there is still significant use of potentially inappropriate medication during the last 48 hours of life.

The percentages found in our acute geriatric ward population for the use of antihypertensives, anti-infectives, anticoagulants and bisphosphonates are similar to the percentages found in previous studies looking at medication practice during the last three days of life in a hospitalized cancer population (19,20). In those studies anti-ulcer drugs and corticosteroids were more often used than in our study population. Possible explanations for these differences are the characteristics of the studied population (cancer versus frail elderly people) and a difference between countries in prescription patterns.

According to the classification of appropriateness of medication developed by Holmes et al (15) lipid lowering drugs and acetylcholinesterase inhibitors would never be appropriate in our population, yet we found them present in, respectively, 8.8% and 5.7% of cases. In the class of rarely appropriate medication, bisphosphonates were still given to 8.6% of patients and anticoagulants to 14.8%. A possible explanation for the high rate of inappropriate medication in the last days of life may be the lack of evidence about the benefits or harms of medication withdrawal. To our knowledge, only one recent RCT has studied the withdrawal of potentially inappropriate medication. For statins it has recently been shown that they can be safely withdrawn in cancer patients with a survival prognosis of less than one year (25). Although recent studies and opinion papers show that the idea of deprescribing PIM in the older frail population is high on the agenda (12-17), we found in our study that patients dying with frailty or dementia, compared with those with cancer, had a higher risk of continuing PIM until death. This together with our finding that the likelihood of the deprescription of PIM is higher in patients whose death is expected, points to the importance of an accurate recognition of the dying phase. However, an accurate prognostication of survival in those with non-malignant diseases seems to be difficult and may lead to postponement of medical decisions (26). This prognostic paralysis can be overcome to some extent by the early instigation of discussion of

the patient's preferences and wishes about their end of life (advance care planning) including the deprescribing of PIM. This approach may enhance trust between the physician and the patient leading to acceptance of the withdrawal of lifelong medication (27). A systematic approach, such as the five key steps to identifying and withdrawing medication in the older patient, can be useful (12). Scott et al have developed a deprescribing protocol starting with the indications for the current drugs, the overall risk of drug-induced harm, the assessment of each drug for its eligibility to be discontinued, a prioritization of drugs for discontinuation and the implementation and monitoring after drug discontinuation (12).

Optimal care during the last days of life also suggests the prescription of appropriate medication to optimize symptom control such as opioids, benzodiazepines, haloperidol and medication suppressing the death rattle (7,9-10). As it has been shown that very old patients have lower requirements in the dose of medications we focused mainly on the presence of an anticipatory prescription during the last 48 hours of life as an indicator of optimal symptomatic care (28). If compared with results from other studies investigating the anticipatory prescription of medication for patients with cancer in acute hospital care (19, 20) and of older patients in a nursing home setting (6,18) the anticipatory prescription of morphine (45.5%), benzodiazepine (15.5%) and scopolamine (13.8%) in our study population was lower than that reported post-implementation in a study of a care pathway in a Dutch cancer population (respectively 53%, 23% and 25%) (20) and than that reported in a nursing home population in Norway (respectively 82.6 %, 70.4% and no reported data for antisecretory drugs) (18). Although slightly more than half of the dying population in our study had an anticipatory prescription, our findings suggest a need for improving end of life care. Introduction of a palliative care consultation and a standardized care pathway such as the Liverpool Care Pathway has been shown to increase the rate of anticipatory prescriptions of medication (20,21).

Surprisingly we found that patients with dementia, especially those with early stage dementia, had a significantly lower anticipatory prescription rate for morphine (only 28%). A possible explanation may be that physicians fear the side effects of morphine on cognitive functioning. This finding is comparable to other studies showing undertreatment of pain with opioids in the very old (29). However, the percentage is in sharp contrast with that found in nursing home residents in the Netherlands and Norway where 77% of those with dementia received opioids (7,18). The observed differences may reflect differences in health care organization or cultural practices as a result of different expectations of family and caregivers towards end of life care.

This study has several strengths and limitations. It is large-scale multicentric study including hospitals from different regions and of different sizes, which increases the generalizability of the findings. A high response rate by treating physicians was obtained (85%). The data were gathered in a systematic way through a validated questionnaire filled in by the treating geriatrician within one week of death. One of the limitations of this study is that only the anticipatory prescription of medication and not the exact dose of medication given during the last 48 hours was registered. Another is that the list of potentially inappropriate medication was developed based on rather implicit criteria and only through a small Delphi procedure and pilot testing. However, according to the existing literature, the list seems to contain all widely accepted potentially inappropriate medications.

In conclusion, this study shows that anticipatory prescription of medication and deprescription of potentially inappropriate medication at the end of life in older patients dying in hospital can be further improved. Future research should focus on the development of well-designed trials to demonstrate the effect of anticipatory prescription of medication on the quality of dying and the safety and benefits of deprescribing PIM. A well-developed intervention to guide health care staff in caring for older patients in the last days of life (24,30) can be a first step towards improving the quality of dying of the older hospitalized patient population.

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# **PART III**

## **DEVELOPMENT AND EVALUATION OF A COMPLEX INTERVENTION TO IMPROVE END-OF-LIFE CARE IN ACUTE GERIATRIC HOSPITAL WARDS**



**CHAPTER 5:**

**DEVELOPMENT OF THE CARE  
PROGRAMME FOR THE LAST DAYS  
OF LIFE IN ACUTE GERIATRIC  
HOSPITAL WARDS: A PHASE 0-I  
STUDY ACCORDING TO THE  
MEDICAL RESEARCH COUNCIL  
FRAMEWORK**

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## **ABSTRACT**

### **BACKGROUND**

The effects of the Liverpool Care Pathway (LCP) have never been investigated in older patients dying in acute geriatric hospital wards and its content and implementation have never been adapted to this specific setting. Moreover, the LCP has recently been phased out in the UK hospitals. For that reason, this study aims to develop a new care programme to improve care in the last days of life for older patients dying in acute geriatric wards.

### **METHODS**

We conducted a phase 0-1 study according to the Medical Research Council Framework. Phase 0 consisted of a review of existing LCP programmes from the UK, Italy and the Netherlands, a literature review to identify key factors for a successful LCP implementation and an analysis of the concerns raised in the UK. In phase 1, we developed a care programme for the last days of life for older patients dying in acute geriatric wards based on the results of phase 0. The care programme was reviewed and refined by two nurses and two physicians working in an acute geriatric ward and by two experts from Italy and the Netherlands.

### **RESULTS**

Phase 0 resulted in the identification of nine important components within the LCP programmes, five key factors for a successful LCP implementation and a summary of the LCP concerns raised in the UK. Based on these findings we developed a new care programme consisting of (1) an adapted LCP document or Care Guide for the older patients dying in an acute geriatric ward, (2) supportive documentation and (3) an implementation guide to assist health care staff in implementing the care programme on the acute geriatric ward.

### **CONCLUSIONS**

Based on the existing LCP programmes and taking into account the key factors for successful LCP implementation as well as the concerns raised in the UK, we developed a care programme for the last days of life and modelled it to the acute geriatric hospital wards after gaining feedback from health professionals caring for older hospitalized patients.

## BACKGROUND

Ageing<sup>1,2,3,4</sup> and the increasing prevalence of chronic and degenerative conditions<sup>5</sup> imply that a growing number of older people in developed countries will need palliative care. The World Health Organization has recently identified palliative care as one of the public health priorities for older people<sup>6</sup>.

Despite the fact that the majority of older people prefers to die at home<sup>7</sup> and the increasing importance of the nursing home as a place of end-of-life care and dying<sup>8</sup>, a large proportion of the aged population (>70 years) die in a hospital<sup>9</sup> where palliative care goals and principles are often achieved with difficulty<sup>10,11,12</sup>. Previous studies have shown the poor quality of care delivered to the older population at the end of life, especially in the hospital setting<sup>13,14</sup>.

Several end-of-life care pathways have been developed to improve the quality of end-of-life care<sup>15,16,17</sup>. The Liverpool Care Pathway (LCP) for the Dying Patient is one such pathway. It was developed in 1997 in the United Kingdom (UK) as a multi-professional document that provides a template of care for the final days and hours of life and aims to transfer the hospice model of care to mainstream hospital services<sup>15,18</sup>. The LCP is based on the principles of palliative care: regular assessment and management of symptoms, comfort measures, effective communication with patients and their families, and provision of psychological, social and spiritual/existential support. It focuses on the individual physical, psychological and spiritual needs of the dying patient and their family during the last hours and days of life and provides health care professionals with guidance on the different aspects of care required, including comfort measures, anticipatory prescribing of medications, discontinuation of inappropriate interventions and the psychological and spiritual/existential support of the patient and family<sup>18</sup>.

Although studies suggest that the LCP can improve the quality of end-of-life care in a cancer population<sup>19,20,21,22</sup>, its effectiveness in people dying of causes other than cancer, especially older people, has not yet been investigated. Furthermore, although the LCP as developed in the UK is meant to be implemented in every health care setting, the provision and organization of end-of-life care can vary between health care settings and specific patient populations should be taken into account<sup>6</sup>. It is for instance known that the recognition of the dying phase is more challenging in older non-cancer patients<sup>15</sup> and that around half of older patients in hospital are cognitively impaired<sup>23</sup>. Older people dying in hospital are thus a specifically vulnerable patient group for which end-of-life care can be significantly improved<sup>13,14</sup>. Hence, if we want to introduce and use a care programme for the last days of life in acute geriatric hospital wards,

the context should also be taken into account, especially during the process of implementation. As the LCP has been widely criticized since June 2012 for failing to help physicians and nurses provide appropriate care, the development of an adapted care programme for the last days of life should also take into account the concerns that have been raised in the UK. Raised concerns regarding the LCP arise mainly from inappropriate implementation and use and not the principles of the LCP itself. This was also recently highlighted in an independent review which recommended phasing out the LCP in the UK by July 2014<sup>24</sup>.

This study aims to develop a new care programme to improve care in the last days of life of older people dying in acute geriatric wards.

## **METHODS**

### **STUDY DESIGN**

To develop a care programme for the older hospital population to improve care in the last days of life the Medical Research Council (MRC) Framework was used. The MRC Framework is an approach aimed at providing a robust methodological basis to the development and evaluation of complex interventions<sup>25</sup>. According to the MRC Framework, interventions should be developed and tested systematically using a phased approach<sup>26,27</sup>. In this study we aimed to complete the first two phases: phase 0 and phase 1.

The study is approved by the Ethics Committee of the University Hospital of Ghent University, the Central Ethics Committee of the University Hospital of the Vrije Universiteit Brussel and by the Local Ethics Committees of the participating hospitals in Flanders.

#### **Phase 0: Preclinical phase**

The preclinical phase consisted of a review of existing LCP programmes, a literature review to identify key factors for a successful LCP implementation and an analysis of the concerns regarding the use of the LCP in the UK.

##### *Review of existing LCP programmes*

We first reviewed the LCP programme developed in the UK, which is a Continuous Quality Improvement Programme to be implemented, disseminated and sustained according to the Service Improvement Model, moving on 4 phases and incorporating 10 different steps<sup>18</sup>. The development of our care programme is also based on this theoretical approach. Also the LCP programmes developed in the Netherlands and Italy, which are based on the original LCP programme from the UK, were selected to be reviewed. The aim of the review was to identify the different components of the LCP programmes, to compare them and to identify useful

components for the development of our care programme for older patients dying in acute geriatric wards. Specific reasons have guided the selection of these programmes: the LCP programme from the UK was the one originally developed<sup>18,28</sup>, the Dutch LCP programme uses similar language to that of Flanders<sup>29</sup> and the Italian LCP programme<sup>30</sup> is, to our knowledge, the only LCP programme which has been rigorously evaluated using a controlled trial design<sup>20,21,31,32,33,30</sup>.

#### *Review of literature to identify key factors affecting a successful LCP implementation*

A PubMed literature search on LCP implementation in the hospital setting was conducted. The search used the terms ‘Liverpool Care Pathway’, ‘hospital’ and ‘implementation’. Studies were included if they were published in English, performed in a hospital setting and if they provided an explanation of the process of implementation, such as facilitating factors or barriers. As the LCP was developed only in the late 1990s we limited our search to relevant literature dated from 1998 to December 2012. The literature retrieved was examined in depth and key factors for a successful implementation of the LCP were identified.

#### *Analysis of the concerns regarding the LCP in the UK*

Our methodology consisted of a close follow up of the media concerns by all involved researchers. We collected and read related reports about the criticisms of the LCP in the UK disseminated in press coverage or published on PubMed between the onset of the public discussion (October 2012) and the development of our care programme (March 2013)<sup>34,35,36,37,38,39,40,41</sup>. During several meetings we discussed the reports with each other and aimed to deduce the main concerns about the use of the LCP. The raised concerns were subsequently discussed with clinicians from the UK, Italy and the Netherlands.

### **Phase 1: Modelling phase**

We developed and modelled a care programme for the last days of life for the older hospital population using the different identified components of the LCP programmes reviewed and the key factors for successful LCP implementation and taking into account the concerns raised regarding the LCP in the UK. In order to take into account the specificities of the older hospital population and the setting in which they are cared for, the preliminary programme was reviewed by two nurses caring for older hospitalized patients, two geriatricians and one internal medicine physician. Also experts from the UK, Italy and the Netherlands were involved in this phase: clinicians and a psychologist responsible for the coordination of project implementations. Five researchers, consisting of one geriatrician, three sociologists and one nurse, discussed all the input gathered and the feedback of the reviewers and used the results

of this discussion for the refinement of the programme. As it is not embedded in our culture to involve family carers in developing care improvement strategies, there was no public involvement.

## RESULTS

### Phase 0: Preclinical phase

#### *Review of existing LCP programmes*

The review of the original LCP programme developed in the UK<sup>18,28</sup> and the LCP programmes used in Italy<sup>30</sup> and the Netherlands<sup>29</sup> identified three common documents: 1) an LCP document, 2) supportive documentation and 3) an implementation guide.

#### 1) The LCP document

The original LCP document was developed in 1997 in the UK and has regularly been updated in accordance with the latest evidence. The latest LCP generic version 12 was launched in December 2009 and can be used in all health care settings where end-of-life care needs to be provided. An algorithm in the LCP document is included to support the clinical decision making process regarding the recognition and diagnosis of dying and the appropriate use of the LCP to support care in what are thought to be the last hours or days of life. The LCP can be used when the multidisciplinary team – physicians, nurses and allied health professionals treating a patient - has agreed that the patient is dying and all reversible causes for the current situation have been considered. Recognizing and diagnosing the last days and hours of life is complex and a second opinion or the support of a palliative care team may be required. When the LCP is initiated, the focus of care changes to care of the dying, including discussion with the family carer and when possible the patient. The current plans of care need to be reviewed and inappropriate interventions stopped when the burden is greater than the benefits. The LCP includes a regular assessment process. If the patient improves and is deemed not to be dying by the multidisciplinary team, the LCP can be stopped<sup>18</sup>.

The LCP document lists a number of care goals that guide health professionals to focus on the major issues that are likely to be relevant for patients and their families in the last hours or days of life. Each care goal is accompanied by prompts in order to help health care staff to better understand the content and importance of the care goal. The LCP document consists of three sections<sup>18</sup>:

Section 1: initial assessment. This section is to be completed when the multidisciplinary team estimates that the patient has entered the dying phase. This section deals with anticipatory

prescription of important medications, discontinuation of inappropriate interventions, spiritual/religious assessment and appropriate information-giving and communication with patients, family and others.

Section 2: ongoing assessment. This section focuses on regular assessment of important indices of comfort for the dying patient and their family including symptom control and maintaining the ongoing physical, psychological and spiritual/religious/existential comfort of the patient and family.

Section 3: care after death. This section focuses on the assessment of important practical issues and appropriate support for family carers after the death of the patient

Care goals are to be documented as either ‘achieved’, ‘not achieved’, or, where appropriate ‘not applicable’. Where ‘not achieved’ is documented, the care professional must make notes concerning the cause or reason and detail the course of action taken. “Not achieved” care goals are not seen as negative but highlight the importance of clinical skills in deciding to deviate from the suggested plan of care in response to individual patient needs<sup>18,42</sup>. An accurate documentation of ‘not achieved’ care goals ensures that each of them can be tracked and monitored<sup>43</sup>.

In Italy, an earlier LCP hospital version 11 was translated in compliance with the original UK format and approved by the LCP Central Team of the Marie Curie Palliative Care Institute Liverpool (MCPCIL)<sup>20</sup>. The content and structure of the Italian document is very similar to the UK LCP document.

In the Netherlands, the LCP generic version 12 was translated into Dutch and substantive changes were made. In the Dutch LCP document some care goals were considerably modified or deleted<sup>44</sup>. The care goals concerning clinically assisted nutrition and hydration are less prominently presented, the care goal concerning the maintenance of the patient’s skin integrity was deleted and the form of documentation of the care goals was changed to ‘yes’ or ‘no’ instead of ‘achieved’ or ‘not achieved’.

## 2) Supportive documentation

In all three countries supportive documentation has been developed. These documents consist of a goal data dictionary and information leaflets for health care professionals and family carers in support of the LCP document. The goal data dictionary, originally developed in the UK, is designed for health care staff to fully understand the care goals stated in the LCP document and to guide them in correctly recording “not achieved” care goals. In all three countries information leaflets were developed. A leaflet for health care professionals about the LCP was developed in the UK and the Netherlands. The following leaflets for family carers

were developed: a leaflet about communication, medication, comfort and reduced need for food and drink to be given following a discussion regarding the plan of care (UK only), a leaflet about the entering of the dying phase (UK and the Netherlands), a leaflet about the facilities in the health care setting (UK, Italy, and the Netherlands), a leaflet about grief and bereavement after the patient's death (UK, Italy, and the Netherlands) and a leaflet about practical arrangements after the patient's death (Italy only).

### 3) Implementation guide

An implementation guide to assist health care staff in correctly implementing the LCP document and its supportive documentation within a health care setting was developed in all three countries. We identified nine components in the implementation guides used in the UK, Italy and the Netherlands: 1) establishing the LCP implementation project and preparing the environment for organizational changes, 2) preparing the documentation, 3) baseline review, 4) training health care staff, 5) LCP use and ongoing support, 6) reflective practice, 7) evaluation, 8) continuing development of competencies and 9) ongoing education, training and support. Consistencies and differences in the components of the different implementation guides are listed in table 1.

**Table 1 Consistencies and differences in the components of three LCP implementation guides**

United Kingdom	Italy	The Netherlands
<b>Component 1-Establishing the LCP implementation project and preparing the environment for organizational change</b>		
1. Informing all relevant clinical staff <sup>1</sup>	1. Informing all relevant clinical staff	1. Informing all relevant clinical staff
2. Executive endorsement	2. Executive endorsement	2. Executive endorsement
3. Involvement of specialist palliative care services is recommended	3. Involvement of specialist palliative care services is obvious: Palliative Care Unit (PCU) is responsible for implementation	3. Involvement of specialist palliative care services is recommended
4. LCP facilitators <sup>2</sup> : members of the ward	4. No LCP facilitators: PCU is responsible for implementation	4. LCP facilitators: members of the ward
5. Steering group <sup>3</sup> : members of the ward	5. Steering group: PCU with two reference persons as a link between ward and PCU	5. Steering group: members of the ward
6. Intensive training <sup>4</sup> : of LCP facilitators	6. Intensive training of PCU	6. Intensive training of LCP facilitators
7. Project registration with LCP Central Team (UK), LCP National Centre (Italy), or Comprehensive Cancer Centre of the Netherlands		
<b>Component 2-Preparing the documentation</b>		
Adapting the LCP document and/or supportive LCP documentation to the ward <sup>5</sup>		
<b>Component 3-Baseline review</b>		
Analyzing end-of-life care data and feedback the results to the staff <sup>6</sup>		
<b>Component 4-Training health care staff</b>		
1. LCP facilitators and specialist palliative care colleagues train health care staff	1. Health care staff follow a mandatory 12 hours training organized by PCU	1. LCP facilitators and specialist palliative care colleagues train health care staff
2. Aim training	2. Aim training	2. Aim training
o To understand and work with LCP document	o To understand and work with LCP document	o To understand and work with LCP document
o An education in LCP related issues <sup>5</sup>	o An education in LCP related issues	

United Kingdom	Italy	The Netherlands
<b>Component 5-LCP use and ongoing support</b>		
1. LCP use after sufficient training and education	1. LCP use after sufficient training and education	1. LCP use after sufficient training and education
2. Ongoing support and supervision of LCP facilitators each time the LCP document is used <sup>7</sup>	2. Intensive support and supervision of PCU through repeated coaching, telephone, and direct guidance, discussion of clinical cases, and clinical audits	2. Ongoing support and supervision of LCP facilitators each time the LCP document is used
<b>Component 6-Reflective practice</b>		
1. To engage staff in ongoing and reflective practice <sup>9</sup>	1. Semi-intensive support and supervision of PCU through repeated coaching, telephone, and direct guidance, discussion of clinical cases, and clinical audits	1. To engage staff in ongoing and reflective practice
2. To develop and deliver ongoing and sustainable education strategies		2. To develop and deliver ongoing and sustainable education strategies
<b>Component 7-Evaluation</b>		
1. To organize a formal and quantitative reflection (= audit) <sup>10</sup>	1. To organize a qualitative evaluation of implementation <sup>11</sup>	1. To organize a formal and quantitative reflection (= audit)
2. The audit acknowledges areas where further education or training is needed	2. The qualitative evaluation acknowledges areas where further support, education, or training is needed	2. The audit acknowledges areas where further education or training is needed
<b>Component 8-Continuing development of competencies</b>		
1. To develop knowledge and skills of staff constantly to embed LCP model within the ward <sup>12</sup>	1. PCU supports ward staff through repeated coaching, telephone, and direct guidance, discussion of clinical cases, and clinical audits	1. To develop knowledge and skills of staff constantly to embed LCP model within the ward
<b>Component 9-Ongoing education, training, and support</b>		
To create structures and processes to underpin the continuing education, training, and support required		
Examples:		
❖ To link with local audit departments to encourage ongoing reflection on the quality of care delivery		
❖ To keep up to date with developments in end of life care		
❖ To encourage ongoing liaison with local specialist palliative care teams		
❖ To participate in regional and national audit		

<sup>1</sup>All clinical staff are to be informed about the project and made aware of the importance to change the care in the last days of life.

<sup>2</sup>LCP facilitators are assigned to preside the steering group.

<sup>3</sup>A steering group needs to be established to coordinate the project and consists of members of the ward who are motivated for this project or the PCU with two reference persons (Italy).

<sup>4</sup>LCP facilitators or PCU (Italy) are intensively trained in order to provide leadership for the project.

<sup>5</sup>The ward implementing the LCP can adapt the LCP document and/or supportive LCP documentation to the local health care setting if these adaptations are approved by the LCP Central Team, LCP National Centre, or Comprehensive Cancer Centre of the Netherlands (i.e. adapting prompts of care goals, adding care goals, adapting information leaflets, local design of information leaflets).

<sup>6</sup>To highlight and reinforce the need for change within the ward, it is important to retrospectively evaluate the care during the last days of life by reviewing the medical and nursing files and giving feedback about these results to the staff.

<sup>7</sup>Training and education is also related to competencies important for good care during the last days of life (i.e. communication, symptom control).

<sup>8</sup>Ongoing support and supervision each time the LCP document is used for a dying patient, is necessary to increase staff's knowledge and confidence in using the LCP and empower them in caring for the dying.

<sup>9</sup>Reflections on the LCP document use and the specific elements of care delivery provide an opportunity to acknowledge which competencies need to be maintained and which need to be improved.

<sup>10</sup>The first LCP documents are quantitatively evaluated in order to provide feedback, highlight improvements since the implementation and identify areas where further education or training is needed.

<sup>11</sup>The PCU qualitatively evaluates and discusses the performance and progress of each of the previous components in order to identify staff's training needs and barriers for the LCP use and provision of optimum end-of-life care.

<sup>12</sup>Solutions for identified training needs and barriers are to be sought and performed in order to embed the LCP programme within the organization.

### *Identification of key factors for a successful implementation of the LCP*

The PubMed search on key factors affecting a successful LCP implementation in the hospital setting resulted in 15 records. The title and abstract of all these records were screened for inclusion criteria and five full-text articles were retrieved for detailed evaluation from which five key factors for a successful LCP implementation could be identified. These factors are: 1) having a dedicated facilitator to provide training and ongoing support on the hospital ward about the benefits and goals of the LCP<sup>45,46,47</sup>, 2) training and ongoing education on why and how to use the pathway, for nurses and especially physicians<sup>45,47,48,46</sup>, 3) the organization of an audit and of feedback opportunities<sup>45,47</sup>, 4) having a central coordinating LCP office to support local LCP facilitators<sup>49</sup> and, 5) funding and time for efforts such as facilitation, education and training<sup>45,46</sup>.

### *Analysis of the concerns regarding the LCP in the UK*

Since the second half of 2012 family carers of dying patients in the UK had begun to express their concerns regarding the LCP. Reports in some newspapers suggested that thousands of patients were being put on the pathway and were having treatment, including hydration and nutrition, withheld because they were difficult to manage and in order to free up beds<sup>34</sup>. Family carers also expressed their concerns because the LCP was often used without their consultation or knowledge<sup>35,36</sup>. Supporters of the LCP reiterated that the LCP is not about ending life but about delivering excellent end-of-life care and published a statement refuting the misconceptions about the pathway<sup>34,37</sup>. Nevertheless, it was acknowledged that there were some problems with it. Consequently, an independent review of the concerns regarding the LCP was performed to better understand them and to investigate ways in which the LCP has worked well<sup>36</sup>. As that review was only published in July 2013, five months after the initiation of our study, we could not use its findings for the development and modelling of our care programme. Nevertheless, we were able to deduce the main concerns over the use of the LCP from reports, letters, reviews and views disseminated in the media and published on PubMed. The concerns centered mainly around (1) improper or poor implementation of the LCP leading to cases of inadequate end-of-life care<sup>35,34,38</sup>, (2) unacceptable and inadequate communication with the patient and/or family carers<sup>39,35,40</sup>, (3) the LCP being used as a tick box exercise<sup>41</sup>, and (4) the use of the term ‘pathway’ which created the perception that a patient has to die once they are placed on the pathway<sup>35,34,38</sup>.

## **Phase 1: Modelling phase**

Results of the phase 0 were used to develop the care programme for the last days of life for the older hospital population. It consists of the following parts: (1) a Care Guide for the Last Days of Life, (2) supportive documentation and (3) an implementation guide.

### 1) Care Guide for the Last Days of Life

We first developed a care guide for the older hospital population. The original LCP generic version 12 from the UK was translated into Flemish in compliance with the original format. Afterwards the translation was grammatically compared with the Dutch LCP version and improved in terms of wordings. The translated document was then reviewed for legibility, usability and applicability by two nurses caring for older hospital patients, two geriatricians and one internal medicine physician, which led to a number of adaptations in order to refine and improve the document. A first adaptation concerned the change of the name ‘Liverpool Care Pathway’ into ‘Care Guide for the Last Days of Life’. According to the reviewers this change was crucial to avoid misconceptions about the true nature of the LCP, as the term ‘care pathway’ was perceived as a protocol rather than an approach to care. This change directly addressed one of the identified concerns regarding the LCP in the UK. A second refinement was the adaptation of the care goals to the older hospital population and the setting in which they are cared for. Table 2 lists these adaptations for section 1 and 2 of the Care Guide. Thirdly, the reviewers suggested the Care Guide should be shortened as the document was perceived as bulky. Therefore the introductory part of the document (i.e. the information for family carers concerning communication, medication, comfort and reduced need for food and drink and information for health care professionals about the LCP) and the prompts illustrating the care goals were left out of the care guide. The information for family carers is instead presented in a separate information leaflet for family carers and the prompts illustrating the care goals are placed in a separate goal data dictionary. To improve the readability of the Care Guide, a fourth refinement was made, namely highlighting in different colours the care goals to be interpreted by physicians and those to be interpreted by nurses.

**Table 2 The adaptation of the care goals of the UK LCP version 12 to the older hospital population**

Section	Subsection	Goal	Changes
1	Communication	1.1	<ul style="list-style-type: none"> <li>Reworded questioning under this care goal: 'Does the patient have an expressed wish for organ/tissue' replaced by 'Does the patient have an expressed wish to donate his/her body to medical science'</li> </ul>
	Spirituality	3.1 and 3.2	<ul style="list-style-type: none"> <li>Changes related to these care goals: 'Spirituality' replaced by 'Religious, spiritual, and cultural needs'</li> <li>More space for the nurse to report on these needs</li> <li>Anointing of the sick is added</li> </ul>
	Medication	4.1	<ul style="list-style-type: none"> <li>Added care goal: 'Current medications are assessed and non-essential medications are discontinued'</li> </ul>
		4.2	<ul style="list-style-type: none"> <li>Addition to care goal: The anticipatory prescribing of medication for the symptom 'anxiety' is added</li> </ul>
		4.3	<ul style="list-style-type: none"> <li>Reworded care goal: 'Equipment is available for the patient to support a continuous subcutaneous infusion (CSCI) of medication where required' replaced by 'If no intravenous or subcutaneous infusion already in place, the need for a subcutaneous infusion is reviewed'</li> </ul>
	Explanation of the plan of care	9.5	<ul style="list-style-type: none"> <li>Added care goal: 'The patient's care providers involved in the hospital and in home care are notified that the patient is dying'</li> </ul>
	2		c
		k	<ul style="list-style-type: none"> <li>Reworded care goal: 'The patient receives fluids to support their individual needs' replaced by 'The need for hydration is reviewed by the multidisciplinary team'</li> </ul>
		p	<ul style="list-style-type: none"> <li>Care goals p and q from the UK are combined: 'The psychological well-being of the family carer and the patient are maintained'</li> </ul>
		q	<ul style="list-style-type: none"> <li>Added care goal: 'Care givers are able to provide the necessary care'</li> </ul>
		r	<ul style="list-style-type: none"> <li>Added care goal: 'The patient/family carer is informed about the patient's condition'</li> </ul>
		s	<ul style="list-style-type: none"> <li>Added care goal: 'The patient/family carer is informed about any change in the plan of care'</li> </ul>

## 2) Supportive documentation

A goal data dictionary and information leaflets for health care staff and for family carers were developed. The goal data dictionary was based on the Dutch version and slightly adapted in compliance with the content of the new Care Guide.

Four information leaflets were developed based on the Dutch versions: a leaflet for health care professionals about the Care Guide and three leaflets for family carers about the entering of the dying phase, grief and bereavement after death and facilities available on the acute geriatric ward.

### 3) Implementation guide

To help health care staff implementing the care programme for the last days of life in acute geriatric hospital wards, an implementation guide was developed. Table 3 shows the different components of our implementation guide and what they are based on. The implementation guide takes into account most of the components identified in the reviewed LCP programmes and the key factors for a successful LCP implementation.

**Table 3 Overview of the components within the implementation guide for the acute geriatric ward**

Components	Source*
<b>Component 1-Establishing the implementation project and preparing the environment</b>	
❖ Informing the health care staff caring for older hospitalized patients about the implementation project and the importance of change in care during the last days of life	1
❖ Executive endorsement: acquiring management approval for the trainings and audits	
❖ Involvement of specialist palliative care services is recommended: at least one member of the Palliative Support Team of the hospital is member of the steering group	1 1
❖ Facilitators: a nurse and a physician of the geriatric ward	1, 2
❖ Formation of steering group: at least four people of the geriatric ward (facilitators included)	1
❖ Intensive 2-day training of facilitators	1, 2
<b>Component 2-Preparing the documentation</b>	
1. Development of an information leaflet for family carers about the facilities in the geriatric ward	1
<b>Component 3-Baseline review</b>	
1. Analyzing end-of-life care data of deceased older hospitalized patients using the patients' medical files	1, 2
2. Feedback of the results to the staff and focusing on improvement within the geriatric ward	
<b>Component 4-Training health care staff caring for older hospitalized patients</b>	
1. Facilitators and specialist palliative care colleagues train health care staff with the aid of a training package (i.e. hand-outs with information about the Care Guide, a copy of the Care Guide, a casus to discuss in group etc.)	1, 2
2. Aim training	
o To understand and work with the Care Guide	1, 2
<b>Component 5-Care Guide use and intensive support</b>	
1. Care Guide use after sufficient training and education	1, 2
2. Intensive support and supervision by the steering group through repeated coaching, telephone, and direct guidance, discussion of clinical cases, and clinical audits	1, 2
<b>Component 6-Semi-intensive support</b>	
1. Semi-intensive support and supervision by the steering group through repeated coaching, telephone, and direct guidance, discussion of clinical cases, and clinical audits	1, 2
<b>Component 7-Evaluation</b>	
1. To organize a qualitative evaluation of the implementation: evaluating and discussing the performance and progress of each of the previous components	1, 2
2. The qualitative evaluation acknowledges areas where further support, education, or training is need	1
<b>Component 8-Consolidation</b>	
1. To adopt a strategy to maintain/improve the implementation and sustainability of the Care Guide	1
2. Support and supervision by the steering group through repeated coaching, telephone, and direct guidance, discussion of clinical cases, and clinical audits	1, 2
<b>Component 9-Ongoing education, training, and support</b>	
1. Keeping up to date with developments in end-of-life care and a continuing education and evaluation within the hospital ward	

Source\*

1: based on the results of the review of the LCP programmes from the UK, Italy, and the Netherlands.

2: based on the results of the literature review on key factors affecting a successful LCP implementation.

## DISCUSSION

This article describes the development of a care programme for the last days of life for the older hospital population consisting of a Care Guide for the Last Days of Life, supportive documentation and an implementation guide to help health care staff in implementing the Care Guide on the acute geriatric ward and to standardize the implementation process across different wards.

An important strength of our study is that it uses the MRC Framework for the development of a complex intervention as a conceptual and methodological basis. This framework, following a five phase iterative approach from pre-clinical phase to large-scale implementation, has proved to be valuable in guiding the development, modelling and evaluation of complex interventions<sup>26</sup>. To our knowledge, the developed care programme is the first programme that aims to improve care in the last days of life for the older hospital population.

Some limitations have to be acknowledged. Firstly, only three existing LCP programmes were reviewed. As the LCP has been implemented in more than 20 countries, reviewing LCP programmes from other countries could possibly have provided us with more information for the development of our care programme. However, the components of the three reviewed LCP programmes were similar which suggests that a more extensive review would not necessarily have had any added value. Secondly, we did not perform a systematic review concerning the key factors for a successful LCP implementation. However, the key factors identified in our study largely correspond with key factors identified in a more recently published systematic review<sup>50</sup>. Only one additional contextual factor was mentioned in the review. It was found that a major cultural shift is needed to change the perception from dying as a failure of medical care into dying as a time of life when care takes priority over cure<sup>50</sup>. Also findings from a recent Dutch qualitative study evaluating barriers and facilitators to LCP implementation confirm the key factors identified in our study<sup>51</sup>.

Older patients, especially those dying in hospital are a specifically vulnerable patient group for which end-of-life care can be significantly improved<sup>13,14</sup>. Despite advances in palliative care, hospitalized older patients do not have access to palliative care services in the proportions that might be expected<sup>52</sup> and do not often die a peaceful death, due to prolonged aggressive life-sustaining treatments<sup>53,54,55</sup>. There is considerable evidence of underassessment and undertreatment of symptoms such as pain in hospitals<sup>52</sup>. Moreover, studies have shown that hospitalized elderly people are less likely to receive appropriate pain control and more often receive burdensome interventions at the end of life than do their younger counterparts<sup>6,56,10,57</sup>.

However, to our knowledge, no initiative has yet been developed or implemented in order to improve end-of-life care in acute geriatric wards in Flanders.

The care programme for the last days of life, developed for the older hospital population, can be considered as being different from the original LCP programme in several ways. It is specifically adapted to the older hospital population and setting although only small changes were deemed necessary by the reviewers. In the care guide, more attention is paid to specific care goals such as those related to communication, medication and existentialism/spirituality/religiosity, and the content of the implementation guide was adapted in such a way that an acute geriatric ward would be better able to implement the Care Guide within its own setting.

The care programme for the last days of life also took into account most of the concerns regarding the use of the LCP raised in the UK. An independent review recently highlighted and confirmed these concerns and subsequently recommended phasing out the LCP in the UK by July 2014<sup>24</sup>. First, the terminology was changed from ‘Pathway’ to ‘Care Guide’. This might prevent misconceptions about the LCP, such as those among health care staff and family carers and patients in the UK who have perceived ‘pathway’ as a ‘route to death’<sup>34,35,38</sup>. The term ‘Care Guide’ suggests that the document is supposed to guide the health care staff in making individualized choices in caring for dying patients, without being a protocol that has to be followed. This change in terminology was later also recommended in the Neuberger review<sup>24</sup>. Secondly, the importance of a thorough and correct implementation of the Care Guide, underpinned by education and training, is stressed in our implementation guide. Therefore it incorporates nine components to be performed and includes a detailed and elaborate training package to help health care staff in educating and supporting their colleagues in using the Care Guide in a correct and compassionate way. This counters the identified problem of poor or improper implementation of the LCP in the UK leading to cases of inadequate end-of-life care in the hospital setting<sup>34,35,38</sup>. The Neuberger review indeed also confirmed that when the LCP is correctly applied it helps patients to have a dignified and pain-free death. Sufficient training and education should prevent staff from using the Care Guide as a ‘tick box’ exercise instead of as a guidance tool to assist them in decision-making in accordance with a patient’s individual needs<sup>24</sup>.

However, not all identified components and key factors could be incorporated into our implementation guide. First, since there is no central coordinating LCP office in Belgium, the project registration with and the support by a central LCP office, which is part of all LCP

programmes and an important key factor for a successful LCP implementation, could not be included in the implementation guide. Secondly, training of health care staff, is included in the implementation guide but is limited to understanding and working with the Care Guide. Education related to providing good end-of-life care such as symptom control and communication is not part of the training. Nevertheless, the steering group – responsible for the coordination of implementation and consisting of at least one physician, two nurses and a member of the Palliative Support Team (PST) - is recommended to identify and tackle problems or difficulties in the provision of good end-of-life care during the whole implementation process and can organize additional training if deemed necessary. Finally, funding for efforts such as facilitation of the implementation process was not available and was thus not included in the implementation guide.

Although the LCP is an evidence-based framework founded on high quality medical practice in palliative care, the Neuberger review underlined the lack of research on the effectiveness of the LCP and on how factors can result in better or worse implementation<sup>24</sup>. We will therefore perform a phase 2 study to evaluate the feasibility of the implementation process and to identify potential problems and difficulties in implementation and use of the care programme in the acute geriatric hospital wards. Based on the results of this phase 2 study we will be able to refine our preliminary care programme. Having developed and modelled this specific care programme it will be important to evaluate its effectiveness thoroughly.

## **CONCLUSIONS**

Performing a phase 0-1 study according to the MRC Framework helped us to develop a care programme for the last days of life for older patients dying in the acute geriatric hospital wards. With the relevant background information we were able to develop a new care programme which takes into account the concerns regarding the LCP in the UK.

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**CHAPTER 6:**

**IMPLEMENTING THE CARE  
PROGRAMME FOR THE LAST DAYS  
OF LIFE IN AN ACUTE GERIATRIC  
HOSPITAL WARD: A PHASE 2 MIXED  
METHOD STUDY**

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Submitted

## **ABSTRACT**

### **BACKGROUND**

To improve the quality of end-of-life care in geriatric hospital wards we developed the Care Programme for the Last Days of Life. It consists of 1) the Care Guide for the Last Days of Life, 2) supportive documentation and 3) an implementation guide. The aim of this study is (1) to determine the feasibility of implementing the Care Programme for the Last Days of Life in the acute geriatric hospital setting and (2) to explore its preliminary effects on end-of-life care.

### **METHODS**

A phase 2 mixed methods study according with the MRC framework was performed in the acute geriatric ward of Ghent University Hospital between 1 April and 30 September 2013. During the implementation process a mixed methods approach was used including participant observation and the use of a quantitative evaluation tool. This tool measured the success of implementation using several indicators, such as whether a steering group was formed, whether and how much of the health care staff was informed and trained and how many patients were cared for according to the Care Guide for the Last Days of Life.

### **RESULTS**

The evaluation tool showed that implementing the Care Programme for the Last Days of Life in the geriatric ward was successful and thus feasible; a steering group was formed consisting of two facilitators, health care staff of the geriatric ward were trained in using the Care Guide for the Last Days of Life which was subsequently introduced onto the ward and approximately 57% of all dying patients were cared for according to the Care Guide for the Last Days of Life. With regard to preliminary effects, nurses and physicians experienced the Care Guide for the Last Days of Life as improving the overall documentation of care, improving communication among health care staff and between health care staff and patient/family and improving the quality of end-of-life care. Barriers to implementing the Care Programme for the Last Days of Life successfully are, among others, difficulties with the content of the documents used within the Care Programme for the Last Days of Life and the low participation rate of physicians in the training sessions and audits.

### **CONCLUSIONS**

Results of this mixed methods study suggest that implementing the Care Programme for the Last Days of Life is feasible and that it has favorable preliminary effects on end-of-life care as reported by health care professionals. Based on the identified barriers during the implementation process, we were able to make recommendations for future implementation and further refine the Care Programme for the Last Days of Life before implementing it in a

phase 3 cluster randomized controlled trial for the evaluation of its effectiveness.

## BACKGROUND

Ageing, coupled with a rising prevalence of chronic and degenerative conditions, means that many more older people will need end-of-life care, and this number will continue to increase in future<sup>1</sup>. Although most people wish to die at home<sup>2,3</sup>, a substantial number of older people die within the acute hospital setting, for example in an acute geriatric ward. It is estimated that deaths in institutions such as hospitals are likely to increase in the next decades<sup>4,5,6</sup>.

Traditionally, high quality care at the end of life has been provided mainly for cancer patients, but optimal end-of-life care should be provided for all patients regardless of diagnosis<sup>1</sup>.

Optimal end-of-life care for older hospitalized patients should include good symptom control, respect for patient preferences, appropriate use of diagnostic and therapeutic interventions at the end of life and support for the family<sup>7</sup>. However, many older people dying in hospital experience poor care<sup>8,9,10,11</sup>. Research shows that they often receive undesired and burdensome interventions that negatively affect their quality of life<sup>11</sup> and there is also considerable evidence of underassessment and undertreatment of symptoms such as pain<sup>1,12</sup>.

A number of barriers to optimal end-of-life care have been identified including difficulty in recognizing the dying phase, difficulties in withdrawing futile diagnostic procedures and treatments, failure to implement an appropriate end-of-life plan of care, inadequate pain and symptom management and ineffective communication with patients and between patients, relatives and professionals<sup>13,14,15</sup>. In addition, during medical education, the need for the provision of optimal end-of-life care as part of a physician's professional duties is insufficiently recognized<sup>14</sup>.

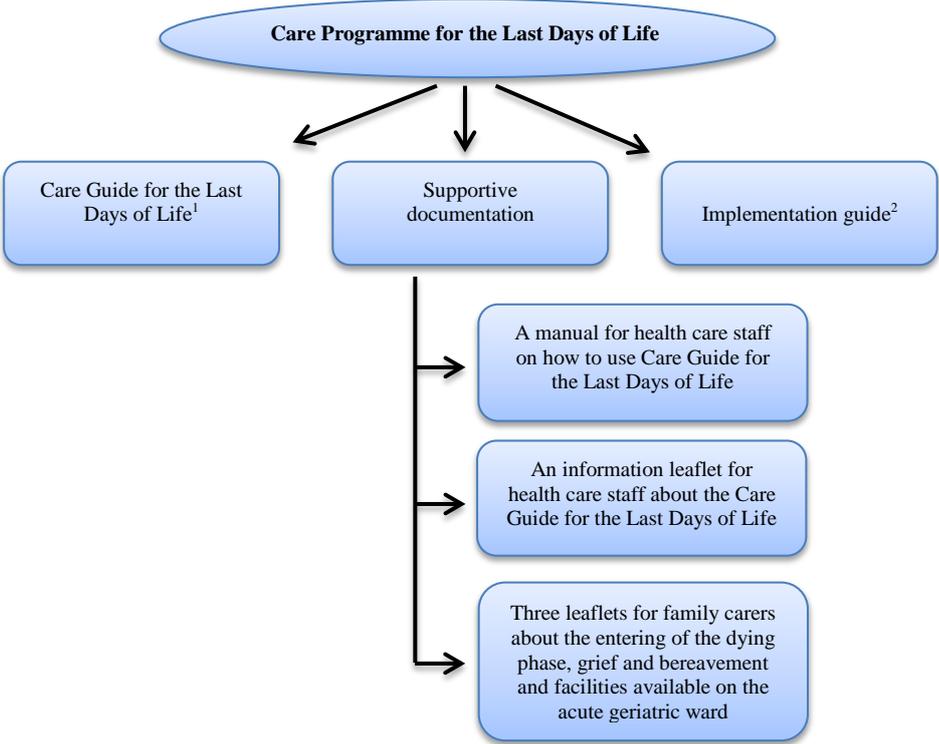
To improve the quality of end-of-life care for older patients dying in hospital, we developed the Care Programme for the Last Days of Life (hereinafter - Care Programme) for acute geriatric hospital wards (Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, van der Heide A, Deliëns L: Development of the care programme for the last days of life for older patients dying in acute geriatric hospital wards: a phase 0-1 study according to the Medical Research Council Framework, in revision).

This programme is based on the Liverpool Care Pathway (LCP) programme, taking into account the raised concerns in the UK regarding the LCP and adapted to the older hospital population and setting. The Care Programme consists of: (1) the Care Guide for the Last Days of Life, (2) supportive documentation and (3) an implementation guide (figure 1). The Care Programme aims to introduce and embed the Care Guide for the Last Days of Life (hereinafter - Care Guide), a multi-professional document that provides a template of care for the last days

and hours of life in order to ensure that optimal end-of-life care is delivered to every patient dying in an acute geriatric ward.

This study aims (1) to assess the feasibility of implementing the Care Programme in the acute geriatric hospital setting and (2) to explore the preliminary effects of the Care Programme on end-of-life care.

Figure 1 The Care Programme for the Last Days of Life



<sup>1</sup> A multi-professional document that provides a template of care for the last days and hours of life with recommendations on different aspects of care and guidance for the psychological and spiritual support of patients and their families

<sup>2</sup> This guide assists health care staff in implementing the Care Programme for the Last Days of Life on the geriatric ward during a six-month period

## **METHODS**

### **STUDY DESIGN**

We performed a phase 2 mixed methods study according to the MRC Framework for the development and assessment of complex interventions<sup>16</sup>. The Care Programme was implemented during a six-month period (April-September 2013). In order to assess the feasibility of the implementation process and explore the preliminary effects of the Care Programme on end-of-life care, a mixed methods approach was used during the implementation process. This approach included a quantitative evaluation tool measuring the success of implementation and participant observation to estimate the feasibility of implementation and the preliminary effects of the Care Programme. For this study we obtained approval of the Medical Ethics Commission of the Brussels University Hospital and Ghent University Hospital.

### **SETTING**

The Care Programme was implemented in the acute geriatric hospital ward of Ghent University Hospital. At the time of the study, the geriatric ward had 30 beds organized in 17 rooms, an overall staff of four geriatricians (including two in training) and 39 nurses and the available support of a hospital-based palliative support team (PST). The PST consists of a palliative care nurse, a social nurse (a combined nurse and social worker), a physician and a clinical psychologist and provides consultation on request and works closely together with existential/spiritual counsellors.

### **DATA COLLECTION**

#### ***Evaluation tool***

We developed an evaluation tool to measure the success of implementation, i.e. the degree to which each of the nine components of the implementation guide is implemented. In order to know how well each component was implemented, a number of indicators were developed. The indicators, for which an ideal outcome or standard was formulated, were measured by the researcher (RV) during the implementation process (Table 1). In this way, the completed evaluation tool could inform us about the success rate of the implementation process.

#### ***Participant observation***

A member of the research team (RV) attended and observed five steering group meetings (i.e. meetings of a work group of persons coordinating the implementation of the Care Programme), two training sessions and one audit related to the implementation and use of the Care Guide. Careful notes were made during each of these meetings and one audit was

recorded and transcribed verbatim. A signed informed consent was obtained from each participant attending the audit. The researcher also made notes of face-to-face and telephone contacts with the members of the steering group and of face-to-face contacts with other health care staff of the acute geriatric ward. Finally, the researcher made notes of a meeting of the Advance Care Planning work group, which she attended and during which the Care Programme was discussed. This work group is organized within the Medical Ethics Commission of Ghent University Hospital in order to discuss end-of-life care issues on a regular basis. In total, qualitative data were gathered from twelve nurses, four physicians and two members of the Palliative Support Team i.e. a nurse and a religious counsellor.

## **OUTCOME MEASURES**

The first outcome measure, the feasibility of implementing the Care Programme, was assessed using two different methods: the quantitative evaluation tool and participant observation. The quantitative evaluation tool measured the degree to which the Care Programme was implemented according to the components of the implementation guide, using several indicators. Most important indicators are: the proportion of health care staff informed about the implementation project, the composition of a steering group, number of facilitators, attendance at a two-day intensive training programme by facilitators, retrospective evaluation of end-of-life care and discussion of the results with health care staff, training health care staff in using the Care Guide, introduction of the Care Guide on the geriatric ward, organization of clinical audits and the proportion of patients cared for according to the Care Guide (Table 1). Participant observation provided additional qualitative data regarding the barriers to the implementation process perceived by the health care staff, which allowed us to gain a deeper understanding of the feasibility of implementing the Care Programme.

The second outcome measure, the preliminary effects of the Care Programme on end-of-life care, was explored using participant observation, including notes taken during meetings, verbatim transcription of a clinical audit and notes based on face-to-face and telephone contacts with the members of the steering group and other health care staff.

## **DATA ANALYSIS**

### ***Quantitative data analysis***

The outcomes of the indicators within the evaluation tool were measured or observed by the researcher (RV). Each outcome was compared with the standard outcome (table 1).

### ***Qualitative data analysis***

In order to assess the feasibility of implementing the Care Programme, the textual data, i.e. notes and a transcript, were thematically analyzed. The analysis process consisted of five interconnected stages: (1) involved familiarization, (2) identifying a thematic framework, (3) coding, (4) charting and (5) interpretation<sup>17</sup>. One researcher (RV) performed thematic coding using the nine components within the implementation guide as a framework. A second researcher (TS) checked the coding process and discussed it with RV.

Insights from each set of transcripts served to deepen understanding of the implementation process and to assess the feasibility of the implementation of the Care Programme.

In order to assess the preliminary effects of the Care Programme on end-of-life care, thematic analysis was used to capture themes. This analysis was inductive, not restricted by any a priori theoretical framework. After reading the textual data, a preliminary coding framework was developed by one researcher (RV) and discussed with a second researcher (TS). Next, all textual data were read line by line and labels were assigned by one researcher (RV). The coding framework was adjusted where needed, in consensus with a second researcher (TS). The results were discussed within the research team to ensure consistency. A final framework, including results and quotes, was agreed within the research team.

## **RESULTS**

### ***Feasibility of implementing the Care Programme***

Findings with regard to the feasibility of implementing the Care Programme are presented in table 1. The results of the evaluation tool showed that for 15 of the 17 indicators the standard was essentially met; a steering group was formed consisting of two facilitators both of whom attended a two-day intensive training workshop, a leaflet concerning the facilities on the ward was developed, end-of-life care was retrospectively evaluated and discussed with the staff, the health care staff of the ward were trained in using the Care Guide, two audits were organized and the steering group organized a meeting to evaluate and discuss the performance and progress of the implementation in order to identify training needs and barriers for using the Care Guide and providing optimum end-of-life care. Lastly, more than half of the deceased patients had been cared for according to the Care Guide, i.e. of the 19 people who died on the ward during the implementation period, 11 were cared for according to the Care Guide. Six months after the implementation of the Care Programme, the Care Guide was still in use. In those six months, of the 30 patients died on the ward 17 were cared for according to the Care Guide.

However, despite the fact that two training sessions were organized, only one out of four geriatricians was trained. Furthermore, for two indicators the standard was not met: 37% instead of 100% of the health care staff were informed about the implementation project and one out of the three audits that should have been organized was not.

Health care staff identified four types of potential barriers to implementing the Care Programme. Firstly, there were barriers related to practical issues, e.g. many health carers perceived the double registration (i.e. the electronic patient file in combination with the Care Guide in printed version) as a barrier to use the Care Guide. A second type of barrier was related to the content of the documents used within the Care Programme, e.g. some staff had difficulties with the term 'care goal' within the Care Guide and perceived the term as being too coercive. A third type of barrier was related to the low motivation of some health care staff. Nurses mentioned that low motivation of health care staff resulted in a low participation rate of staff in collective and essential meetings to implement the Care Programme on the geriatric ward. For example, few physicians attended the training sessions and nurses perceived this as an important barrier to introducing and using the Care Guide. A fourth and important barrier was related to difficulties inherent in the organization and provision of care in the last days of life rather than to using the Care Programme. It was for instance found that health care staff had difficulties with recognizing when the dying process had started and, related to this, medical staff often felt resistant to initiating the Care Guide. Furthermore, in relation to the organization of end-of-life care, nurses often felt uneasy about communicating with the physician that a patient had entered the dying phase. They also indicated that they found it difficult to take responsibility for caring for the dying patient according to the Care Guide.

Table 1 Quantitative and qualitative evaluation of the feasibility of implementing and sustaining the Care Programme for the Last Days of Life in the geriatric ward of Ghent University Hospital

Component	Quantitative evaluation using the evaluation tool			Perceived difficulties <sup>1</sup> among staff in implementing the Care Programme <sup>2</sup>
	Indicator	Standard	Outcome	
1. Establishing the implementation project and preparing the environment	<p>(1) Proportion of health care staff informed about implementation project (%)<sup>3</sup></p> <p>(2) Executive endorsement: management approval for organization training and audits</p> <p>(3) Composition of steering group</p> <p>(4) Facilitators: Number Function</p> <p>(5) Attendance at the 2 day intensive training by 2 facilitators</p>	<p>100%</p> <p>Yes</p> <p>2 nurses 1 physician 1 PST member<sup>5</sup></p> <p>≥2 nurse &amp; physician</p> <p>Yes</p>	<p>37% (23/62)</p> <p>Yes</p> <p>2 nurses 1 physician 1 PST member</p> <p>2 nurse &amp; physician</p> <p>Yes</p>	<ul style="list-style-type: none"> <li>▪ Limited time to establish the implementation project, e.g. composition of steering group with facilitators</li> <li>▪ Information moment<sup>4</sup> was organized too early</li> <li>▪ Information moment did not reach all geriatric health care staff (1)</li> <li>▪ Content of the 2 day intensive training is not yet fully adjusted to geriatric hospital setting</li> </ul>
2. Preparing the documentation	<p>(6) Development of information leaflet concerning the facilities on the geriatric ward</p>	<p>Yes</p>	<p>Yes</p>	
3. Baseline review	<p>(7) Retrospective evaluation of medical/nursing files of deceased patients</p> <p>(8) Feedback of results to staff</p>	<p>Yes</p> <p>Yes</p>	<p>Yes</p> <p>Yes</p>	<ul style="list-style-type: none"> <li>▪ Feedback of results to health care staff more feasible if incorporated in training sessions</li> </ul>

<sup>1</sup> Perceived difficulties that emerged from the qualitative evaluation

<sup>2</sup> In the further course of this table we used 'Care Programme' for the complete term 'Care Programme for the Last Days of Life'

<sup>3</sup> Health care staff refers to all health carers involved in care on the acute geriatric hospital ward, i.e. nurse, nursing aide, psychologist, physiotherapist, physician, etc.

<sup>4</sup> During the information moment, the steering group aims to inform health care staff about the implementation project

<sup>5</sup> One health carer of the Palliative Support Team (PST) should be member of the steering group

Component	Quantitative evaluation using the evaluation tool			Perceived difficulties among staff to implement the Care Programme
	Indicator	Standard	Outcome	
4. Training health care staff on the geriatric ward	(9) Training health care staff Duration (minutes per edition) Editions (No.) Nurses involved (%) Physicians involved (%)	≥90 minutes ≥2 editions 100% 100%	120 minutes 2 editions 67% (26/39) 25% (1/4)	<ul style="list-style-type: none"> <li>▪ Only feasible if training content is well prepared by steering group</li> <li>▪ Documents for training health care staff need adaptations (i.e. hand-outs, geriatric casus, manual for using the Care Guide for the Last Days of Life<sup>6</sup>)</li> <li>▪ Care Guide needs adaptations</li> </ul>
5. Use of the Care Guide for the Last Days of Life with intensive support	(10) Introduction of the Care Guide on the ward	Yes	Yes	<ul style="list-style-type: none"> <li>▪ Training sessions did not reach enough physicians (9)</li> <li>▪ No audit was organized (11)</li> <li>▪ Physicians are hesitant to initiate or use the Care Guide</li> <li>▪ The term ‘care goal’ lead to misinterpretations and is perceived as being too coercive</li> </ul>
	(11) Clinical audit Organized Nurses involved (%) Physicians involved (%)	Yes 100% 100%	No No audit organized No audit organized	
6. Use of the Care Guide with semi-intensive support	(12) Clinical audit Organized Nurses involved (%) Physicians involved (%)	Yes 100% 100%	Yes 20% (9/39) 25% (1/4)	<ul style="list-style-type: none"> <li>▪ Low attendance of health care staff during audit (12)</li> <li>▪ Diagnosing dying is difficult</li> <li>▪ Physicians are hesitant to initiate or use the Care Guide</li> <li>▪ Nurses are too scared of taking responsibility</li> <li>▪ The term ‘care goal’ is perceived as being too coercive</li> <li>▪ High workload with double registration</li> </ul>

<sup>6</sup> In the further course of this table we used ‘Care Guide’ for the complete term ‘Care Guide for the Last Days of Life’

Component	Quantitative evaluation using the evaluation tool			Perceived difficulties among staff to implement the Care Programme
	Indicator	Standard	Outcome	
7. Evaluation <sup>7</sup>	(13) Qualitative evaluation of the implementation	Yes	Yes	
8. Consolidation	<p>(14) Clinical audit Organized Nurses involved (%) Physicians involved (%)</p> <p>(15) Proportion of dying patients cared for according to Care Guide during the implementation period (from component 5-8) (%)</p>	<p>Yes 100% 100%</p> <p>≥50 %<sup>8</sup></p>	<p>Yes 26% (10/39) 0% (0/4)</p> <p>57.9% (11/19)</p>	<ul style="list-style-type: none"> <li>▪ Low attendance of health care staff during second audit <b>(14)</b></li> <li>▪ Diagnosing dying is difficult</li> <li>▪ Physicians are hesitant to initiate or use the Care Guide</li> <li>▪ Continuing support by all steering group members is important (one nurse of the ward is not sufficient)</li> </ul>
9. Use of the Care Guide with ongoing education, training and support	<p>(16) Care Guide still in use on the ward after 1 year</p> <p>(17) Proportion of dying patients cared for according to Care Guide during the 6 months after completion of implementation period</p>	<p>Yes</p> <p>≥50%</p>	<p>Yes</p> <p>56.7% (17/30)</p>	<p><i>The researcher only followed up during the implementation period</i></p>

<sup>7</sup> The steering group needs to qualitatively evaluate and discuss the performance and progress of each of the previous components in order to identify staff's training needs and barriers for the use of the Care Guide for the Last Days of Life and provision of optimum end-of-life care

<sup>8</sup> Based on the results of a study performed in the UK and the Netherlands

### ***Preliminary effects of the Care Programme***

Four key themes relating to the effects of the Care Programme on end-of-life care emerged from the data analysis. These key themes were: 1) documentation of end-of-life care, 2) content and quality of end-of-life care, 3) communication between health care staff and family carers, and 4) communication among health care staff.

#### *Documentation of end-of-life care*

Nurses and physicians agreed that there had been an improved documentation of care since the introduction and use of the Care Guide.

*“Previously they said, yes, he is uncomfortable, but, what does that mean? What is uncomfortable? And now you will document it more in detail, it was because of that kind of pain, or it was his breathing, or it was something else”* [Nurse A ]

According to the nurses, the improved documentation of care in the Care Guide also led to a better understanding and delivering of care for the dying patient.

*“For example, if we document the aspiration frequency as four, other caregivers know that we did it four times, I mean that they know, if they are aspirating for the third time, that this is normal”* [Nurse B ]

#### *Content and quality of end-of-life care*

Since the introduction of the Care Guide nurses felt empowered to approach the patient holistically. Where nurses tended to pay more attention to physical aspects in the care of the dying patient before the introduction of the Care Guide, they claimed they were now more focused on psychosocial and existential/spiritual aspects of care.

*“The Care Guide helps nurses, who were previously focused on the physical aspects, to also think about other care dimensions”.* [Nurse C ]

There was a consensus of opinion between the nurses that the Care Guide stimulates them to study each perceived symptom or problem of the dying patient as well as to reflect on an adequate approach to alleviate the symptom.

*“I often hear, people are not comfortable, and then you are wondering what needs to happen, but now the Care Guide has the advantage that this problem is elaborated in depth, that we can find out what the underlying reason is and how we can solve it”.* [Nurse D]

Nevertheless, one nurse was not convinced of the idea that the Care Guide delivers better care for the dying patient. According to her, delivering good symptom control is much more than symptom assessment and reflecting on an ideal approach; a nurse must also be capable of ensuring good symptom control, which is not always the case.

Nurses and physicians also agreed that using the Care Guide ensures better continuity of care at the end of life. Because of the four-hour registration of symptoms and reported interventions or actions in the Care Guide, each staff member involved in the care of the dying patient has knowledge of the clinical status of the patient and of the medical and nursing interventions previously taken, which allows them to ensure continuity of care.

*“I think it is very interesting as a communication tool, in the continuity of care, if one nurse takes it over from another nurse, that she clearly sees what already happened and how far we are in the provision of end-of-life care, and what she can further improve during her late shift”* [Nurse E]

According to some nurses the Care Guide provides a structure in delivering optimal end-of-life care to patients and family carers. One nurse stated:

*“When I start to support a dying patient with the Care Guide, I will do it in a structured way, I will tell him, it is not going well and you will die, and I will consider his spiritual/existential needs and wishes, then I will think about all these issues”* [Nurse A]

Nurses and physicians agreed that the Care Guide serves as a memory aid as it reminds them to consider all relevant aspects of end-of-life care. Two physicians perceived this as one of the most important advantages of the Care Guide. However, these physicians felt that for them the Care Guide was only an aide-memoire as they believed end-of-life care was already optimal in their ward though in hospitals struggling to deliver good end-of-life care it could be of more benefit.

Reference was also made by several nurses and one physician to medication policy, i.e. anticipatory prescribing and effective medication use. Nurses confirmed that the Care Guide implied a clearer policy regarding anticipatory prescribing of medicines to ensure that there is no delay in responding to symptom if they occur.

*“Previously, before the introduction of the Care Guide, it happened that I had to call the on-call physician during a weekend and ask him to prescribe Morphine, which often resulted in a delayed response to pain”.*  
[Nurse A]

One respondent mentioned that, since the Care Guide had been introduced, she gives medicines for symptom control only when needed, at the right time and just enough and no more than is needed to relieve the symptom.

However, another respondent expressed concerns about the management of pain medication.

*“Once a patient is supported by the Care Guide, some nurses think they must give and increase all the medication, whereas this is not necessary for every patient, and it must be more tailored to the individual needs and wishes of the patient”* [Nurse C]

#### *Communication between health care staff and family carers*

Some nurses agreed that the Care Guide helped them to reflect on practical issues that are important to relatives, for example:

*“It is a control check for us, do I have a phone number of the patient’s family carer, or do I know when I can call this person, or that you are at least reflecting on it”.* [Nurse F]

Nurses agreed that since the introduction of the Care Guide communicating with the relatives had been given a higher priority. According to them the impending death and care of the dying person could be discussed in a more open way.

However, the Care Guide did not change the extent of involvement of the patient’s family carer in discussions regarding the plan of care. Some nurses believed that decisions and reasons for them were already communicated and explained well enough to family carers before the introduction of the Care Guide.

*“Actually, what we are doing, we say, yes, it’s a bit...”* [Nurse A]

*“I don’t think it’s different than before the introduction of the Care Guide”* [Nurse E]

*“No no”* [Nurse C]

*“No, I think it’s indeed a bit the same as we did before”* [Nurse A]

*“Actually it doesn’t change; from the moment you see that someone’s condition is worse, you communicate that and you say, look, we stop antibiotics”* [Nurse C]

#### *Communication among health care staff*

There was an overall agreement among nurses and physicians that communication between health care staff was improved after implementation of the Care Guide. They were convinced that introduction of the Care Guide 1) facilitates discussion between medical and nursing staff about recognizing the dying phase in patients, 2) stimulates hospital staff to inform the patient’s general practitioner about their impending death and 3) creates the opportunity to evaluate and discuss the delivered care between each other.

*“You have to report a lot...”* [Nurse B]

*“Yes, to describe details, so that you can check with your colleague...”* [Nurse G]

*“It will be a little more objective”* [Physician]

*“...why he doesn't think that...or that you think someone should have more comfort. You've got a medium now, in order to evaluate the care commonly”* [Nurse G]

*“Your arguments are more clear for each other”* [Nurse E]

*“So the communication between us improves”* [Nurse G]

## DISCUSSION

The results of this mixed methods study suggest that implementing the Care Programme in the acute geriatric hospital setting is feasible and also has valuable preliminary effects on end-of-life care: nurses and physicians experienced it as improving the overall documentation of care, improving communication among health care staff and between health care staff and patient/family and improving the quality of end-of-life care. However, difficulties with the content of the documents used within the Care Programme and the low participation rate of physicians in the training sessions and audits were perceived as important barriers to successful implementation of the Care Programme in the geriatric ward.

The proportion of dying patients cared for according to the Care Guide is an important indicator of the success of implementation in terms of consolidation and ongoing use of the Care Guide. During the implementation period and six months after, approximately 60% of all patients who died in the geriatric ward were cared for according to the Care Guide. Other studies performed in the UK and the Netherlands found that the LCP, an end-of-life care pathway for the last days of life similar to our Care Guide, had been used for around 85% of all cancer patients who died during the research period in a hospice, and for 50% of all cancer patients who died in a Palliative Care Unit<sup>18</sup>. Nevertheless, we deem 60% as a sufficient result for our study<sup>19,20</sup>, recognizing that the dying phase is considered to be more difficult in older patients who often suffer from multiple chronic conditions than in those dying from cancer as the actual death is often more unexpected<sup>19</sup>. In addition, our mixed methods study was conducted in a hospital setting, where the focus may be more on cure or life-prolonging than in hospices or palliative care units<sup>20</sup>. Furthermore, results from an Italian cluster randomized controlled trial performed in hospitalized cancer patients showed that during LCP implementation only 34% of dying patients were cared for in accordance with the programme and that this percentage decreased during the six months after implementation<sup>21</sup>. Other factors that indicate that implementing the Care Programme is feasible are that the acute geriatric ward was able to create a steering group, involve palliative care services (e.g. members of a Palliative Support Team), appoint two facilitators responsible for the coordination of the implementation process, organize training sessions on why and how to use the Care Guide and organize audits.

The health care staff of the geriatric ward perceived the Care Programme as having predominantly positive effects on end-of-life care, which confirms the findings of earlier qualitative studies<sup>22,23,24</sup>. More specifically, according to nurses and physicians, use of the

Care Programme improves the overall documentation of care and positively influences communication among health care staff and between health care staff and patients/families. They also experienced a positive effect of the Care Programme on the quality and content of end-of-life care. For instance, according to nurses and physicians, using the Care Guide stimulates a multidisciplinary approach in care at the end of life. It also stimulates greater reflection among health care staff on end-of-life care, stimulates continuity of care, helps structure care delivery and promotes a clearer policy regarding anticipatory prescribing of medicines. Moreover, as no additional resources or persons were needed to implement the Care Programme, positive effects could be achieved without any additional cost.

Since one nurse remarked that good end-of-life care requires more than just the use of the Care Guide, training of health care staff in symptom management and in delivering optimal end-of-life care is required if we want the Care Guide to add value to end-of-life care. This confirms what was recently recommended by a review performed in the UK in response to the concerns about the LCP<sup>25</sup>. According to that review, the importance of a well thought-out implementation strategy, underpinned by training and education of all staff involved, cannot be overestimated, and should therefore be considered as a priority when implementing the pathway<sup>25</sup>.

Barriers to implementing and using the Care Programme in the acute geriatric hospital ward identified in our study include practical issues such as insufficient time, the administrative burden of using the Care Guide and the lack of integration with electronic patient files. The same barriers were identified in a recently published qualitative study about barriers and facilitators to implementation of the LCP in a hospital, a hospice, a home care setting and a nursing home in the Netherlands<sup>26</sup>.

Lack of motivation of some health care staff, for instance reflected in the low involvement of physicians during the training sessions, was another important barrier to successful implementation. This lack of motivation may have been related to the insufficient authority and influence of the steering group, which was also identified as an important barrier in the Dutch qualitative study<sup>26</sup>.

Finally, the difficulties with recognizing the dying phase and the resistance of health care staff to initiating the Care Guide also seem to be important barriers to adequately use of the Care Guide. This barrier was also identified in a study investigating barriers to implementation of an integrated care pathway for the last days of life in nursing homes<sup>27</sup>. Diagnosing when a

patient is dying, understanding the dying process and communicating about dying are indeed very difficult issues in practice, but they are a prerequisite for delivering good end-of-life care.

The barriers identified enabled us to further refine the Care Programme. For instance, the Care Guide and other supportive documents were adapted to overcome the barriers related to the content of the documents. For example, the term ‘care goal’ which was used in the Care Guide was changed into ‘point of attention’; another example is that practical barriers such as a lack of time can be overcome by recommending and predicting more time for preparation within the implementation guide. Furthermore, based on the barriers identified, we were also able to make recommendations for future implementation. Firstly, wards that are willing to implement the Care Programme are encouraged to seek management approval to create more time to compose a steering group and inform all involved health care staff. Secondly, in order to overcome the low motivation of some health care staff and thus the low participation in training and audits, the importance of a very motivated steering group and good facilitators who can enthuse other staff cannot be overestimated as they are key to successful implementation<sup>26</sup>. Thirdly, difficulties inherent to the organization and provision of end-of-life care need to be incorporated into and discussed during the training sessions and audits. It is therefore essential that all health care staff who will use the Care Guide attend these meetings. Further research in order to gain a better understanding of these barriers and how they could best be approached or addressed would also be very helpful.

Over many years various pathways have been developed and implemented in order to improve end-of-life care<sup>28,29,30</sup>. Since 2012 the LCP has been widely criticized for failing to provide appropriate care and an independent review has recommended that it should be phased out in the UK<sup>25</sup>. However, this should not be a reason to abandon any efforts to structure and further improve end-of-life care in health care settings. Rather, it pinpoints the need to develop, evaluate and implement ameliorated end-of-life care improvement programmes (Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, van der Heide A, Deliens L: Development of the care programme for the last days of life for older patients dying in acute geriatric hospital wards: a phase 0-1 study according to the Medical Research Council Framework, in revision). We believe that the Care Programme makes an important contribution to the acute geriatric hospital ward in that respect. One of the lessons learned from the UK is that an end-of-life care programme should never be implemented in practice without proper evaluation of its beneficial effects and potential harms. Our mixed methods study is only a first, but important, step in evaluating the feasibility and effectiveness of the

Care Programme; however it allows us to further improve our programme before evaluating it in a larger cluster randomized controlled trial and before further wide-scale implementation.

An important strength of our study is that it uses a phase 2 approach according to the MRC Framework for the development of a complex intervention<sup>16</sup>. This framework, following a five phase iterative approach from pre-clinical phase to large-scale implementation, provides a valuable structure to guide the development and modelling of a complex intervention to improve end-of-life care in acute geriatric hospital wards<sup>16</sup>. Secondly, our study uses methodological triangulation<sup>31</sup>; multiple qualitative methods (i.e. notes and transcripts) and a quantitative method to evaluate the feasibility and effects of the Care Programme.

There are also limitations in the study that need to be considered. Firstly, because it took place only in one geriatric hospital ward, located in a university hospital, our results cannot be automatically generalized to other wards in other hospitals. Secondly, we only explored the perceptions of health care staff whereas family carers and patients could have provided additional information on the effects of the Care Programme.

## **CONCLUSIONS**

Results of this mixed methods study suggest that implementing the Care Programme in an acute geriatric hospital setting is feasible as most of our indicators for a successful implementation were met. Nurses and physicians also found that the Care Programme has favorable preliminary effects on the documentation of care and the content and quality of end-of-life care and communication among health care staff and between health care staff and patient/family. However, several barriers to the implementation process were perceived relating to practical issues, the content of the supportive documents within the Care Programme, the low involvement of health care staff during meetings and training and difficulties inherent to the organization and provision of end-of-life care in the last days of life. To resolve most of these barriers, adaptations were made to the Care Guide and implementation guide that have resulted in a refined Care Programme. However, barriers related to the low motivation of staff and the organization and provision of end-of-life care are more challenging to resolve. Health care staff desiring to implement and use the Care Programme on their ward should take these challenges into consideration. Further research should focus on gaining a better understanding of the barriers and of how they could best be addressed.

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**CHAPTER 7:**

**IMPROVING END-OF-LIFE CARE IN  
ACUTE GERIATRIC HOSPITAL WARDS  
USING THE CARE PROGRAMME FOR  
THE LAST OF LIFE: STUDY  
PROTOCOL FOR A PHASE III  
CLUSTER RANDOMIZED  
CONTROLLED TRIAL**

Rebecca Verhofstede, Tinne Smets, Joachim Cohen, Massimo Costantini, Nele Van Den Noortgate, Luc Deliens

BMC Geriatrics. 2015 February; 15:13

## **ABSTRACT**

### **BACKGROUND**

The Care Programme for the Last Days of Life has been developed to improve the quality of end-of-life care in acute geriatric hospital wards. The programme is based on existing end-of-life care programmes but modeled to the acute geriatric care setting. There is a lack of evidence of the effectiveness of end-of-life care programmes and the effects that may be achieved in patients dying in an acute geriatric hospital setting are unknown. The aim of this paper is to describe the research protocol of a cluster randomized controlled trial to evaluate the effects of the Care Programme for the Last Days of Life.

### **METHODS AND DESIGN**

A cluster randomized controlled trial will be conducted. Ten hospitals with one or more acute geriatric wards will conduct a one-year baseline assessment during which care will be provided as usual. For each patient dying in the ward, a questionnaire will be filled in by a nurse, a physician and a family carer. At the end of the baseline assessment hospitals will be randomized to receive intervention (implementation of the Care Programme) or no intervention. Subsequently, the Care Programme will be implemented in the intervention hospitals over a six-month period. A one-year post-intervention assessment will be performed immediately after the baseline assessment in the control hospitals and after the implementation period in the intervention hospitals. Primary outcomes are symptom frequency and symptom burden of patients in the last 48 hours of life.

### **DISCUSSION**

This will be the first cluster randomized controlled trial to evaluate the effect of the Care Programme for the Last Days of Life for the acute geriatric hospital setting. The results will enable us to evaluate whether implementation of the Care Programme has positive effects on end-of-life care during the last days of life in this patient population and which components of the Care Programme contribute to improving the quality of end-of-life care.

### **TRIAL REGISTRATION**

ClinicalTrials.gov Identifier: NCT01890239. Registered June 24th, 2013.

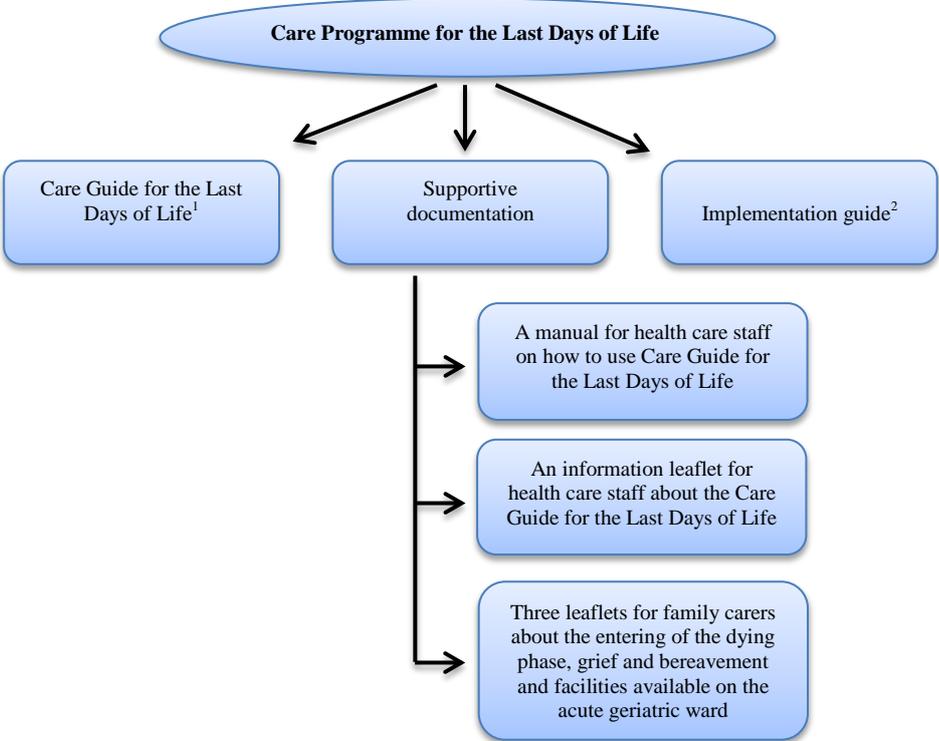
## **BACKGROUND**

Pain and symptom management, appropriate treatments and medication and communication about end-of-life issues are identified as key elements of quality care for terminally ill patients [1]. However, clinicians are often inadequately prepared to diagnose dying effectively [2] or to discuss the likelihood of imminent death with patients and families [3-7]. Studies have also shown that older hospitalized people are less likely to receive appropriate pain control and more likely to receive burdensome interventions at the end of life than their younger counterparts [8-11]. Although end-of-life care has been identified as a priority for older people [8,12] and a large proportion die in hospital [13-15], the quality of end-of-life care for older hospitalized patients is suboptimal, leaving room for improvement [16]. As a significant number of older patients may die within the acute geriatric ward of a hospital, it is an important setting in which end-of-life care could be improved.

To improve the quality of care at the end of life in the geriatric hospital population we developed and successfully piloted the Care Programme for the Last Days of Life (Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, van der Heide A, Deliens L: Development of the care programme for the last days of life for older patients in acute geriatric hospital wards: a phase 0–1 study according to the Medical Research Council Framework, submitted; Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, Deliens L : Feasibility and preliminary effects of the Care Programme for the Last Days of Life in an older acute hospital population: mixed-methods study of the success of implementation and staff perceptions, in preparation). This programme is based on the Liverpool Care Pathway (LCP) programme, taking into account the concerns regarding the LCP raised in the UK and adapted to the geriatric hospital population and setting (Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, van der Heide A, Deliens L: Development of the care programme for the last days of life for older patients in acute geriatric hospital wards: a phase 0–1 study according to the Medical Research Council Framework, submitted). The Care Programme essentially aims to raise awareness among geriatric health care staff of the importance for improving end-of-life care and to prepare them for a change in end-of-life care, to train staff in delivering good end-of-life care with the support of a multi-professional document called the Care Guide for the Last Days of Life, to support dying geriatric patients with the Care Guide for the Last days of Life, to regularly evaluate the delivered end-of-life care and support and to further educate the staff in delivering optimal end-of-life care.

The Care Programme consists of the following documents: (1) the Care Guide for the Last Days of Life, (2) supportive documentation and (3) an implementation guide (Figure 1).

Figure 1 The Care Programme for the Last Days of Life



<sup>1</sup> A multi-professional document that provides a template of care for the last days and hours of life with recommendations on different aspects of care and guidance for the psychological and spiritual support of patients and their families

<sup>2</sup> This guide assists health care staff in implementing the Care Programme for the Last Days of Life on the geriatric ward during a six-month period

Although end-of-life care programmes have been developed since the 1990s and have already been implemented in more than 20 countries [17], the available evidence regarding their effectiveness is weak and studies are limited to the cancer population. Two systematic reviews conclude that randomized controlled trials or other well designed controlled studies are needed to obtain additional evidence about the effectiveness of end-of-life care pathways [18]. To date, only one cluster randomized controlled trial has been performed to study the effects of the LCP in oncology patients dying in Italian hospitals [19,20]. Results of that study show that a well-implemented LCP programme has the potential to reduce the gap in quality of care between hospices and hospitals. However, the results also show that the effects of the LCP programme are smaller than those shown in qualitative and before-and-after non-controlled studies, and no significant effects on the overall quality of care were found [20]. Nonetheless, the effectiveness of the LCP programme was evaluated in a cancer population whereas end-of-life care pathways or programmes are often used for patients who are dying from diseases

other than cancer. Furthermore, the study was underpowered and therefore may have led to underestimated results.

Although it is now widely accepted that clinical practice should be, wherever possible, evidence-based, clinical pathways to improve the quality of end-of-life care are often implemented without a thorough evaluation of their effectiveness [21]. Additional and robust evidence is required [18,22] before realizing a large scale implementation of an end-of-life care pathway. Hence, a thorough evaluation of the effectiveness of the Care Programme for the Last Days of Life is needed before implementing it in practice. We will therefore evaluate the Care Programme in a phase 3 trial according to the MRC framework [23].

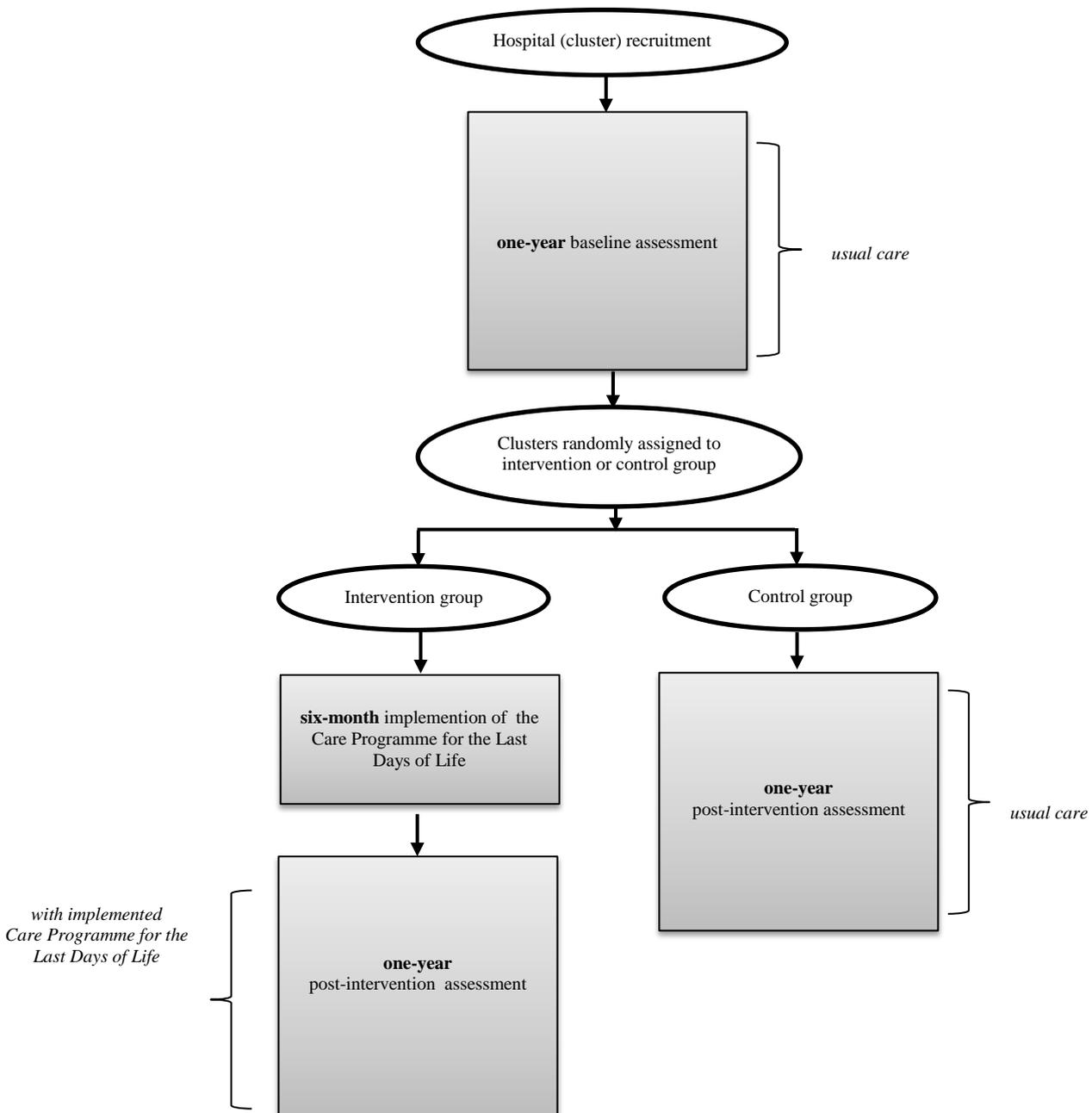
The aim of this article is to describe the research protocol of the cluster randomized controlled trial that will be performed to evaluate the effectiveness of a complex intervention, the Care Programme for the Last Days of Life, in acute geriatric wards.

## METHODS

### TRIAL DESIGN

While a classic randomized clinical trial is known as the most appropriate method to study the effect of an intervention, it is impossible to randomize a complex intervention within a hospital without contamination of the control arm [24]. For this reason, a multicentre two arm cluster randomized controlled trial will be performed. To prevent possible bias at the level of the hospital, a clustering will take place on the hospital level. Consequently, randomization will be carried out at the level of the hospital. The flow diagram of the study protocol is outlined in Figure 2. The CONSORT guidelines have been followed to design this study [25]. The trial is registered in ClinicalTrials.gov, identifier NCT01890239.

Figure 2 Flowchart of the cluster randomized controlled trial



## **STUDY POPULATION**

The inclusion criteria of the hospitals in the trial are:

- the cluster or hospital has one or more acute geriatric wards
- the medical and nursing head of one or more acute geriatric wards per hospital give consent for participation in the study

The inclusion criteria of patients are:

- those dying in the acute geriatric ward between October 2012 and March 2015
- those that having been hospitalized for more than 48 hours
- those having given informed consent at admission for the use of their personal information from medical or nursing records for the purposes of the study

## **GENERAL PROCEDURES OF THE CLUSTER RCT**

First, a one-year baseline assessment will be conducted in all participating acute geriatric wards of participating hospitals. During that period care will be provided as usual. At the end of the baseline assessment all participating hospitals with one or more participating wards will be randomized into intervention or control groups. In the intervention group the Care Programme for the Last Days of Life will be implemented over a six-month period with the support of an implementation guide (Figure 2). After the implementation period, the intervention group will conduct a one-year post-intervention assessment during which the Care Guide for the Last Days of Life will continue to be used. The control group will continue to provide care as usual and will conduct a one-year post-intervention assessment directly following the one-year baseline assessment (Figure 2).

## **INTERVENTION**

The Care Programme aims to introduce and embed the Care Guide for the Last Days of Life, which will be initiated when a patient is diagnosed as dying and which provides a comprehensive template of evidence-based, multidisciplinary care for the last days and hours of life. The Care Programme will be implemented and subsequently established according to an implementation guide incorporating nine components: (1) establishing the implementation project and preparing the environment for organizational changes, (2) preparing the documentation, (3) baseline review, (4) training geriatric health care staff, (5) use of the Care Guide for the Last Days of Life with intensive support, (6) semi-intensive support, (7) evaluation, (8) consolidation and (9) ongoing education, training and support (Table 1).

**Table 1 Overview of the nine components within the implementation guide**

N°	Content
<b>Component 1</b>	<p><b>Establishing the implementation project and preparing the environment</b></p> <ul style="list-style-type: none"> <li>▪ Informing the geriatric health care staff about the implementation project and the importance of change in care during the last days of life</li> <li>▪ Executive endorsement: acquiring management approval for the trainings and audits</li> <li>▪ Involvement of specialist palliative care services is recommended: at least one member of the Palliative Support Team of the hospital is member of the steering group</li> <li>▪ Facilitators: a nurse and a physician of the geriatric ward</li> <li>▪ Formation of steering group: at least four people from the geriatric ward (facilitators included)</li> <li>▪ Intensive 2-day training of facilitators</li> </ul>
<b>Component 2</b>	<p><b>Preparing the documentation</b></p> <ul style="list-style-type: none"> <li>▪ Development of an information leaflet for family carers about the facilities in the geriatric hospital ward</li> </ul>
<b>Component 3</b>	<p><b>Baseline review</b></p> <ul style="list-style-type: none"> <li>▪ Analyzing end-of-life care data of deceased geriatric hospital patients using the patients' medical files</li> </ul>
<b>Component 4</b>	<p><b>Training geriatric health care staff</b></p> <ul style="list-style-type: none"> <li>▪ Feedback of the results to the staff and focusing on improvement within the geriatric ward</li> <li>▪ Facilitators and specialist palliative care colleagues train geriatric health care staff with the aid of a training package (i.e. hand-outs with information about the Care Guide for the Last Days of Life, a copy of the Care Guide for the Last Days of Life, a casus to discuss in group etc.)</li> </ul>
<b>Component 5</b>	<p><b>Care Guide use and intensive support</b></p> <ul style="list-style-type: none"> <li>▪ Care Guide use after sufficient training and education</li> <li>▪ Intensive support and supervision by the steering group through repeated coaching, telephone and direct guidance, discussion of clinical cases and clinical audits</li> </ul>
<b>Component 6</b>	<p><b>Semi-intensive support</b></p> <ul style="list-style-type: none"> <li>▪ Semi-intensive support and supervision by the steering group through repeated coaching, telephone and direct guidance, discussion of clinical cases and clinical audits</li> </ul>
<b>Component 7</b>	<p><b>Evaluation</b></p> <ul style="list-style-type: none"> <li>▪ To organize a qualitative evaluation of the implementation: evaluating and discussing the performance and progress of each of the previous components</li> <li>▪ The qualitative evaluation acknowledges areas where further support, education or training is needed</li> </ul>
<b>Component 8</b>	<p><b>Consolidation</b></p> <ul style="list-style-type: none"> <li>▪ To adopt a strategy to maintain/improve the implementation and sustainability of the Care Guide</li> <li>▪ Support and supervision by the steering group through repeated coaching, telephone and direct guidance, discussion of clinical cases and clinical audits</li> </ul>
<b>Component 9</b>	<p><b>Ongoing education, training and support</b></p> <ul style="list-style-type: none"> <li>▪ Keeping up to date with developments in end-of-life care and a continuing education and evaluation within the hospital ward</li> </ul>

The development and content of the Care Programme for the Last Days of Life are extensively described elsewhere (Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, van der Heide A, Deliens L: Development of the care programme for the last days of life for older patients in acute geriatric hospital wards: a phase 0–1 study according to the Medical Research Council Framework, submitted).

## **OUTCOME MEASURES**

### ***Primary outcome***

Quality of dying during the last 48 hours of life: the patient's symptom frequency and symptom burden measured using the EOLD-SM and EOLD-CAD [26]

### ***Secondary outcomes***

1. the quality of care during the last three days of life as perceived by nurses, i.e. physical symptoms, emotional, psychological and spiritual/existential needs and provision of information and support measured using the POS [27]

2. the quality of care during the last 48 hours of life as perceived by family carers, i.e. satisfaction with the care provided to the patient during the last 48 hours of life measured using the EOLD-SWC [26]
3. the content of care during the last 48 hours of life, i.e. the goal of treatment, medical and nursing interventions, medication policy
4. the communication among clinical staff, i.e. informing the family physician about the impending death
5. the communication between clinical staff and patients and/or family carers, i.e. the perception of communication with the physician during the dying phase by family carers measured using the FPPFC [28]
6. the level of bereavement of family carers after the death of the patient measured using the PGD scale [29]

### ***Process evaluation***

We will also evaluate the quality of the process of implementation in the intervention group. An evaluation tool was developed to measure the degree to which the Care Programme for the Last days of Life was implemented in each ward in compliance with the implementation guide. For each component of the Care Programme indicators were developed so that the implementation of each individual component as well as the entire implementation process could be documented and quantitatively evaluated. This evaluation tool has been developed and piloted in a phase 2 study (Verhofstede R, Smets T, Cohen J, Costantini M, Van Den Noortgate N, Deliens L : Feasibility and preliminary effects of the Care Programme for the Last Days of Life in an older acute hospital population: mixed-methods study of the success of implementation and staff perceptions, in preparation).

### **MEASUREMENT INSTRUMENTS**

Primary and secondary outcomes will be measured retrospectively after each death on the ward using questionnaires to be filled out by three different respondent types: the nurse who was most closely involved in the care for the deceased patient, the physician who was most closely involved in the care for the deceased patient, and a family carer of the deceased patient. The nurse and family carer questionnaires contain validated measurement instruments, in addition to self-developed questions. The physician questionnaire only contains self-developed questions (Table 2). Regarding the validated measurement instruments, the nurse questionnaire contains: the End-of-Life in Dementia Scales Symptom Management (EOLD-SM) [26], the End-of-Life in Dementia Scales Comfort Assessment in Dying Management (EOLD-CAD) [26] and the Palliative care Outcome Scale (POS) [27].

**Table 2 Content of the three different questionnaires for nurses, physicians and family carers**

<b>Questionnaire</b>	<b>Questions</b>	<b>Scale</b>	<b>Primary and secondary outcomes</b>
<b>Nurse</b>	Used from a scale	EOLD-SM EOLD-CAD POS	Symptom frequency* Symptom burden* Quality of care
	Self-developed questions		Content of care, i.e. nursing interventions, Communication between clinical staff and patients and/or family carers of dying patients Communication among clinical staff
<b>Physician</b>	Self-developed questions		Content of care, i.e. goal of treatment, medical interventions, medication policy Communication among clinical staff
<b>Family carer</b>	Used from a scale	EOLD-SM EOLD-CAD FPPFC EOLD-SWC PGD	Symptom frequency* Symptom burden* Communication between clinical staff and patients and/or family carers of dying patients Quality of care Level of bereavement
	Self-developed questions		Communication between clinical staff and patients and/or family carers of dying patients

\* primary outcome

In the questionnaire for the family carer the following validated instruments are included: the EOLD-SM [26], the EOLD-CAD [26], the End-of-Life in Dementia Scales Satisfaction With Care (EOLD-SWC) [26], the Family Perception of Physician-Family Caregiver Communication (FPPFC) [28] and the Prolonged Grief Disorder (PGD) Scale [29]. All three questionnaires have been cognitively tested in face-to-face interviews with four nurses, four physicians and three family carers respectively, and were subsequently refined where needed.

## **DATA COLLECTION**

During the baseline and post-intervention assessment, questionnaires will be filled in for all patients who died in the participating geriatric hospital wards and who met the inclusion criteria. The nurse and physician most closely involved in the care of the deceased patient will be asked to fill in a questionnaire within one week of the death. Six weeks after the death the researcher will send a questionnaire to a family carer, if they have given informed consent to being contacted by the researcher. In cases where the family carer does not respond to the questionnaire up to two reminders will be sent, two weeks after the initial sending of the questionnaire and two weeks later.

## **SAMPLE SIZE CALCULATION**

The hypothesis of this cluster randomized trial is that there will be significant differences in symptom frequency and symptom burden between patients dying in the intervention group and those dying in the control group. Symptom frequency and symptom burden will be measured using the EOLD-SM and the EOLD-CAD. Because our primary outcome is a reduction in

symptom frequency and symptom burden during the last 48 hours of life, we consider a total EOLD-CAD score of 3.2 (7.6%) as the minimum clinically important difference for implementing the Care Programme for the Last Days of Life [30]. A minimum increase of 3.2 in the intervention group compared to the control group corresponds with an effect size (EC) of about 0.55. A minimum change of 5% to 10% has been found to be clinically significant for symptom and quality-of-life analyses [31]. In order to calculate the sample size of this cluster trial two other elements are essential: the intra-cluster correlation coefficient and the average size of the cluster (number of cluster deaths). We estimate an intra-cluster correlation coefficient of between 0.02 and 0.05 [32] and a conservative average of 30 deaths per hospital per year based on observed mortality statistics, taking into consideration the non-included deceased patients. In Table 3 four ICC scenarios (from 0.02 to 0.05) intersect with three scenarios of average size of the cluster (from 20 to 40). This table reports different sample size scenarios necessary to detect an ES of 0.55 with  $\alpha = 0.05$  and a power of 80% conditional on the hypothesized levels of ICC (from 0.02 to 0.05) and average size of cluster (from 20 to 40).

**Table 3 Total number of clusters required according to different average sizes of the clusters and ICC (ES = 0.55, alpha = 0.05, power = 0.80)**

		Average size of the clusters		
		20	30	40
ICC	0.02	10	8	8
	0.03	12	10	10
	0.04	12	10	10
	0.05	14	12	10

A sample size of six clusters per group with 30 individuals per cluster achieves 80% power to detect a difference of 3.2 between the group means when the intraclass correlation is 0.05 using a Two-Sided *T*-test with a significance level of 0.05.

## **RECRUITMENT OF HOSPITALS**

Based on the cluster size calculation, 10 to 12 hospitals with one or more acute geriatric wards must be recruited. In order to recruit these hospitals, the study has been presented at three geriatric meetings. Shortly after these meetings information letters were sent to geriatricians. Geriatricians who were interested in participating were contacted by the researcher to make an appointment to explain and discuss the study and to sign an agreement of participation form. If geriatricians did not spontaneously contact the researcher, the researcher took the initiative herself to contact the geriatricians by phone about their interest and possible participation.

## **RANDOMIZATION**

At the end of the baseline assessment the included hospitals with one or more participating acute geriatric wards will be randomly assigned to the intervention group (implementing the Care Programme for the Last Days of Life) or to the control group (usual care).

As the number of clusters to be randomized is considerably smaller than in trials where the unit of randomization is the patient, there is a chance of baseline imbalance between the randomized groups. The risk of baseline differences can be reduced using pair-matched randomization [33]. Hospitals will be matched in comparable pairs in terms of 1) the number of deaths per year for the participating geriatric wards, and 2) the motivation of the participating wards in terms of the number of patients from whom they will acquire informed consent for participation in the baseline measurement period. Information related to the number of deaths and motivation per hospital will be sent to a statistician outside the research group, who will then match the pairs and randomize the hospitals into the experimental and control group using a random number generator.

## **STATISTICAL ANALYSIS**

All data collected through the three different questionnaires will be stored and collected in Ghent University Hospital using IBM SPSS Statistics. Data cleaning will be performed via SPSS syntax operations. All statistical tests will be done two-tailed with 95% confidence intervals. A p-value  $<0.05$  will be considered statistically significant.

### ***Descriptive statistics***

Cluster and patient characteristics will be reported as mean and standard deviation (SD) or frequency and percentage respectively for continuous and categorical variables. The distribution of characteristics of clusters allocated as experimental or control hospitals will be compared with the Student *t*-test (for continuous variables), with non-parametric tests (for ordinal variables) and with the Pearson Chi-square (for binary or nominal variables).

### ***Multivariable analysis***

Our primary aim is to detect any differences in the EOLD-SM [26] and EOLD-CAD [26] between those dying in the intervention wards and those dying in the control wards. The primary statistical analysis will be by intention-to-treat, using multi-level models, taking into account clustering by hospitals. Because these primary outcomes are continuous, hierarchical linear models will be used which will be adjusted for the average level of quality of life and quality of care provided to the baseline assessment. This method of analysis will also be used for our secondary outcome measures. For the assessment of categorical secondary outcomes, the hierarchical logistical model will be used.

## **INFORMED CONSENT PROCEDURE**

In order to guarantee privacy for patients whose data is collected in the study, certain procedures are necessary. As the Central Ethics Committee requires that data can only be collected from deceased patients who have given informed consent prior to the study, written informed consent to use personal data for the study will be requested by a nurse from each patient at the time of admission of the patient to the ward. If the patient is lacking in capacity, written informed consent will be requested from a family carer. Questionnaires will be filled in only for patients with informed consent at admission.

The physician and the nurse who were closely involved in the care of a deceased patient will be asked to fill in a questionnaire about the patient. If one of them refuses to complete the questionnaire the nurse who is responsible for the study on the ward will pass the questionnaire to another nurse or physician. A closely involved family carer will also be asked to fill in a questionnaire about their deceased relative and about their own experiences of care in the dying phase. In order for the researcher to be allowed to send a questionnaire to the family carer, a nurse will ask informed consent of the family carer shortly after the death of the patient. Family carers who give informed consent will be asked to sign a written informed consent form including their contact details. If the nurse in the hospital is unable to ask informed consent from the family carer shortly after the death of the patient, the hospital will send an informed consent form by post to the family carer two weeks after the death of the patient asking permission for the researcher to contact them. Family carers who give informed consent to being contacted by the researcher will be sent a questionnaire six weeks after the patient's death. Family carers are also asked for their informed consent to fill in the questionnaire.

## **ETHICAL APPROVAL**

The study is approved by the Central Ethics Committee of the Vrije Universiteit Brussel (VUB) (Belgium) and by the Local Ethics Committees of the participating hospitals in Flanders.

## DISCUSSION

This will be the first cluster randomized controlled trial to evaluate the effectiveness of the Care Programme for the Last Days of Life for the acute geriatric hospital setting. Following a baseline assessment, geriatric hospital wards will be randomized to the intervention or control group where the Care Programme will be implemented or care will be provided as usual. A post-intervention assessment should allow us to detect differences in the symptom frequency and symptom burden between patients in the intervention wards and those in the control wards.

A cluster RCT design has several important strengths. The first advantage of this robust design is that a control group will be used. Working with control hospitals can avoid the situation where differences between the baseline and post- intervention assessments within the intervention group are caused by changes other than the intervention that is being studied. Secondly, in all participating hospital wards the quality of care and the quality of life during the last 48 hours of life will be assessed before and after implementation of the care programme. That means that we will be able to compare end-of-life care in geriatric hospital wards before and after the implementation of our intervention, and that each hospital operates as its own control. A third strength of this design is that cluster randomized trials, unlike individually randomized controlled trials, can reduce the effect of treatment contamination as one or more geriatric wards from one hospital will handle the same care principles [34]. Fourth, this design may also increase compliance due to group participation.

This study also has several limitations. Firstly, the study questionnaires address symptoms and care during the last 48 hours of life, which is more or less the target period of the Care Guide. However, it is unknown how long the geriatric patients will be supported by the Care Guide for the Last Days of Life. Earlier studies have shown that the median duration and average time of use of the LCP in the hospital setting was 16 and 29 hours respectively [35,36]. However, another study found that 44% of hospice patients were supported by the LCP during two days [37]. We therefore cannot preclude that we may be measuring the quality of care during a period when the Care Guide had not yet been put into effect, which could dilute the apparent effect of the Care Programme. A second limitation, inherent to the focus on the last 48 hours of life, is that evaluations of a patient's quality of life, content of care and communication will depend on after-death evaluations by proxies (nurses, physicians and family carers). However, in selecting the items for the questionnaires, we have taken into account the reliability and validity of proxy-reporting. Proxy measurements have, for

instances, been shown to be relatively valid for relatively objective information such as the processes of care [38]. In former retrospective studies, bereaved family carers and professional caregivers, like nurses and physicians, have acted as proxy respondents and the reliability of proxy assessments for various aspects of end-of-life care and quality of life are well described [39]. The aspects we choose to measure are those that have shown sufficient agreement between patients and proxy respondents: observable physical symptoms, evaluation of care, service use and awareness of diagnosis [40]. We will also investigate some aspects that are more subjective such as psychological symptoms. It is known that in comparison with patients, nurses and family carers tend to overestimate the severity of such symptoms whereas physicians tend to underestimate them [39]. We therefore take into account the different perspectives of nurses, physicians and family carers.

Most end-of-life care pathways or programmes such as the LCP have been studied in different healthcare settings and have focused mainly on oncology patients. However, due to the ageing population and a simultaneous increase in the incidence of chronic diseases, future research evaluating the effects of end-of-life care pathways or programmes should also focus on elderly people dying of causes other than cancer [12,8]. Evaluating the Care Programme for the Last Days of Life for the acute geriatric hospital patient would therefore add evidence of the effectiveness of initiatives aimed at improving the quality of life and care for older patients dying in acute geriatric hospital wards.

By using a cluster randomized controlled trial design, the proposed study will contribute substantially to the increase in evidence for end-of-life care interventions. To our knowledge only one other cluster RCT in this area has studied the effects of the LCP programme on cancer patients dying in Italian hospitals [19,20]. A cluster RCT is a challenging, high-risk research design. However, results from a before-after cluster phase 2 trial support the need for multi-centre cluster randomized controlled trials [41], as this is the only feasible method of assessing the effectiveness of end-of-life care interventions [19].

## **CONCLUSIONS**

This will be the first cluster randomized controlled trial aimed at evaluating the effectiveness of the Care Programme for the Last Days of Life to improve the quality of care and quality of life during the last 48 hours of life of patients dying in acute geriatric hospital wards. Using this robust study design will allow us to describe in detail the quality of care and quality of life of elderly people dying in hospitals and will add to the evidence about the effectiveness of the Care Programme in the acute geriatric hospital setting. The poor quality of end-of-life care in hospitals remains a concern and dealing with that problem is a public health priority. We hope that this study will not only show whether the Care Programme for the Last Days of Life is effective in geriatric hospital wards but will also provide an understanding of the contribution of the different components of the Care Programme to end-of life care.

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# **PART IV**

## **GENERAL DISCUSSION**



**CHAPTER 8:  
MAIN RESULTS AND GENERAL  
DISCUSSION**

## **8. Main results and general discussion**

This doctoral thesis consists of four main parts. The first part is a general introduction followed by chapter 2 in which we aim to further expand the existing knowledge about end-of-life care in older patients by providing a population-based evaluation of the main goal of treatment that older people of different ages receive at the end of life.

In the second part we explore end-of-life care in 23 acute geriatric hospital wards by (1) describing the performed nursing and medical interventions in the last 48 hours of life and the quality of dying and (2) describing the policy of anticipatory prescribing and deprescribing of potentially inappropriate medication during the last 48 hours of life.

In the third part we present (1) the development of the Care Programme for the Last Days of Life for patients in acute geriatric hospital wards, (2) the feasibility of implementing the Care Programme and (3) the protocol for a cluster Randomized Controlled Trial (RCT) to evaluate the effectiveness of the Care Programme on symptom frequency and symptom burden of patients in the last 48 hours of life as the primary outcome.

In this fourth part, we provide an overview of the main findings followed by a discussion and a number of implications of the study results for practice, policy and future research.

## **8.1. Summary of main findings**

In the following paragraphs, the results of the previous chapters are summarized according to the three research aims, i.e. (1) to evaluate the main goal of treatment at the end-of-life in older patients, (2) to describe end-of-life care in acute geriatric hospital wards and (3) to develop and evaluate the Care Programme for the Last Days of Life to improve end-of-life care in acute geriatric hospital wards.

### **8.1.1. Main goal of treatment at the end-of-life in older people**

In chapter 2 (part I), the death-certificate study allowed us to investigate which factors are associated with an indicator of quality of end-of-life care such as having comfort care as main goal of treatment in the last week of life .

After controlling for confounder variables, age was independently related to the main goal of treatment in the last week of life. Those in the older group (86 years and older) were more likely of having a comfort care goal in the last week of life as compared with the younger group (75-85 years) (OR 1.61; CI 1.20 – 2.17). In both age groups, also cause and place of death were independently related to the goal of treatment, with those dying from non-malignant diseases and those dying in the hospital being less likely to receive comfort care in the last week of life. Patients between 75 and 85 years and those lacking capacity to make decisions were less likely to receive comfort care at the end-of-life than were those of the same age group with capacity to make decisions (71.9% vs. 92.7%;  $p < 0.001$ ).

### **8.1.2. End-of-life care in acute geriatric hospital wards**

Chapter 3 (part II) presents the results regarding the nursing and medical interventions and the quality of dying of patients in 23 acute geriatric hospital wards during the last 48 hours.

According to family carers approximately 14% of the deceased patients definitely desired to die in hospital and the majority preferred home as place of death.

With respect to nursing interventions at the end-of-life, we found that approximately half of the patients received one or more visits of a palliative care nurse, for 98% mouth care was performed, and for at least 75% of the patients experiencing breathing difficulties due to mucus production necessary measures were taken. Of the nursing interventions wound care, aspiration, blood pressure measurement, pulse measurement, temperature measurement, repositioning and washing, the latter three were most frequently performed until the patient's death, ie . 70.3%, 80.7% and 69.3% respectively.

As death approached the patient's vital signs - blood pressure, pulse and temperature - were significantly less often taken and washing and wound care were significantly less often performed.

Regarding medical interventions, 49.7% of the patients received oxygen therapy, 30% intravenous fluids and nutrition, 22.8% antibiotics and in 19.2% of the patients a routine blood test was performed during the last 48 hours until death. On the other hand, in 17.2% of all dying patients antibiotics were stopped, in 15.7% intravenous fluids and nutrition and in 12.5% blood sugar regulation.

Chapter 3 also describes the quality of dying in acute geriatric wards by using the Comfort Assessment in Dying End-of-Life in Dementia (CAD-EOLD). We notified that in the last 48 hours of life lowest levels of comfort were reported for shortness of breath, serenity, peace and calm. The reported level of pain was moderate, according to nurses and family carers.

In chapter 4 (part II), an overview of the anticipatory prescribed and deprescribed medication during the last 48 hours of patients in acute geriatric hospital wards is provided.

During the last 48 hours of life, 65.4% of the patients had an anticipatory prescription of medication. In 45.5% of the dying patients, morphine was anticipatory prescribed. For 15.5% and 13.8% of the dying patients, benzodiazepines and scopolamine were prescribed respectively. After performing a multivariate analysis controlling for confounders, expected death by the physician and dementia were independently related to the anticipatory prescription of medication. The likelihood of having anticipatory medication prescribed was significantly higher in patients where death was expected by the physician (OR 19; CI 9 – 40;  $p < 0.001$ ) and significantly lower in patients with a diagnosis of dementia (OR 0.35; CI 0.16 – 0.74;  $p = 0.006$ ).

Somewhat more than half of the potentially inappropriate medication with which the patients were treated at admission was withdrawn during the last 48 hours of life. The extent to which the potentially inappropriate medication, i.e. statins, antidiabetics, antihypertensiva, diuretics, antibiotics, aerosols, corticosteroids, aspirins, anticoagulants, osteoporosis medications, antiulcer drugs, laxatives and acetylcholinesterase inhibitors, were continued until death, fluctuated between 29.2% and 54.9%. After performing a multivariable logistic regression analysis controlling for confounders, we found that patients for whom death was expected by the physician were more likely to have a deprescription of potentially inappropriate

medication than patients for whom death was not expected by the physician (OR 21; CI 10 – 43;  $p < 0.001$ ). Moreover, patients dying from an oncological disease diagnosis were also more likely to have potentially inappropriate medication deprescribed compared with patients dying from frailty or dementia (OR 7.0; CI 1.1 – 45.6;  $p = 0.042$ ).

### **8.1.3. Developing and evaluating the Care Programme for the Last Days of Life to improve end-of-life care in acute geriatric hospital wards**

Results regarding the third research aim are reported according to the first four phases of the MRC Framework i.e. (a) phase 0-I; (b) phase II and (c) the protocol of phase III<sup>1</sup>.

#### **(a) Phase 0-I: Development of the Care Programme for the Last Days of Life**

Chapter 5 describes the development of the Care Programme for the Last Days of Life for the acute geriatric hospital setting, i.e. **phase 0** (preclinical phase) and **phase I** (modeling phase).

In **phase 0** we aimed to identify and compare different components of the Liverpool Care Pathway (LCP) programmes from the UK, Italy and the Netherlands. Simultaneously, this phase consisted of an identification of the key factors for a successful implementation of the LCP. The LCP was chosen as a basis for the development of our Care Programme since it is the most well-known end-of-life care pathway<sup>2,3,4,5</sup>. Though, during this preclinical phase we observed the increasing criticisms regarding the LCP in the UK. These concerns arose mainly from inappropriate implementation and use and not the principles of the LCP itself<sup>6</sup> and we therefore took them as much as possible into account when developing our Care Programme. We found that all three LCP programmes contain common documents, i.e. an LCP document, supportive documentation and an implementation guide. We identified nine components in the implementation guides used in the UK, Italy and The Netherlands: (1) establishing the LCP implementation project and preparing the environment, (2) preparing the documentation, (3) baseline review of the care delivered in the last days of life, (4) training of health care staff, (5) LCP use and ongoing support, (6) reflective practice, (7) evaluation of the use of the LCP, (8) continuing development of staff competencies and (9) ongoing education, training and support of staff.

The identified key factors for a successful implementation were: having a dedicated facilitator, training and ongoing education of the staff, the organization of an audit and of feedback opportunities, having a central regional or nationwide coordinating LCP office to support local LCP facilitators and, funding and time for implementation efforts.

As it was our initial intent to develop an end-of-life care improvement initiative especially for patients in acute geriatric hospital wards, the specificities of the older hospital population and the setting in which they are cared for were taken into account, i.e. **phase I** or the modelling of the Care Programme. Therefore, our Care Programme - which was initially developed based on the results of phase 0 - was reviewed by health care staff and experts from the UK, Italy and the Netherlands. Subsequently, researchers discussed all the input gathered and the feedback of the reviewers and used the results of this discussion for the refinement of the Care Programme. Finally, a preliminary Care Programme for the Last Days of Life was developed and modeled consisting of (1) the Care Guide for the Last Days of Life, (2) supportive documentation and (3) an implementation guide to help health care staff in implementing the Care Guide on the acute geriatric ward.

**(b) Phase II: an evaluation of the feasibility of implementing the Care Programme for the Last days of Life and exploring its preliminary effects**

In chapter 6 the results of the phase 2 mixed methods study are reported which suggest that implementing the Care Programme for the Last Days of Life in the acute geriatric hospital ward of Ghent University Hospital is feasible and that the Care Programme has positive preliminary effects on end-of-life care.

Most of the components of the Care Programme were successfully performed. It was for instance found that more than half of the deceased patients (11 out of 19) had been cared for according to the Care Guide during the implementation period. Six months after the implementation of the Care Programme, the Care Guide was still in use. In those six months, of the 30 patients who died on the ward, 17 were cared for according to the Care Guide. However, despite the fact that two training sessions were organized, only one out of four geriatricians was trained. Furthermore, not all health care staff were informed about the implementation project and one out of the three audits that should have been organized was not.

Additionally, health care staff identified four types of potential barriers to implementing the Care Programme: (1) barriers related to practical issues, e.g. many health carers perceived the double registration as a barrier to use the Care Guide, (2) barriers related to the content of the documents used within the Care Programme, e.g. some staff had difficulties with the term 'care goal' within the Care Guide and perceived the term as being too coercive, (3) barriers related to the low motivation of some health care staff and (4) barriers related to difficulties

inherent to the provision and organization of care in the last days of life, such as difficulties with the recognition of the dying phase or difficulties with an open and clear communication between nurses and physicians regarding the entrance of the dying phase.

With respect to the effects of the Care Programme on end-of-life care, our study showed that according to nurses and physicians the Care Guide for the Last Days of Life is experienced as improving the overall documentation of care, improving the communication among health care staff and between health care staff and patient/family, and improving the quality of end-of-life care.

### **(c) Phase III: The research protocol of a cluster RCT to evaluate the effectiveness of the Care Programme for the Last Days of Life**

In [chapter 7](#), we outlined the protocol of a cluster RCT to evaluate the effectiveness of the Care Programme for the Last Days of Life to improve the quality of care and quality of dying during the last 48 hours of life of patients dying in acute geriatric hospital wards.

The data collection of the cluster RCT has already been initiated in October 2012 and was recently finished in March 2015. After a one-year baseline assessment hospitals were randomized to the intervention (implementation of the Care Programme) or control group (usual care). Subsequently the Care Programme was implemented in the intervention group over a six-month period followed by a one-year post-intervention assessment. In the control group, the post-intervention assessment was performed immediately after the baseline assessment.

During the baseline and post-intervention assessment primary outcomes, ie symptom frequency and symptom burden in the last 48 hours of life, and secondary outcomes were retrospectively measured after each death on the ward using questionnaires to be filled out by a nurse, physician and family carer. The questionnaires contain validated measurement instruments and self-developed questions. The validated measurement instruments are: the End-of-Life in Dementia Scales Symptom Management (EOLD-SM)<sup>7</sup>, the End-of- Life in Dementia Scales Comfort Assessment in Dying Management (EOLD-CAD)<sup>7</sup>, the End-of-Life in Dementia Scales Satisfaction With Care (EOLD-SWC)<sup>7</sup>, the Palliative care Outcome Scale (POS)<sup>8</sup>, the Family Perception of Physician-Family Caregiver Communication (FPPFC)<sup>9</sup> and the Prolonged Grief Disorder (PGD) Scale<sup>10</sup>. All three questionnaires have been cognitively tested in face-to-face interviews with four nurses, four physicians and three family carers respectively, and were subsequently refined where needed.

Although the performance of the cluster RCT has recently been finalized, the results have yet to be analysed in order to evaluate the effectiveness of the Care Programme for the Last Days of Life. We hope that this study will also provide an understanding of the contribution of the different components of the Care Programme to the quality of end-of life care.

## 8.2. Methodological strengths and limitations

This doctoral thesis has made use of several methods to address three specific research aims, each having their own strengths and limitations.

To evaluate the **main goal of treatment at the end-of-life in older people of different ages**, we used a robust design including a large representative sample of death certificates. Although a non-response bias cannot be completely excluded, our non-response survey did not point in that direction. Consequently, we believe our results to be representative for all non-sudden deaths of those older than 75 in 2007 in Flanders, Belgium.

However, this data collection has been completed almost seven years ago, and we therefore have to bear in mind that end-of-life care practices may have changed in the meantime.

Furthermore, because we performed a secondary analysis of a survey primarily intended to study end-of-life practices, certain aspects that would have provided a more complete insight, such as the severity of the patient's condition and their functional status, the content of care in the last week of life, the patient's wishes for end-of-life care or the existence of an advance care plan were not studied. Moreover, as this doctoral thesis mainly focuses on end-of-life care in acute geriatric hospital wards, it would have been useful if the death-certificate study had provided us with more information regarding the place of death, i.e. whether or not a patient died in an acute geriatric ward. Additionally, while chronological age is an independent risk factor for adverse outcomes in many conditions, it would have also been interesting to compare outcomes between patients with and without frailty in this patient population<sup>11</sup>.

Finally, the delay between the patient's death and the study of that death has reached as much as four months in our study as death certificates have to be processed by the proper authorities before they can be made available for research. We therefore cannot exclude the influence of recall bias. However, to address this issue, physicians were encouraged to fill out their questionnaire using the patient files.

The cross-sectional descriptive study that we have set up to describe **end-of-life care in acute geriatric hospital wards in Flanders**, ie the baseline assessment as part of the cluster RCT to evaluate the effectiveness of the Care Programme for the Last Days of Life, was large-scale and multicentric with 338 patients recruited from 23 acute geriatric wards in 13 Flemish hospitals. As we included hospitals from different regions and of different sizes, this may have increased the generalizability of the study findings<sup>12</sup>. Unlike earlier conducted studies, we did not use a retrospective case note review methodology to examine end-of-life care and quality of dying. Due to incomplete documentation and lack of standardized structure, case note

review methodology may lead to underreported variables and thus the validity of the findings may be questioned<sup>13,14</sup>. In contrast, our study adopted a more valid methodology by retrospectively completing questionnaires. Furthermore, three different questionnaires were developed to be filled out by a nurse, a physician and a family carer, which permitted us to investigate the perspectives of different proxies and to assess different constructs within end-of-life<sup>15</sup>.

However, our results may have been affected by assessment bias. Due to the vulnerability and poor health conditions of dying patients, our data are based on proxy measures and not on the experiences of the patients themselves. However, in selecting the items for the proxy questionnaires, we have taken into account the reliability and validity of proxy-reporting. Proxy measurements have, for instances, been shown to be relatively valid for relatively objective information such as the processes of care<sup>16</sup>. In former retrospective studies, bereaved family carers and professional caregivers, like nurses and physicians, have acted as proxy respondents and the reliability of proxy assessments in older patients with and without dementia for various aspects of end-of-life care and quality of life are well described<sup>17</sup>. Assessments made by health care staff and family carers are reasonably accurate and nurses may be the most suitable source of proxy information, though proxy assessments should always be interpreted with caution<sup>18</sup>.

Additionally, our results may also have been affected by selection bias. A possible reason for this bias is that participants in the study are acute geriatrics wards which may obviously have a prior interest in end-of-life care have. Furthermore, only 34% of patients in these wards could be included in the study due to the informed consent procedure. The included patients had a significant longer mean length of hospital stay than those not included; however, no differences were found between included and non-included patients in terms of age and gender. Also the low response rate for family carers (35%) could have biased our results with regard to the quality of end-of-life care and the quality of dying. A non-response analysis detected that only age and dying circumstances were independently associated with evaluation by a family carer; older patients and those surrounded by family members or friends when dying had a higher response rate. It may thus be that younger patients and/or those dying alone had a different quality of dying as reported by the family carer. Unlike for family carers, there was a high response rate for both nurses (91%) and physicians (85%).

Finally, we adopted the **Medical Research Council (MRC) Framework**<sup>19</sup> to develop and evaluate a complex intervention to improve end-of-life care in acute geriatric hospital wards. This approach has proved to be valuable in guiding the development, modelling and evaluation of complex interventions<sup>19-21</sup> and we may affirm that this Framework definitely has potential as a broad guide to help researchers move from facing a considerable health problem to finding an appropriate solution and evaluating its effectiveness, ie from the preclinical phase to phase III.

The MRC Framework guidance suggests the use of appropriate quantitative and/or qualitative methodologies depending on the specific objectives of the phases as well as a specific study design taking into account the theoretical basis, any evidence on the issue and the context's specificity<sup>19</sup>. Nonetheless, we experienced some shortcomings within the Framework's guidance. For example, we did not find any details or references in the guidance on how a complex intervention could be developed and/or modeled starting from an existing intervention, or on how to identify the core components as part of the intervention. More comprehensive guidelines on how complex interventions should be developed, tested and evaluated with respect to palliative and end-of-life care may thus be helpful for future practical and research purposes.

Nevertheless, we have succeeded in performing the first four phases of the MRC Framework thoroughly and correctly, with all of them having their specific strengths and limitations.

Importantly, our preclinical phase (**phase 0**) consisted of a review of the existing LCP programmes, a literature review to identify key factors for a successful LCP implementation and an analysis of the concerns regarding the use of the LCP in the UK, which provided us with considerable information so that important components of the intervention could be deduced. Subsequently, the specificities of the older hospital population and the setting in which they are cared for were taken into account by thoroughly reviewing, discussing with among others international experts and modeling the preliminary intervention (**phase I**). Although we did not perform a systematic review concerning the key factors for a successful LCP implementation, the key factors identified in our study largely correspond with key factors identified in a more recently published systematic review<sup>22</sup>. Only one additional contextual factor was mentioned in the review. It was found that a major cultural shift is needed to change the perception from dying as a failure of medical care into dying as a time of life when care takes priority over cure<sup>22</sup>. Also findings from a recent Dutch qualitative study

evaluating barriers and facilitators to LCP implementation confirm the key factors identified in our study<sup>23</sup>.

An important strength of our **phase II** mixed-methods study is that a methodological triangulation was used<sup>24</sup>; multiple qualitative methods (i.e. analysis of observation notes and audit transcript) and a quantitative method (i.e. evaluation tool) to evaluate the feasibility and effects of the Care Programme.

However, this study took place in only one geriatric hospital ward, located in a university hospital. Hence, our results cannot be automatically generalized to other wards in other hospitals. Besides, we only explored the perceptions of health care staff whereas family carers and patients could have provided additional information on the effects of the Care Programme.

A robust cluster RCT design was chosen for the **phase III** trial according to the MRC Framework. Unlike individually randomized controlled trials, this design can reduce the effect of treatment contamination as one or more geriatric wards from one hospital will implement the same care principles<sup>25</sup>. Other strengths of this design are that a control group was used and that the quality of care and dying during the last 48 hours was assessed before and after implementation of the Care Programme. Moreover, results from a before-after cluster phase 2 trial support the need for multi-centre cluster RCTs<sup>26</sup>, as this is the only feasible method of assessing the effectiveness of end-of-life care interventions<sup>27</sup>.

However, qualitative methods supplementing our quantitative evaluation approach would have been valuable. Thoroughly assessing the effectiveness of the Care Programme is a challenge due to the presence of different types of components, activities, interventions and outcomes to be achieved<sup>28</sup>. Qualitative methods such as participant observation or interviews would have enabled us to better understand to what extent components were performed and to which outcomes they may be related.

Nevertheless, the evaluation tool that has been developed and piloted in our phase II study may be helpful in measuring the degree to which each individual component, as well as the entire Care Programme for the Last days of Life, was implemented in each ward in compliance with the implementation guide.

For strengths and limitations regarding the assessment procedure of this cluster RCT, we refer to the methodological considerations of the abovementioned cross-sectional descriptive study which corresponds with the baseline assessment of the cluster trial.

### 8.3. Discussion of the findings

The following paragraphs provide some reflections on the main results of this study. We first attempt to (1) reflect on end-of-life care for older people in acute geriatric wards and (2) discuss how potential inadequacies in end-of-life care in acute geriatric wards could optimally be addressed. Subsequently, (3) we argue the relevance of developing a new initiative to improve end-of-life care for older people dying in acute geriatric wards and reflect upon the results of the development and evaluation of the Care Programme for the Last Days of Life to improve end-of-life care for patients dying in acute geriatric wards.

#### **(1) Which aspects of end-of-life care can be improved for older people dying in acute geriatric wards?**

##### *Main goal of treatment in the last week of life as an indicator of the quality of end-of-life care*

It is well known that end-of-life care should always be delivered in accordance with individual patient needs. We know for example that many dying older patients do not wish to prolong their dying, implying that life-prolongation is no longer a priority when death approaches<sup>29,30</sup>. When palliation or comfort care is prioritized in the last week of life, a patient will receive better end-of-life care than when the goal of treatment is cure or life-prolongation<sup>31,32</sup>. The continuation of unnecessary and often aggressive treatments does not only affect the patient, but also the patient's family and health care professionals<sup>33,34</sup>. However, according to the results of the death-certificate study the chance of palliation being the main goal of treatment in the last week of life was much lower for older patients dying in hospital and dying from non-malignant diseases. We may thus infer from these results that there is room for improvement regarding the main goal of treatment in the last week of life of patients dying in acute geriatric wards.

The greater likelihood of cure or life-prolonging being the main goal of treatment in the last week of life in acute geriatric wards may be due to the hospital setting. It is well known that changing the focus of the care trajectory from a strictly disease-modifying, curative path to a more symptom-focused palliative care path is challenging in the hospital setting<sup>35</sup>. Moreover, patients are often admitted to hospital for a curative or life-prolonging treatment which makes it more challenging for health care professionals to distinguish people who can still be treated from those for whom end-of-life care would be more appropriate<sup>36</sup>. Also the disease may affect whether or not health care staff adopt a palliative care approach in the last week of life. Older people more often suffer from slowly progressive or fluctuating long term conditions in

which the timing of death often remains unpredictable until they are close to it<sup>37</sup>. This is different from patients dying from cancer for whom recognizing and diagnosing the dying phase is often less challenging than in older patients mostly dying from non-malignant diseases<sup>37</sup>.

We need thus to ensure that health care staff on geriatric wards are attentive to individual end-of-life care needs and focus on comfort care as it may help in preparing for the end of life, and may increase family satisfaction with end-of-life care<sup>38</sup>.

#### *Involvement of specialized palliative care services*

A palliative care nurse visited about half of the patients dying in the acute geriatric wards at the end of life. A growing body of evidence suggests that input from specialists in palliative medicine can improve the quality of and satisfaction with patient care, identify and deal with patient and family needs and reduce costs<sup>39,40,41</sup>.

Although the other half of the patients did not receive a visit from a palliative care nurse, the number that we found is higher than that found in other studies performed in the acute hospital setting<sup>42,43</sup>. One possible explanation for this finding is that health care staff in acute geriatric hospital wards may be more willing to adopt a palliative care approach than health care staff in other acute hospital wards. Consequently, they may more often contact a member of the palliative care team if they themselves are not able to address the patient's needs.

Alternatively, it could be that in our study health care staff had better or easier access to palliative care services or that the palliative care team is more integrated in acute geriatric wards than in other wards.

However, specialized palliative care services may not always be required. For patients who did not receive a visit of a palliative care nurse at the end of life, it could be that the physicians and nurses on the ward were perfectly able to deal with the patient's end-of-life care needs themselves. However, it is also possible that a palliative care nurse was not involved in those patients for whom death came suddenly and was unexpected.

#### *Discontinuation of potentially inappropriate nursing and medical interventions*

Several nursing and medical interventions that are deemed to be potentially inappropriate were continued until death in a substantial number of patients dying in the acute geriatric hospital setting, e.g. repositioning, antibiotics. Nonetheless, health care staff should review the need to continue nursing and medical interventions at the end of life and should discontinue those interventions that are no longer appropriate or beneficial for the patient<sup>5</sup>. However, as the

appropriateness of some interventions at the end of life are controversial, reviewing and discontinuing inappropriate interventions may be challenging for health care staff<sup>44-51</sup>, although some of the potentially inappropriate nursing interventions were significantly less often performed as death approached. It may thus be that when health care staff are aware of a patient's impending death, those interventions that seem to harm the patient's comfort are discontinued.

#### *Deprescribing potentially inappropriate medication*

Our study also investigated the degree to which potentially inappropriate medications are continued at the end of life in acute geriatric wards. Although more than half of the medication with which the patients were being treated at admission was withdrawn during the last 48 hours of life, the importance of reviewing the continued need for medication and discontinuing all those medications that seem to be potentially inappropriate is important when striving for optimal end-of-life care in acute geriatric hospital wards<sup>5,52</sup>. It may be that health care staff are not always aware of the importance of reflecting upon the need to continue or discontinue potentially inappropriate medication at the end of life. However, there is still no consensus about the appropriateness of some medication at the end of life, which may hamper health care staff reflecting on and stopping potentially unnecessary medication.

As patients for whom death was not expected by the physician and those dying from frailty were especially disadvantaged regarding the deprescription of potentially inappropriate medication, we may conclude that the recognition and diagnosis of the dying phase and the patient's disease trajectory may determine whether or not potentially inappropriate medications are continued until death.

#### *Anticipatory prescription of medication*

In our study we found that 65.4% of the patients dying in acute geriatric hospital wards had an anticipatory prescription of medication. This means there is still room for improvement regarding end-of-life care in acute geriatric hospital wards. One study performed in the hospice setting has for instance shown higher anticipatory prescription rates for end-of-life care symptoms<sup>53</sup>. Although hospice care is by definition aimed at comfort and palliation and thus different from the care provided in hospitals, we believe that the current anticipatory prescription rates in acute geriatric wards can be improved. However, this requires a shift from a disease-modifying curative attitude in the hospital to a more symptom-focused palliative care approach.

Anticipatory prescription of medication for end-of-life care symptoms seemed to be especially challenging in patients for whom death was not expected by the physician. Hence we may conclude that when the dying phase is not recognized and diagnosed, a physician is less likely to provide comfort care and to prescribe medication for end-of-life care symptoms. In addition, patients with dementia - especially those with early stage dementia – were disadvantaged regarding the anticipatory prescription of morphine. A possible explanation for this finding may be that physicians fear the side effects of morphine on the cognitive functioning of the patient.

### *Symptom management*

Our study showed that according to nurses and family carers the quality of dying of patients in acute geriatric wards was reasonably good. We may therefore assume that comfort measures were appropriately adopted in accordance with the patient's needs. However, results from nurses and family carers showed that there is some room for improvement in the care regarding the physical symptom 'shortness of breath' and symptoms related to the patient's well-being, such as 'serenity', 'peace' and 'calm'. This was also found in other studies performed in hospitals and nursing homes, which also revealed the magnitude of unmet psychological and existential needs at the end of life<sup>43,54-57</sup>. One possible explanation for this finding, among others, may be that in the acute hospital setting less attention is given to psychosocial and existential aspects of end-of-life care than to medical aspects of care. A second possible explanation is that health care staff in hospitals may not be well trained in treating psychological and existential problems. A third explanation is that identifying and addressing these needs in the older patient population is challenging because of the specific patient characteristics. Nearly half of the patients who die in an acute geriatric hospital ward are not able to communicate in the last 48 hours of their life, which may hamper health care staff in identifying and dealing with complex psychosocial and existential issues. Finally, it may be that the patient and his/her family are actually aware that the patient will die soon whereas health care staff may fail to appreciate the impending death. This situation could possibly adversely affect the patient's wellbeing.

## **(2) How can inadequacies in end-of-life care in acute geriatric wards be addressed?**

When interpreting and discussing the main findings regarding end-of-life care for older people in acute geriatric wards, we also aimed to reflect upon how identified inadequacies in that care can be addressed.

### *Striving for a care-oriented approach within the hospital setting*

The realization that a shift from a diseases-modifying attitude to a more symptom-focused palliative care approach within the hospital setting may help to address inadequacies related to, for example, the main goal of treatment in the last week of life and the anticipatory prescription of medication, although we believe that health care staff from acute geriatric wards may possibly be more willing to adopt a palliative care approach than health care staff in other acute hospital wards. A study performed earlier in Belgium has shown that geriatricians treat their older patients at the end of life less aggressively than physicians on non-geriatric wards<sup>58</sup>. It may thus be that individual end-of-life care needs are already taken into account more in this specific hospital setting. In fact, geriatric medicine already has much in common with palliative care, such as its focus on improving quality of life as well as its holistic patient view and its multidisciplinary approach<sup>59</sup>. However, that does not mean that geriatricians and nurses appropriately recognize the dying phase, which is an important prerequisite for adopting a palliative care approach in patients dying in hospital. In other words, as geriatric medicine is more often centred on the improvement and the rehabilitation of a patient's functional status, geriatric medicine could learn from palliative care to better recognize the dying phase<sup>59</sup>.

### *Timely recognition and diagnosis of the dying phase*

Addressing the challenge of timely recognition and diagnosis of the dying phase especially in older patients dying from non-malignant diseases<sup>37</sup> may help to address several of the abovementioned inadequacies in end-of-life care for older people. For example, the lower percentage of palliation as the main goal of treatment in the last week of life in hospitalized older patients, the discontinuation of potentially inappropriate medication and the anticipatory prescription of medication. The impact of timely recognition and diagnosis of the dying phase on optimal end-of-life care has been shown in a Dutch intervention study in cancer patients. Results indicated that the anticipatory prescription rates increased after implementation of the Liverpool Care Pathway<sup>60</sup>. This could be due to the fact that this pathway aims to guide health care staff in timely recognition and diagnosis of the dying phase and simultaneously stresses

the importance of adequate symptom management by, among other things, anticipatory prescription of medication.

#### *Raising awareness and increasing knowledge among health care staff*

Firstly, to address the identified inadequacies related to the discontinuation of potentially inappropriate medication and symptom management, health care staff should be made aware of the importance and relevance of identifying end-of-life care needs, such as psychosocial and existential needs, and adopting the right comfort measures in order to address them appropriately. They should also be encouraged to properly determine whether interventions and medication should be continued in accordance with the individual patient's needs. In order to establish an adequate end-of-life care plan, health care staff on geriatric wards have to identify and discuss a patient's individual end-of-life care needs and preferences.

Secondly, health care staff could be taught which interventions and medications are appropriate at the end of life. In order that health care staff have better guidance in this respect further research should be conducted to determine the appropriateness or inappropriateness of nursing and medical interventions and medication at the end of life. In addition, health care staff should know and learn how for instance psychological and existential problems need to be treated or dealt with. Enhancing knowledge and increasing communication skills with for example family caregivers are thus of utmost importance, especially in an older population, where approximately half of the patients are no longer able to communicate their wishes and preferences. In addition, advance care planning in this population is extremely relevant.

#### *Paying attention to patients with non-malignant diseases*

Because recognizing the dying phase is easier in cancer patients and palliative care has historically been focused on patients dying with cancer<sup>37</sup>, patients dying from non-malignant diseases are still disadvantaged with respect to end-of-life care.

In order to address inadequacies related to the continuation of potentially inappropriate medication and anticipatory prescription of medication, particular attention should be paid to patients dying from frailty or dementia. To address for instance the potential fear by physicians of side effects of morphine in patients with dementia, guidelines could be developed to ensure optimal symptom control in this specific patient population.

#### *Paying attention to patients lacking capacity at the end of life*

It is revealed in the death-certificate study that patients lacking capacity in the younger group, namely those between 75-85 years, are more likely to receive life-prolonging or curative treatment at the end of life than those of the same age group having capacity. This may

suggest that difficulty in discussing a patient's end-of-life preferences could impede a shift in focus to end-of-life care. However, our results indicate that this phenomenon did not occur in patients above 85 years, which might suggest the different attitudes of care givers towards the treatment of older people, irrespective of their capacity to make decisions.

### **(3) The Care Programme for the Last Days of Life**

Guidelines and care trajectories may help us to address the identified inadequacies in end-of-life care on acute geriatric wards by implementing one or more of the abovementioned improvement strategies. Hence, we aimed to develop the Care Programme for the Last Days of Life – an extensive initiative including or meeting most of the abovementioned improvement strategies and criteria.

Over the years, several pathways have been developed and implemented in order to improve end-of-life care<sup>2,3,4</sup>. The Liverpool Care Pathway (LCP), on which the Care Programme for the Last Days of Life has been partly based, has been widely criticized since 2012 for failing to provide appropriate care and subsequently an independent review has recommended phasing out the LCP in the UK<sup>6</sup>. However, this should not be a reason to abandon any efforts to structure and further improve end-of-life care in health care settings. Rather, it pinpoints the need to develop, evaluate and implement ameliorated end-of-life care improvement programmes, taking into account the lessons learned from the UK. Although the LCP was an evidence-based framework founded on high quality medical practice in palliative care, the Neuberger review underlined the lack of research on the effectiveness of the LCP itself and on how various factors can result in better or worse implementation<sup>6</sup>. Our study is one of the first studies that aims to thoroughly evaluate the effects of an end-of-life care programme using a robust research design before implementation and dissemination in practice.

In this study, we developed the Care Programme for the Last Days of Life and evaluated its effects using the Medical Research Council (MRC) Framework approach<sup>19,21</sup>.

Our Care Programme is different from the original LCP programme in several ways. Firstly, it is specifically adapted to the older hospital population and setting, for example the content of the implementation guide is adapted to the acute geriatric hospital ward. Secondly, most of the concerns regarding the use of the LCP raised in the UK were taken into account. For example, the terminology was changed from 'Pathway' to 'Care Guide for the Last Days of Life'. This might prevent misconceptions about our programme, such as the misconceptions among health care staff and family carers and patients in the UK who have perceived 'pathway' as a 'route

to death'<sup>61,62,63</sup>. The term 'Care Guide' suggests that the document is supposed to *guide* the health care staff in making individualized choices in caring for dying patients, without being a protocol that has to be followed. This change in terminology was later also recommended in the Neuberger review<sup>6</sup>. Furthermore, the importance of a thorough and correct implementation of the Care Guide, underpinned by education and training, is stressed in our implementation guide. The implementation guide incorporates nine components that have to be performed and includes a detailed and elaborate training package to help health care staff in educating and supporting their colleagues in using the Care Guide in a correct and compassionate way. This may counter as far as possible the identified problem of poor or improper implementation of the LCP in the UK leading to cases of inadequate end-of-life care in the hospital setting<sup>61,62,63</sup>. The Neuberger review indeed also confirmed that when the LCP is correctly applied it helps to achieve a dignified and pain-free death. Sufficient training and education should prevent staff from using the Care Guide as a 'tick box' exercise instead of as a guidance tool to assist them in decision-making in accordance with a patient's individual needs<sup>6</sup>.

Barriers identified in the phase II study to implementing and using the Care Programme in the acute geriatric hospital ward were also found in earlier performed studies<sup>23,64</sup>. These identified barriers enabled us to further refine the Care Programme in light of the future phase III trial and potential dissemination. For instance, the term 'care goal' which was used in the Care Guide and was perceived as being too coercive was changed into 'point of attention'. Secondly, we emphasized in our implementation guide that wards willing to implement the Care Programme must be supported by the management to invest in a steering group responsible for implementation and information of all involved health care staff. Managers of the ward should be aware that a motivated steering group and facilitators who can enthuse the staff are key factors for successful implementation<sup>23</sup>. Finally, the feasibility study also learned that difficulties inherent in the organization and provision of end-of-life care need to be incorporated and discussed during the training sessions and audits. Therefore, we insist that all health care staff who will use the Care Guide attend these meetings.

According to health care staff involved in the feasibility study the Care Programme has predominantly positive effects on end-of-life care, which confirms the findings of earlier qualitative studies<sup>65,66,67</sup>. An encouraging finding was that the Care Programme positively affects the quality and content of end-of-life care. Namely, using the Care Guide seemed to stimulate a multidisciplinary approach in care at the end of life, greater reflection among health care staff on end-of-life care and continuity of care. It may also help to structure care

delivery and promote a clearer policy regarding anticipatory prescribing of medicines. Moreover, as no additional resources or persons were needed to implement the Care Programme, positive effects could be achieved without any additional cost.

After performing the phase II study, we performed a phase III RCT to evaluate the effectiveness of the Care Programme. By using this robust design, results will contribute substantially to the evidence for end-of-life care interventions. To our knowledge only one other cluster RCT in this area has studied the effects of the LCP programme on cancer patients dying in Italian hospitals<sup>27,68</sup>. Although a cluster RCT is a challenging design, results from a before-after cluster phase II trial support the need for multi-centre cluster RCTs<sup>26</sup>, as this is the only feasible method of assessing the effectiveness of end-of-life care interventions<sup>27</sup>. The data collection of this trial was completed in March 2015. Results of the phase III are not adopted in this doctoral thesis and will be analyzed in a follow-up project.

## **8.4. Implications for practice, policy and research**

Following the summary and discussion of the main findings of this thesis, we formulated some important implications for health care staff, policy makers and researchers regarding end-of-life care for older people in acute geriatric hospital wards.

### **8.4.1. Implications for practice and policy**

As this thesis has identified some important challenges and issues in end-of-life care in acute geriatric hospital wards, we have delineated several implications for practice and policy. Health care staff working on acute geriatric wards and policy makers are capable of making a difference to end-of-life care for older people. Meeting the implications mentioned below might thus be a first step in the right direction.

#### *Changing attitudes and behaviors of health care staff on acute geriatric wards*

In order that a shift is made from a disease-modifying curative attitude to a more symptom-focused palliative care approach within the hospital setting, the attitudes and behaviors of nurses and physicians towards end of life must be changed. As evidence suggests that education alone may be insufficient to engender a significant cultural change in hospital culture<sup>69</sup>, further research should seek to explore practical and policy-driven initiatives that more effectively moderate attitudes and behavior, namely interventions aiming at realizing a transition from ‘cure’ to a more palliative care approach<sup>35</sup>.

This challenging recommendation is based on our findings that older patients dying in hospital are at a higher risk of receiving burdensome curative or life-prolonging interventions than patients dying in other settings. Additionally, results from our retrospective cross-sectional study performed in acute geriatric hospital wards have shown that anticipatory prescription of medication can be improved in comparison with the hospice setting. However, it may be that our developed Care Programme succeeds in its intent of improving the quality of end-of-life care delivery on the acute geriatric ward by shifting the attitudes and actions of clinical staff towards a more care-oriented approach and subsequently better care practices.

#### *Invest in education and training to enhance the knowledge and communication skills of nurses and geriatricians*

An additional step forward could be made by enhancing health care professionals’ knowledge of end-of-life care, including symptom management and comfort in the last days of life, in the basic curriculum, in post-graduate training, through training courses, workshops and seminars.

We for instance identified some problems such as the continuation of unnecessary interventions and medications in the last days of life. Furthermore, our study results and those from earlier performed studies have shown that the recognition and diagnosis of the dying phase in older hospitalized patients is also a challenging issue, mainly due to the difficulty of survival prediction in older patients dying from non-malignant diseases and physicians' reluctance to acknowledge treatment failure<sup>70-75</sup>.

Also communication between health care staff of geriatric hospital wards and patients/family carers can be improved. For the patient and/or family carers, to accept the fact that there is no treatment option other than palliative care can be hard to deal with. The burden of explaining the patient's situation, which can be difficult and stressful, falls on the physicians and nurses. This might be different from the situation encountered in a hospice, where the patient usually goes after being informed of the fact that no further curative treatment is available.

Furthermore, terminally ill patients and their families have serious and diverse issues to tackle, such as physical, psychological, social and spiritual problems. To deal with these issues, good communication skills are essential<sup>75</sup>.

To address the identified problems and challenges in a population whose needs are complex and multifaceted, education and development of skills in health care professions caring for older dying patients is thus crucial.

#### *Encouraging and improving multidisciplinary collaboration*

In addition to education and training, good collaboration between all involved parties is strongly recommended in order to meet the complex and multifaceted needs of older hospitalized patients at the end of their life, e.g. geriatricians, oncologists, cardiologists, palliative care clinicians, pharmacists, psychologists, social workers, dieticians, nursing staff and chaplains<sup>76</sup>. Health care staff caring for older patients, such as on acute geriatric wards, should particularly be encouraged to seek the support of the palliative care team for dealing with the psychosocial and existential needs of dying patients. This is highly recommended as our study findings stress the magnitude of unmet psychosocial and existential needs at the end of life and the need to address these needs. Also for complex symptoms such as shortness of breath, or for deciding which nursing or medical interventions and which medications should be continued and which can be stopped the services of a palliative care team can provide a substantial contribution.

#### *Developing guidelines for optimal symptom control at the end of life in patients with dementia*

Our results showed that during the last 48 hours of life, 65.4% of the older patients dying in an

acute geriatric ward had an anticipatory prescription of medications, and 34.6% did not. Physicians should be made aware of the importance of ensuring no delay in responding to end-of-life symptoms when they occur, particularly in dementia patients, as our study results showed that patients with dementia, especially those with early stage dementia, are less likely to have an anticipatory prescription than those without dementia.

As patients with dementia are less likely to have an anticipatory prescription of medications, which may be due to the fact that physicians fear to prescribe for instance opioids in this population, it might be helpful to develop guidelines for optimal symptom control in patients with dementia. Guidelines could also help physicians in decision-making regarding the deprescription of unnecessary medications at the end-of-life. Physicians should take into account a patient's individual needs and determine an appropriate medication policy.

#### *Structuring end-of-life care processes*

The structuring of care processes in the last days of life could help health care staff in delivering good end-of-life care, for instance by contributing to the management of symptoms in dying older patients. End-of-life care processes could be structured by using individualized end-of-life care plans based on best practices for care in the last days of life. These plans could be especially valuable in acute geriatric wards, where approximately half of the patients are no longer able to communicate their wishes and preferences for end-of-life care. Structuring end-of-life care processes with individualized end-of-life care plans could enable health care staff to track the delivery of care easily and to see at one glance which care has been delivered by the different members of the multidisciplinary team and what still has to be done. This may contribute positively to the continuity of the care delivered.

#### *Dissemination of the developed Care Programme for the Last Days of Life if positive effects are shown*

Most of the abovementioned recommendations can be realized by implementing the Care Programme for the Last Days of Life. This Care Programme aims (1) to raise awareness about the importance of recognizing and diagnosing the dying phase, (2) to educate and train health care staff in order to enhance their knowledge about end-of-life care and their communication skills, (3) to encourage multidisciplinary collaboration and (4) to structure end-of-life care processes.

However, only when the cluster RCT shows positive effects and no potential harm from the Care Programme for the Last Days of Life can be identified, should the intervention be disseminated on a larger scale. This further dissemination of the Care Programme would imply

among other things (1) publication(s) in peer-reviewed literature, (2) communication with policy makers using peer reviewed publications, conference presentations, public engagement activities, newsletters, and open access web deposition of publications at the end of the trial and (3) the surveillance and monitoring of long-term outcomes to measure long-term impacts of the Care Programme.

#### **8.4.2. Implications for future research**

Demographic, epidemiological and societal changes increasingly confront societies with challenges regarding the organization of end-of-life care and dying. As a number of these changes will persist in the future, challenges concerning the organization of end-of-life care and the pursuit of a good death should be dealt with in time, especially for the large group of older patients. Older patients frequently experience multiple and complex health problems and disabilities until death and will therefore have special care needs at the end of life<sup>76,77</sup>. Hence, more funding should be made available for future research in end-of-life care for older patients.

Firstly, in order to better understand the needs of patients of different ages at the end of life and how age influences end-of-life care, further research should be encouraged. It may for instance be valuable to investigate why differences exist in the main goal of treatment in the last week of life between patients of 75-85 years and those older than 85. Getting more insight into the needs of older patients could be a first step towards future interventions aiming to improve end-of-life care.

Secondly, as appropriate end-of-life care for older people should always be delivered in accordance with the patient's individual needs and preferences, further research should focus on how a cultural change within the acute hospital setting may be achieved. By shifting from a disease-modifying curative attitude to a more symptom-focused palliative care approach, caregivers may be enabled to take into consideration and address individual end-of-life care needs and preferences. Therefore, further research should explore which interventions are effective in making transitions from 'cure' to a more palliative care approach. However, as there may be cases in which the health care staff is palliative care oriented whereas family caregivers and/or patients persistently insist on curation or life-prolongation, research should also focus on how family carers' and patients' attitudes could optimally be addressed.

Thirdly, in order to provide evidence based guidelines for health care staff, it will be of great interest to explore the appropriateness of medical and nursing interventions during the last

hours of life and to investigate which medications are (in)appropriate at the end of life.

Besides, future research should focus on how optimal symptom control could be ensured for patients with dementia and how the side effects of medication such as morphine could be avoided.

Fourthly, further research should focus on tools to overcome prognostic paralysis especially in non-cancer terminal illnesses.

In conclusion, an essential suggestion for future research is the continued investigation of the Care Programme for the Last Days of Life. As the phase III cluster randomized controlled trial on the effectiveness of the Care Programme has recently been finished, analysis of the results of this trial should be performed as soon as possible in order to judge whether or not the Care Programme for the Last Days of life has potential to improve end-of-life care in acute geriatric hospital wards.

If it appears that the Care Programme provides a positive contribution to end-of-life care in the acute geriatric hospital setting, its implementation and use should be further monitored and ameliorated where needed.

In addition and according to the results of the phase II study, further research to gain a better understanding of the barriers to implementing the Care Programme and how they could best be approached or addressed may also be needed.

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