PALLIATIVE CARE IN NURSING HOMES IN EUROPE

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IN EUROPE

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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 (VUB)

&

Health Sciences
Faculty of Medicine and Health Sciences Universiteit Gent (UGent)

End-of-Life Care Research Group
January 2021

This doctoral thesis is part of the ‘PAlliative Care for older people in nursing homes in Europe (PACE)’ project, a European funded project (FP7, 2014-2019) comparing the effectiveness of palliative care for elderly people in care or nursing homes in Europe and aiming to advise policy-makers on optimal palliative care practices.

Illustration cover: Shutterstock
Language editing: Jane Ruthven, Maxime Honinx

2021 Uitgeverij VUBPRESS Brussels University Press
VUBPRESS is an imprint of ASP nv (Academic & Scientific Publishers nv)
Keizerslaan 34
B-1000 Brussels
Tel. +32 (0)2 289 26 50
Fax +32 (0)2 289 26 59
E-mail: info@aspeditions.be
www.aspeditions.be

ISBN 978 94 611 714 12
NUR 883
Legal deposit D/2021/11.161/056

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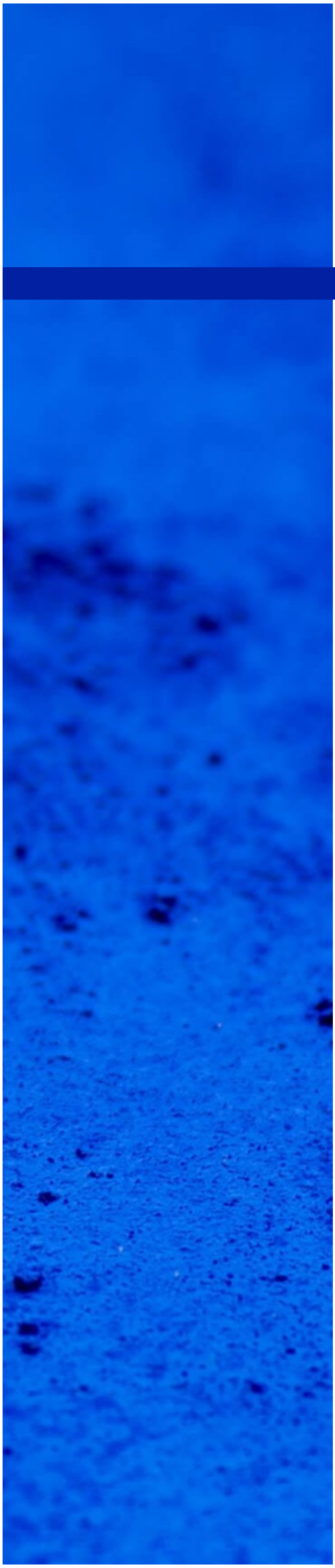
WE CANNOT CHANGE THE CARDS WE ARE DEALT.
JUST HOW WE PLAY THE GAME.

– Randolph Frederick Pausch



contents

CHAPTERS ARE BASED ON THE FOLLOWING PUBLICATIONS

Chapter 1

Honinx E, Van Dop N, Smets T, et al. Dying in long-term care facilities in Europe: the PACE epidemiological study of deceased residents in six countries. BMC Public Health. 2019;19(1). doi:10.1186/s12889-019-7532-4

Chapter 2

Honinx E, Smets T, Piers R, et al. Agreement of Nursing Home Staff With Palliative Care Principles: A PACE Cross-sectional Study Among Nurses and Care Assistants in Five European Countries. Journal of Pain and Symptom Management. Published online July 2019. doi:10.1016/j.jpainsymman.2019.06.015

Chapter 3

Honinx E, Van den Block L, Piers R, et al. Large differences in the organization of palliative care in nursing homes in six European countries: findings from the PACE cross-sectional study (*submitted*).

Chapter 4

Honinx E, Van den Block L, Piers R, et al. Potentially inappropriate treatments at the end of life in nursing home residents: Findings from the PACE cross-sectional study in 6 European countries. Journal of Pain and Symptom Management. Published online September 2020. doi:10.1016/j.jpainsymman.2020.09.001

Chapter 5

Honinx E, Piers R, Onwuteaka-Philipsen BD, et al. Hospitalization in the last month of life and in-hospital death of nursing home residents: an analysis of six European countries (*submitted*).

Chapter 6

Van den Block L, Honinx E, Pivodic L, et al. Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries. JAMA Internal Medicine. Published online 2020. doi:10.1001/jamainternmed.2019.5349

Chapter 7

Honinx E, Smets T, et al. Lack of Effect of a Multicomponent Palliative Care Program for Nursing Home Residents on Hospital Use in the Last Month of Life and on Place of Death: A Secondary Analysis of a Multicountry Cluster Randomized Control Trial. Journal of the American Medical Directors Association. Published online 2020. doi:10.1016/j.jamda.2020.05.003

ACKNOWLEDGEMENTS

Ten eerste, bedankt **voorzitter en juryleden.**
Om zelfs in deze aparte tijden in werking te treden.

Ook danku aan **Lieve**, eeuwig enthousiast.
Goedlachs, gemotiveerd, en immer koersvast.

Tinne, jij maakte tijd voor al mijn vragen, de grote…en de kleine.
De beste begeleider, dat was toevallig de mijne.

Luc, de onderzoeksgroep die je uitbouwde is enorm impressief.
Bedankt voor deze kans, je wijsheid en je verregaand perspectief.

Ruth, wonderwoman van UZ Gent.
Jouw kennis en ervaring genereerden menig leermoment.

Spread across Europe, the amazing group of **PACE.**
I really hope to see you all again, face-to-face.

Dankjewel liefste **bureaugenoten** van het warmste lokaal uit Jette.
En niet alleen voor de dagelijkse vraag of ze voor mij "écht géén koffie moesten zetten?!"

My other **EOLC colleagues**, every last one of them, what a team!
Having such nice people to work with, that can only be a dream.

Stefanie, Sander en Roos, stuk voor stuk een rekenwonder.
Via skype, mail of telefoon, statistiek op speed dial, ik kon niet zonder.

Een dankuwel aan mijn **vrienden**, of ik haar nu pas heb ontmoet of hij me al wat langer kent.
Of ze nu in Brussel wonen, in Antwerpen of in de provincie met het mooiste accent.

Mijn twee inspiratiebronnen, **Pitou en Oma.**
Mede dankzij jullie heb nu ik een extra diploma.

Soms ver en soms dichtbij, **mijn zussen**, alletwee
In ogni lingua, sempre entusiaste.

Mama, papa, bedankt voor de ongelofelijke support.
Voor de studies en de kansen, aan liefde niks tekort.

ABBREVIATIONS

PACE PAlliative Care for older people in Europe

EAPC European Association for Palliative Care

RCT Randomized Controlled Trial

IMPACT IMplementation of quality indicators in PAlliative Care sTudy

EOLD-CAD End-of-Life in Dementia – Comfort Assessment in Dying

QOD-LTC Quality of Dying in Long-Term Care

S-EOLC Self-efficacy in End-of-Life Care survey

EPCS End-of-life Professional Caregiver Survey

EORTC European Organisation for Research and Treatment of Cancer

ATOME Access to Opioid Medication in Europe

BANS-S Bedford Alzheimer Nursing Severity - Scale

ENRICH ENabling Research In Care Homes

ER Emergency Room

ICU Intensive Care Unit

OR Odds Ratio

NH Nursing Home

NA Not Applicable

SD Standard Deviation

PC Palliative Care

GENERAL INTRODUCTION

1 BACKGROUND

1.1. AGEING AND ILLNESS IN THE OLDER POPULATION

Along with population growth, international migration and urbanization, population ageing is one of the major trends of the world's population today[1]. Up until recently, people aged 65 or over were outnumbered by children under the age of five[2]. Currently, this ratio is reversing, while fertility rates are dropping. This will put us in the unique position of living in a world with more older than younger people, a world in which human life span will continue to increase[2]. The group of people aged 85 years and over, referred to as the oldest-old, will show the greatest percentual increase[3]. The shift in life expectancy also comes with a change in leading causes of illness and death, as part of an epidemiologic transition. Even though a longer lifespan can also entail a longer activity and contribution to society and economy – provided this is supported by the environment (cfr. active ageing[4]) – chronic and degenerative diseases, characterized by a longer and dynamic illness trajectory, will become prevalent[5]. Therefore, long-term care provided in nursing homes, long-term care facilities, hospices, residential homes and other residential settings will play an important role in the care for older people[3]. The demand for long-term care depends on the influx of people in the oldest-old group and on changes in disease rates, and will most likely grow during the following years[2].

Although the changes in illness and causes of death were already noticeable years ago and should have elicited enormous changes in the organization and functioning of our health care systems, our population still faces important challenges. One of these challenges is the provision of high-quality palliative care for all those who need it, regardless of age, setting or disease.

1.2. PALLIATIVE CARE FOR NURSING HOME RESIDENTS

Palliative care is defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual"[6]. In the past, palliative care was mainly provided to cancer patients in a hospice setting. However, due to the typical longer trajectory of illnesses in older people, many older people with complex illnesses may benefit from palliative care at certain points during their illness trajectory, and not only in the terminal phase[7]. Palliative care should therefore be integrated as an important part of all health care, as advocated by the WHO[3,8]. More and more fields within the healthcare sector start to consider the complex care needs of older people and their relatives. The idea that palliative care is only helpful during the last week of life when curative treatments fail has gradually being abandoned[3]. It becomes clear that during the course of a disease, multiple problems might occur that need specific attention. Palliative care aims to be responsive to what is needed to support people in their unique situation.

Palliative care is of particular relevance for people living and dying in nursing homes. Currently, almost 40% of people of 65 years and over come to die in a nursing home (particularly in developed countries), and this percentage is expected to grow over the following years[9]. For decades, nursing home deaths were considered a negative result from inadequate care at home, and something that needed to be avoided[10]. Deterioration of nursing home residents has often been perceived as a sign of poor care[11]. Together with the fact that rehabilitation is often financially stimulated, this has led to nursing homes being hesitant in accepting decline or death in their residents. In recent years, however, numbers show that more and more residents are already in their final stage of life when they enter a nursing home, with deterioration and death being unavoidable[12,13]. People who enter the nursing home are usually at an advanced age, with multiple chronic diseases and a poor functional status[14,15]. Care must therefore be adapted to the characteristics and complex care needs of nursing home residents[16]. The contrast between living and dying challenges staff in the care for nursing home residents and forces them to balance between supporting life and preparing for death. This would mean that staff are more and more required to answer the needs of a group considered to be 'at the end of life' i.e. last years or months of life[14].

From previous studies we have learned that the quality of palliative care and the quality of dying in European nursing homes are not optimal and that nursing staff knowledge concerning basic palliative care issues is substandard[17,18]. In a recent EU study on the palliative care knowledge of nursing home staff (PACE) it was found that knowledge of nurses and care assistants on the use of feeding tubes and the management of pain was poor in the included European countries[19]. However, some important knowledge gaps regarding palliative care in nursing homes still remain. First, from an epidemiological viewpoint, there is a lack of high-quality and representative socio-demographic and clinical data on the population of dying residents in nursing homes. There is, for example, a lack of reliable estimates of the number of people dying with various stages of dementia or with various levels of functional disability in nursing homes, data that are very relevant for policy-makers who need to make decisions regarding adequate resources and staffing. Also, the extent to which nurses and care assistants from European nursing homes have developed basic palliative care attitudes is quite unknown, but nevertheless important to inform educational initiatives for this sector. Related to this, there are currently no data available to policy-makers on the extent to which important organizational structures for the delivery of quality palliative care are present in different EU countries, such as a specialist palliative care team, bereavement support, or access to specialized equipment or medications such as opioids[20]. Such knowledge, particularly when comparing different countries, would be relevant for national policy-makers as well as nursing home directors or umbrella organizations as this would provide opportunities to learn from each other and improve where needed.

1.3. POTENTIALLY INAPPROPRIATE TREATMENTS IN NURSING HOMES

Care today is often still centered around the disease of the resident, leading to a prolonged curative treatment during the disease trajectory, and is less focused on palliative care. The challenge in predicting when an older person will die, complicates the decision on the appropriateness of a treatment and whether or not to administer such treatment[21]. Certain treatments are considered potentially inappropriate when provided at the end of life to older people with comorbidities and should thus be considered cautiously[22]. Examples of these treatments are: artificial nutrition and hydration treatments, antimicrobial treatments, certain medications such as statins, critical care treatments such as resuscitation or surgery, and treatments like chemotherapy[23–25]. In order to offer more patient-centered palliative care, it is crucial to first learn about the prevalence of those treatments in nursing homes in different countries.

End-of-life hospitalizations, together with the high amount of residents that die in-hospital, is another area of concern within the challenging journey towards high-quality palliative care for nursing home residents[26,27]. Hospital transfers at the end of life are considered to be of limited clinical benefit to residents, are often in violation with the resident's care preferences and comfort, and come with high costs and negative risks[28]. More specifically, these transfers might increase the risk of declined functioning upon return to the nursing home, and can lead to infections, complications and other disruptions[29]. Nursing home residents in particular are vulnerable for hospital-acquired infections or treatment errors associated with care transitions and hospital stays. For residents with dementia, for whom an unknown environment can cause disorientation, a transfer is even more burdensome[30]. The influx of older people with complex care needs into the hospital demands for adequate palliative care in this setting[31].

Place of death is viewed as a quality indicator for palliative care, which includes avoiding unwanted in-hospital deaths and taking into consideration a resident's wish to die at home[32,33]. Still, the majority of studies on hospitalizations at the end of life of nursing homes residents primarily focused on place of death, while leaving unexplored other hospitalization-related outcomes, such as the frequency of hospitalization and the length of stay, the reason for the hospital admission and at whose request the admission to the hospital took place[34]. Moreover, only a few studies explored factors associated with hospitalization: of those studies, most merely focused on resident-level factors such as age or gender and reported diverse hospitalization rates with sometimes inconsistent results[35]. Lastly, many of these studies are limited to the United States. We lack representative and international comparative data on potentially inappropriate treatments, hospitalizations and place of death. Studying cross-national variation in these end-of-life events can generate representative data and provide useful information for the development of palliative care policies and targeted interventions to meet the needs of nursing home residents, their relatives, and society as a whole.

1.4. A EUROPEAN PERSPECTIVE ON PALLIATIVE CARE IN NURSING HOMES

Policies on palliative care and health care differ strongly between countries, creating considerable differences in the quality of palliative care in nursing homes[36,37]. Aside from the differences in national policies, culture and beliefs also may be included as barriers to adequate palliative care. Some factors even appear to be a barrier in one country or institution and a facilitator in another. For example, being part of a care network can stimulate the access to palliative care services in some countries or nursing homes, whereas it might increase competition between institutions for others[38]. European representative and comparative studies on palliative care practice in nursing homes are thus crucial. That is, international data enables policymakers to gain insight into the main issues of the nursing home population. Contrasting data between countries could facilitate a better understanding of national and international challenges and assist decisionmakers in creating hypotheses on palliative care organization.

Earlier studies have mapped the different European palliative care policies, services and initiatives[15,39,40]. A report by the Long-term Care Facilities Taskforce of the European Association for Palliative care (EAPC) describes different palliative care development initiatives in 13 European countries, including the clinical and cultural challenges each country must face. This EAPC study classified the implementation activities on macro (policy, legislation and finances), meso (implementation activities e.g. education and research) and micro level (palliative care delivery in nursing homes) and revealed that on all three levels, palliative care development and implementation were limited in many of the countries studied. A previous PACE study that described and compared palliative care provision in representative samples of nursing homes in six European countries found a late initiation of palliative care in nursing homes and concluded that palliative care for residents without cancer, dementia or closely involved relatives deserved attention[41]. Finally, another PACE study on the quality of dying and quality of end-of-life care of nursing home residents indicated that even though European countries varied in terms of quality of end-of-life care and quality of dying, all showed room for improvement, even the countries with higher levels of palliative care development in nursing homes[18].

These studies identified the variety in palliative care provision, integration and quality in nursing homes across European countries and the difficulties these countries still need to overcome. There is a clear need to improve palliative care in this setting.

1.5. INITIATIVES TO IMPROVE PALLIATIVE CARE IN NURSING HOMES

Evidence-based initiatives to improve palliative care in nursing homes in Europe are limited. Many palliative care interventions are aimed at one aspect, e.g. treating specific symptoms or advance care planning[42–44]. Research suggested that individual initiatives only targeting one specific element seem insufficient to change nursing home care if they are not part of a broader approach. Achieving actual change appears to require a comprehensive, whole-setting approach, while targeting specific aspects that are underdeveloped[45,46]. Only a few large-scale interventions have been implemented and even fewer were evaluated using high-quality study designs[47].

A 2011 Cochrane review of three American studies on interventions for improving palliative care for older people living in nursing care homes – one controlled before-and-after study[48] and two RCTs[49,50] – rated all three studies as being of poor quality with multiple bias sources[47]. Even though the studies were multi-faceted and complex, the assessment of resident outcomes was limited. The RCT by Casarett only included residents that fit the criteria for receiving specialist palliative care – being in the last six months of life – and thus excluded residents with more general palliative care needs[49]. Several challenges came forward in this study, such as the already existing hospice programmes in the participating nursing homes, the dependence on the communication between nursing home staff and hospice staff and other barriers hindering the integration of external specialist palliative care into general nursing home care[1]. This makes the external validity of said study uncertain. The two other studies focused on the provision of a palliative approach by nursing home staff for all residents, and both involved staff training. A review analyzing the effect of palliative care teams, presented a rise in satisfaction with care[51]. Another review of the effectiveness of specialized palliative care showed almost none of the 22

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[1] General palliative care refers to the standard palliative care that can be provided by all healthcare professionals in all services. Specialist palliative care services represent an extra layer of palliative care, provided by experts, often a trained multi-disciplinary team of trained professionals.

included interventions had significant benefits, again except for higher caregiver satisfaction[52]. However, this effect was small. In a survey of 25 Cochrane systematic reviews, 23 of the 25 interventions were rated as weak due to small size, clinical heterogeneity, poor external validity and poor quality[53].

Although all these interventions appeared insufficient to improve palliative care, they can however be useful in pointing out the weaknesses of evidence on successful palliative care interventions for nursing homes. Moreover, many of these interventions were conducted in the United States. Since European countries differ from the US in many respects e.g. healthcare systems and palliative care organization, it is important to conduct high-quality trials in Europe. Besides the lack of effective interventions, high-quality studies evaluating the existing interventions are scarce, often due to methodological weaknesses or flaws in the interventions themselves[52,54–58].

Clearly there is a need for research on initiatives to improve outcomes of palliative care in nursing homes across Europe. In this regard, the ‘PACE Steps to Success Programme’ was developed[59]. The programme aimed to enhance high-quality palliative care for all nursing home residents in Europe, by promoting organizational change and assisting staff in developing their roles as a palliative caregiver. The intervention ran for 12 months in the participating nursing homes, while being evaluated in a randomized clinical trial (RCT) that studied the impact of the programme. The RCT compared the effect of the programme with usual nursing home care in terms of resident and relative outcomes, staff knowledge and attitudes, quality of palliative care, quality of dying and cost-effectiveness. This dissertation includes the evaluation of the effectiveness of the PACE programme.

PART I **aims to** describe facility-, resident-, and staff characteristics of palliative care in nursing homes in Europe and to compare those characteristics between six European countries.

PART II **aims to** study the prevalence of potentially inappropriate treatments and hospitalizations at the end of life of nursing home residents and to explore the differences in prevalence between the six countries.

PART III **aims to** evaluate the effect of a palliative care programme in nursing homes in Europe on resident and staff outcomes and on hospitalizations.

Aim of PART I : To describe facility-, resident-, and staff characteristics of palliative care in nursing homes in Belgium, England, Finland, Italy, The Netherlands, and Poland and to compare those characteristics between the six countries.

Chapter 1: To identify the demographic, facility-stay and clinical characteristics of nursing home residents in Europe, and to determine how these differ between six European countries.

Chapter 2: To explore to what extent nurses and care assistants working in nursing homes in Europe agree with the basic principles of palliative care and which factors are associated with their level of agreement.

Chapter 3: To examine structural indicators for quality of palliative care in nursing homes in Europe and to evaluate the differences between six European countries.

Aim of PART II : To study the prevalence of potentially inappropriate treatments and hospitalizations at the end of life of nursing home residents in Belgium, England, Finland, Italy, The Netherlands and Poland, and to explore the differences in prevalence between the six countries.

Chapter 4: To estimate the prevalence of potentially inappropriate treatments in the last week of life in nursing home residents in Europe and to study the differences in prevalence of these treatments between six European countries.

Chapter 5: To identify the characteristics of hospitalization and in-hospital deaths of nursing home residents in Europe in the last month of life, and the factors associated with those characteristics.

Aim of PART III: To evaluate the effect of a palliative care programme in nursing homes in Belgium, England, Finland, Italy, The Netherlands, Poland and Switzerland on resident and staff outcomes and on hospitalizations.

Chapter 6: To assess the effect of the PACE 'Steps to Success Programme' on resident outcomes as reported by staff, and on staff outcomes in Europe.

Chapter 7: To evaluate the effect of the PACE 'Steps to Success Programme' on hospitalizations in the last month of life and on place of death of nursing home residents in Europe.

3 METHODOLOGY

PACE is a European funded project (European Union’s Seventh Framework Programme, 2014-2019) which compares the effectiveness of palliative care for elderly people in care or nursing homes in Europe and aims to advise policymakers on optimal palliative care practices.
Two studies were used for this dissertation: PACE study I and PACE study II.

Within Europe, several types of nursing homes can be distinguished, depending on whether care by specific health care professionals is provided onsite or off-site. The term nursing home in this dissertation commonly refers to a long-term care facility, i.e. ‘a collective institutional setting where care, on-site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time’[36]. We distinguished three types of nursing homes: type 1 with 24/7 care from on-site physicians and nurses/care assistants, type 2 with 24/7 care from on-site nurses/care assistants and off-site physicians, and type 3 with 24/7 care from on-site care assistants, and off-site nurses and physicians[60].

PACE study I

The first major study within PACE aimed to describe and compare six European countries in terms of resident outcomes, quality, costs and structures of palliative care and staff knowledge and attitudes toward palliative care, and analyzes the relationship among these structures, processes, and outcomes. In 2015, we therefore performed the PACE cross-sectional study of nursing homes in Belgium, the United Kingdom, Finland, Italy, the Netherlands and Poland. In Belgium and the UK, a sample of nursing homes was drawn from the region where most of the population lives (Flanders and England respectively). In each country, participating nursing homes reported every death that occurred among the residents over the preceding three-month period. Deceased residents were included in the study when death occurred in the nursing home, as were those whose deaths were registered outside (e.g. in acute care hospitals). For each identified deceased resident, structured questionnaires were sent to the key respondents: the nursing home administrator, the nursing staff member most involved in care (preferably a nurse) and the treating physician (a general practitioner, elderly care physician or physician employed in the nursing home). For each participating nursing home, the administrator was also asked to fill out a questionnaire on nursing home characteristics. More details on the methodology of the first PACE study can be found in the protocol article of study I[61].

PACE study II

We conducted a multifacility cluster-randomized clinical trial (2015-2017) in Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland, to compare the PACE 'Steps to Success Programme' with usual care. The PACE 'Steps to Success Programme' is a multicomponent intervention programme to integrate basic non-specialist palliative care in nursing homes. It is based on the 'Route to Success in Long-term Care Facilities', a national end-of-life care intervention from the UK[62]. That intervention expands on the 'Gold Standards Framework', a prominent palliative care programme that was originally designed to enhance palliative care in primary care before it was modified to be used in nursing homes[63,64]. Using a train-the-trainer approach, an external trainer supports staff in the nursing homes to introduce a palliative care approach over the course of one year following a six-step program. The programme has three phases, implemented over a 12-month period (two months preparation, six months implementation of six steps, and four months consolidation with ongoing support where needed). The six steps of the programme include (1) advance care planning with residents and family via discussions about current and future care; (2) care planning, assessment, and review of needs and problems via the 'Mapping changes in condition' chart; (3) coordination of care via monthly multidisciplinary review meetings; (4) high-quality care delivery focusing on pain and depression via assessment and management tools; (5) care in the last days of life using a structured checklist; and (6) after-death care via reflective debriefing sessions for staff[59].

For this study, only type 2 nursing homes were recruited. All participating nursing homes were divided into two groups based on the median number of beds in the country; half were randomized to the intervention group, half to the control group delivering care as usual. In each country, participating nursing homes reported every death that occurred among the residents over the preceding four-month period. For deceased residents, baseline data were collected in all participating nursing homes (at month zero) through after-death structured questionnaires given to all the key respondents. Postintervention (at month 13 and at month 17), the same data were collected on residents who had died during the previous four months. For nurses and care assistants employed in the facility, baseline data were collected in all participating nursing homes (at month zero) through structured questionnaires. Postintervention (at month 13), the same data were collected on nurses and care assistants employed in the facility at that time.

More information on the study methodology has been published in the study II protocol[59].

Ethics of study I and II

Ethics approval from the relevant ethics committees were obtained in all participating countries. Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: NHS – NRES Committee North West-Haydock, 10/09/2015; Finland: Terveyden jahyvinvoinnin laitos, Institutet för hälsa och välfärd, 30/6/2015; Italy: Comitato Etico, Universita Cattolica del Sacro Cuore, 6/11/2017; Netherlands: Medisch Ethische Toetsingscommissie VUMedisch Centrum, 2/7/2015; Poland: Komisja Bioetycza, Uniwersytetu Jagiellonskiego, 25/6/2015; Switzerland: Commission cantonale d'éthique de la recherché scientifique de Genève (CCER), 6/8/2015. For study I, the consulted ethics committees of Italy and the Netherlands judged that no formal ethics approval was needed and provided waivers. Nursing home directors provided an informed consent in writing. The questionnaires sent to the participants in the surveys were anonymous and did not collect identifiable data of respondents or residents. For study I, all participants took part on a voluntary basis; hence, their written responses were taken as valid informed consent. For study II, participants filling in the questionnaires gave their prior informed consent in writing. In Poland and the Netherlands, informed consent was not required given the questionnaires were filled in anonymously. To protect personal data of the deceased residents, questionnaires were pseudonymized with a code at nursing home level. The key for the codes was kept by the nursing home director. Researchers were not informed on the identity of the residents.

Trial registry study II

The study is registered at www.isrctn.com – ISRCTN14741671 (FP7-HEALTH-2013-INNOVATION-1603111). Registration date: July 30, 2015.

4 DISSERTATION OUTLINE

Chapters 1 – 7 are based on articles that have been published or accepted for publication in peer-reviewed journals. All chapters can be read individually.

The three main aims of this PhD project are addressed in three separate parts of this dissertation. Each part consists of different chapters that answer the specific underlying objectives and research questions. The **GENERAL INTRODUCTION** describes the rationale for this PhD project as well as its aims, objectives and methodology.

PART I focuses on the description and comparison of characteristics of palliative care in nursing homes in Europe. **Chapter I** presents the results of the PACE epidemiological study of deceased nursing home residents. **Chapter II** reports on the agreement of nursing home staff in the six European countries with palliative care principles. **Chapter III** describes large differences in the organizational structures of palliative care in nursing homes in the different countries.

PART II zooms in on inappropriate treatments and hospitalizations at the end of life of nursing home residents in six European countries. More specifically, **Chapter IV** explores potentially inappropriate treatments in the last week of life of nursing home residents. **Chapter V** outlines hospitalizations in the last month and in-hospital deaths of nursing home residents.

PART III evaluates the PACE palliative care programme for nursing homes in Europe. **Chapter VI** analyzes the effectiveness of the PACE programme in a cluster-randomized clinical trial. **Chapter VII** describes the lack of effect of the PACE palliative care programme on hospital use in the last month of life and on place of death of nursing home residents in a secondary analysis. The **GENERAL DISCUSSION** concludes the dissertation with a summary and discussion of the main findings, describes the strengths and limitations of the research methods, and aims to suggest some useful implications for practice, policy and future research.

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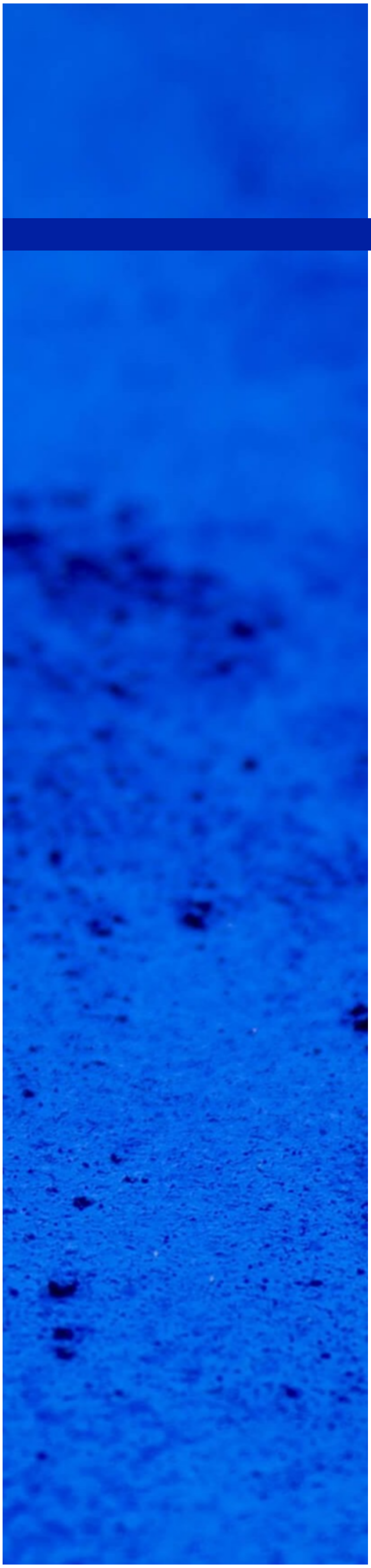

PART I

PALLIATIVE CARE IN NURSING HOMES IN EUROPE

CHAPTER 1

DYING IN LONG–TERM CARE FACILITIES IN EUROPE: THE PACE EPIDEMIOLOGICAL STUDY OF DECEASED RESIDENTS IN SIX COUNTRIES

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Honinx E, Van Dop N, Smets T, et al. *Dying in long-term care facilities in Europe: the PACE epidemiological study of deceased residents in six countries.* BMC Public Health. 2019;19(1). doi:10.1186/s12889-019-7532-4

Abstract

Background

By 2030, 30% of the European population will be aged 60 or over and those aged 80 and above will be the fastest growing cohort. An increasing number of people will die at an advanced age with multiple chronic diseases. In Europe at present, between 12% and 38% of the oldest people die in a long-term care facility. The lack of nationally representative empirical data, either demographic or clinical, about people who die in long-term care facilities makes appropriate policy responses more difficult. Additionally, there is a lack of comparable cross-country data; the opportunity to compare and contrast data internationally would allow for a better understanding of both common issues and country-specific challenges and could help generate hypotheses about different options regarding policy, health care organization and provision. The objectives of this study are to describe the demographic, facility stay and clinical characteristics of residents dying in long-term care facilities and the differences between countries.

Methods

Cross-sectional study (2015) in a proportionally stratified random sample of 322 facilities in Belgium, Finland, Italy, the Netherlands, Poland and England. The final sample included 1384 deceased residents. The sampled facilities received a letter introducing the project and asking for voluntary participation. Facility manager, nursing staff member and treating physician completed structured questionnaires for all deaths in the preceding three months.

Results

Of 1384 residents the average age at death was 85 years (81 in Poland – 87 in Belgium and England; $p<0.001$) and length of stay from six months (Poland, Italy) to two years (Belgium) ($p<0.05$); 47% (the Netherlands) to 74% (Italy) had more than two morbidities and 60% (England) to 83% (Finland) dementia, with a significant difference between countries ($p<0.001$). Italy and Poland had the highest percentages with poor functional and cognitive status one month before death (BANS-S score of 21.8 and 21.9 respectively). Clinical complications occurred often during the final month (51.9% England, 66.4% Finland and Poland).

Conclusions

The population dying in long-term care facilities is complex, displaying multiple diseases with cognitive and functional impairment and high levels of dementia. We recommend future policy should include integration of high-quality palliative and dementia care.

Key Words. End-of-life care; long-term care facility; nursing homes; palliative care; policy.

Introduction

By 2030, 30% of the European population will be aged 60 or over and those aged 80 and above will be the fastest growing cohort[1]. An increasing number of people will die at an advanced age with multiple chronic diseases[2-4]. In Europe at present, between 12% and 38% of the oldest people die in a long-term care facility[5]. The term long-term care facility in this study is used for all 'collective institutional settings where care, on-site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there 24 hours a day, seven days a week, for an undefined period of time'[6]. There are many types of long-term care facilities, due to the different health care systems and funding mechanisms in different countries[6]. Also, the number of older people in need of high-quality end-of-life care in such facilities is increasing[2,4]. Studies of the complexity of challenges posed by people spending their end-of-life period in long-term care facilities have so far been small-scale and limited to specific regions or illnesses[5-8].

The lack of nationally representative empirical data, either demographic or clinical, about people who die in long-term care facilities makes appropriate policy responses more difficult[7]. There are very few statistics comparable across Europe on the prevalence of dementia and multimorbidity, on functional and cognitive status or on clinical complications at the end of life in the residential setting. This lack of data makes it difficult for policy and decision-makers to gain insight into the key challenges of this population and provides them with few opportunities to monitor changes over time. Additionally, there is a lack of comparable cross-country data; the opportunity to compare and contrast data internationally would allow for a better understanding of both common issues and country-specific challenges and could help generate hypotheses about different options regarding policy, health care organization and provision.

Palliative Care for Older People (PACE) is an EU-funded project (2014-2019) which set out to conduct comparative research on older people dying in long-term care facilities in Europe. It is the first study aiming to describe and compare the characteristics of dying residents across six European countries, Belgium, the Netherlands, England, Finland, Italy and Poland. These countries were selected to reflect a variety of health care systems and geographic regions in Europe[9-10].

The main research questions are: (1) what are the demographic and facility-stay characteristics of people who die in long-term care facilities and how do they differ between the six participating countries, and (2) what are the clinical characteristics of the residents who die there, including the prevalence of dementia and other conditions, their functional and cognitive status one month before death and the clinical complications during the last month of life, and how do these differ between the six countries.

Methods

Study design

An epidemiological study of deceased residents in long-term care facilities was conducted in Belgium, the Netherlands, England, Finland, Italy and Poland in 2015[9]. To obtain representative samples of facilities, a proportional stratified random sampling procedure was used within each country. Based on available national or regional lists of all long-term care facilities, facilities were randomly and proportionally selected from several strata (based on at least region/province and facility size by beds). In Belgium and the UK, a sample was drawn from the region where most of the population lives (Flanders and England respectively). In England, the nationwide ENRICH (Enabling Research in Care Homes) network was used to increase participation of facilities. In Italy there was no public national list available and instead a convenience sample was used based on a previously constructed cluster of facilities interested in research, which covered the three macro regional areas and took into account different sizes and types of facilities.

In each country, participating facilities reported every death that occurred among the residents of their facility over the preceding three-month period. Deceased residents were included in the study when death occurred in the facility, as were those whose deaths were registered outside (e.g., in acute care hospitals). More details about the study design and protocol have been published[9].

Setting and participants

Several types of long-term care facilities can be distinguished within the six countries, depending on whether care by specific health care professionals is provided on-site or off-site (see Table 1)[6,9]. Type 1 includes facilities with 24 hour care from on-site physicians, nurses and care assistants, type 2 are facilities with 24 hour care from on-site nurses and care assistants and care from physicians who are based off-site and type 3 consists of facilities with 24 hour on-site care from care assistants and care from nurses and physicians who are based off-site. For each identified deceased resident, structured questionnaires were sent to the facility administrator/manager, the nursing staff member most involved in care (preferably a nurse) and the treating physician (TP; a general practitioner, elderly care physician or physician employed in the facility). For each participating facility, the administrator/manager was also asked to fill out a questionnaire on facility characteristics.

Data collection

The long-term care facilities that were sampled in each country received a letter introducing the PACE project and asking for voluntary participation. Additional contact was made by phone or e-mail. Each participating facility appointed a contact person and was visited by a researcher. During this visit, the contact person listed all residents who had died in the preceding three months and identified three key respondents for each deceased resident (facility administrator/manager, nursing staff member, treating physician) with the use of a structured checklist. Questionnaires were sent to the key respondents and up to two reminders were sent to non-responders (after three and six weeks). To ensure high-quality data collection, researchers in all countries were trained to follow a quality assurance manual designed for this project.

Measurements

After-death questionnaires included validated instruments and were forward-backward translated according to European Organization for Research and Treatment of Cancer guidelines[11] in cases where official translations did not exist.

The questionnaire for the facility administrator/manager included questions about the resident's age, sex, residency before admission, length of stay, placement in ward or unit for residents with dementia at the time of death, place and cause of death, ownership (public, private-nonprofit or private-profit) and size of the facility.

The questionnaire for the nursing staff member included questions about the presence of dementia at the time of death in the staff member's opinion, the clinical complications during the last month of life (pneumonia, febrile episode, eating or drinking problem, hip fracture, stroke, gastrointestinal bleeding) and the functional and cognitive status of the resident one month before death. The Bedford Alzheimer Nursing Severity Scale (BANS-S)[12], the Global Deterioration Scale (GDS) stage 7 yes/no[13] and the Cognitive Performance Scale (CPS)[14] were used. The GDS classifies dementia into seven stages based on cognition and function: Stage 7 is described as very severe cognitive decline with minimal to no verbal communication, assistance needed with toileting and feeding, incontinence and loss of basic psychomotor skills. The CPS assigns residents to cognitive performance categories, ranging from borderline intact to very severe impairment.

The questionnaire for the treating physician included questions on the presence of dementia and other diseases at the time of death in the physician's opinion (malignant cancer, severe cardiovascular disease, cerebrovascular accident, severe pulmonary disease, severe neurological disease, severe renal disease, severe diabetes, other severe disease) and the presence of multimorbidity (counting the number of diseases at time of death from the eight diseases listed above).

Statistical analysis

All analyses were performed with SPSS 23. Preliminary analyses included creating a variable for dementia that does not underestimate its prevalence. When either the physician or the nurse (or both) considered the resident to have dementia, this was coded as 'yes'. Stage of dementia was based on the CPS and GDS scores, as answered by nursing staff, after selecting residents with dementia: $CPS \geq 5$ and $GDS = 7$ was classified as 'very severe or advanced dementia', $CPS \geq 5$ and $GDS < 7$ or $CPS \leq 5$ and $GDS = 7$ as 'severe dementia', $CPS \leq 5$ and $GDS < 7$ as 'moderate or mild dementia'[15].

All primary analyses had to account for the clustering of the data (in countries, facilities and physicians or nurses), thus a multilevel model was created for each analysis. Depending on the outcome or target variable (continuous, binary or categorical), generalized linear mixed models were designed with a normal, binomial or multinomial distribution. Country was included as a fixed effect in each model in order to test for differences between the six countries. The alpha level of α=0.05 defines statistical significance. Facility was included as a random effect in each model. For variables that were based on questions answered by physicians or nursing staff, either physician or nursing staff member was added as a random effect. Significance of random effects are not reported as this is not the main focus of this paper.

Because countries, except for Belgium and Finland, had different facility types, we additionally conducted multilevel models per country for each analysis with facility type used as a fixed effect.

Ethical aspects

The study protocol was approved by the relevant ethics committee in 2015 in each country or waivers for the collection of data of deceased residents were obtained (the Netherlands and Italy). Participation was completely anonymous and voluntary.

Results

In total in the six countries, 322 long-term care facilities participated. Participating facilities identified 1707 residents who had died within the previous three months. Average response rates to the questionnaires for facility manager/administrators were 95.7% (Belgium 94.2%, the Netherlands 90.6%, England 96.4%, Finland 98.6%, Italy 96.5%, Poland 98.9%), for nursing staff 81.6% (Belgium 85.1%, the Netherlands 67.5%, England 54.2%, Finland 95.1%, Italy 91.7%, Poland 87.4%) and for treating physicians 68.3% (Belgium 66.9%, the Netherlands 63.1%, England 23.8%, Finland 80.2%, Italy 88.4%, Poland 75.6%). Figure 1 provides an overview of the total numbers of questionnaires in six countries that were distributed and returned per respondent. The final sample of interest accounting for all missing information was 1384 deceased residents.

Non-response analysis

Using data provided by the facility administration, non-response analysis showed no differences for important demographic characteristics of the residents (age, sex, length of stay, place of death) between participating and non-participating nursing staff (data not shown). Between participating and non-participating physicians, non-response analysis showed similar results except for place of death ($p=0.04$). The physicians more often participated in cases where the resident died in the facility than when they died outside the facility.

Demographic and facility stay characteristics of dying facility residents

The mean age of the residents at the time of death was over 85 years except for those in Poland where it was 81. (Table 2). About 2/3 of the residents were female (63.5% to 75.0%) with no significant differences between countries. Most residents studied lived in a facility with on-site care from nurses and care assistants but off-site care from physicians. In the Netherlands and Poland however, most lived in a facility with on-site care from physicians, nurses and care assistants ($p<0.001$). The facilities in which they lived also differed in size from an average of 41 beds in Finland and England to 126 beds in Belgium ($p<0.001$). They also differed in type of ownership ($p<0.001$); in most countries, the largest proportion of residents lived in public non-profit facilities, except for Italy and England where more stayed in private for-profit facilities (41.8% and 86.8% respectively). Most of the residents were admitted to the facility from their own home (30.0% to 57.9%) and a large proportion from a hospital (25.9% to 34.2%) except in the Netherlands and Italy where fewer residents were admitted from hospital (8.8% in the Netherlands and 16.8% in Italy; $p<0.001$). The median length of stay in the facility ranged from less than six months in Poland to over two years in Belgium ($p<0.05$). At the time of death, most residents were not living in a ward or unit specifically designed for residents with dementia. The largest proportion of residents who did stay in a dementia ward was found in the Netherlands (47.5%) and the smallest proportion in Poland (18.4%). Between 80% of the residents in Poland and 90% of the residents in the Netherlands died in the facility and no significant differences were found between the countries regarding place of death.

Clinical characteristics

In all 6 countries, more than 60% of the residents had dementia at the time of death according to their treating physician and/or nurse (Table 3). However, there was a significant difference between countries ($p<0.001$) with the prevalence of dementia ranging from 60.2% in England to 82.5% in Finland. Among residents who died with dementia, no statistical difference between the countries was found for the stage of dementia 1 month before death. More than half of these had very severe or advanced dementia shortly before death in Poland (64.0%), Italy (55.0%) and Belgium (52.5%).

Other than dementia, the most prevalent disease at the time of death was severe cardiovascular disease in all countries (30.8%-55.7% of residents) except England (9.5%) ($p<0.001$), where nearly half of the residents had cancer (42.9%). For cerebrovascular accidents, severe neurological disease, severe renal disease and severe diabetes no significant differences between countries were found. Most of the residents had 2 or more morbidities at the time of death (52.4% to 74.2%), except in the Netherlands (47.3%), but no significant difference was found between countries.

One month before death, residents in Italy and Poland had the poorest functional and cognitive status (BANS-S mean score of 21.8 and 21.9 respectively; $p<0.001$) (Table 3).

Clinical complications during the last month of life occurred very often in residents in long-term care facilities in all countries. These mostly consisted of eating or drinking problems (51.9% England, 66.4% Finland and Poland, no significant difference) (Table 3). The proportion of people, according to the nurse, who had pneumonia during the last month of life varied between 21.2% in Poland and 37.7% in the Netherlands ($p<0.01$). Febrile episodes other than pneumonia occurred in the last month of life most often in Italy (52.4%). Other clinical complications during the last month (hip fracture, stroke, gastrointestinal bleeding and other) varied between 24.2% in Finland and 41.8% in England ($p<0.05$).

Differences between types of long-term care facilities within countries

In England, we found no differences in resident characteristics between types of facility. In Italy, having more than 2 morbidities occurred more often in type 2 facilities (84.9%), no other differences were found. Table 4 displays the differences between facility types for the Netherlands and Poland.

In the Netherlands, type 1 facilities were larger than type 2 facilities (mean 149 and 95 beds respectively; $p<0.05$), they had a higher percentage of residents with dementia (72.2% and 45.7% respectively; $p<0.01$) and poorer functional and cognitive status ($p<0.05$). In type 2 facilities, residents were more often admitted from their own home ($p<0.05$) and stayed less often in a dementia ward ($p<0.05$).

In Poland, type 1 facilities were smaller than type 2 (mean 56 and 104 beds respectively; $p<0.001$), the length of stay was considerably shorter (median length of stay 60 and 1007 days respectively; $p<0.001$) due to a difference in admission criteria and the functional and cognitive status of residents was poorer (BANS-S $p<0.001$). Also, residents of type 1 facilities were more often admitted from a hospital while those in type 2 facilities were more often admitted from their own home ($p<0.001$) and almost all residents died in the facility (93.5%) while in type 2 facilities residents more often had another place of death (39.7%) such as the hospital ($p<0.001$).

Discussion

We found that residents of long-term care facilities currently die at a very old age, on average around 85 years, except in Poland where the mean age of death is 81. Between 80% of the residents in Poland and 90% of the residents in the Netherlands die in the facility. A large proportion of the residents (47%-74%) have multiple comorbidities at the end of life and at least 60% have a diagnosis of dementia, often at a very severe or advanced stage. Clinical complications during the last month are frequent and consist mainly of eating or drinking problems (51.9% England; 66.4% Finland and Poland). The average length of stay is relatively short in all countries and varies between six months in Poland and Italy and two years in Belgium. The highest percentages of residents with poor cognitive and functional status one month before death are found in Poland and Italy, where residents also have the shortest length of stay.

This study has several strengths. Firstly, it is the first large-scale study to describe and compare demographic and clinical characteristics of deceased residents of long-term care facilities across six European countries. In Italy and Poland this is the first time that nationally representative data have been collected in such facilities. We were able to include 1384 people from 322 facilities in six countries, providing cross-country comparable data and giving policy- and decision-makers insight into the key international and national challenges facing the long-term care facility population. Secondly, this study provides an excellent starting point for monitoring changes over time. Thirdly, response rates from all countries were high except in England and non-response analysis shows minimal indication of bias. However, the low numbers of residents included in England contribute to statistical uncertainty for this country. Finally, the use of different proxy respondents allowed for collection of data for many characteristics of the same group of deceased residents.

This study also has some limitations. Firstly, the risk of highly achieving facilities or those with a special interest in palliative care being more prone to participate cannot be excluded. However, due to the proportional stratified random sampling procedure, a nationally (or regionally in the UK and Belgium) representative sample of long-term care facilities in terms of region/province and facility size was achieved. Secondly, the possibility of recall bias cannot be excluded because of the retrospective character of the study. As only deaths from the three previous months were included, memory bias is likely to be minimal. Finally, it should be noted that our measure for multimorbidity is based on a predefined list of severe diseases, which explains why the proportion found in our study is lower than in other studies[3].

We found that the large majority of residents of long-term care facilities are female (table 2). This is not a surprising finding given that females generally live longer[16]. This is also likely a feature of them having been widowed and alone for some time, or having no one able to care for them at home (e.g. death of spouse, high age or frailty of spouse, no tradition for informal care). With population ageing and people having to work longer, it is likely that older women will increasingly die in nursing homes, unless greater home support is available.

The length of stay can be considered short in all six countries and is shorter now in Belgium and the UK than it was a few years ago[17-18] (there are no comparable data available for the other countries). The length of stay is particularly short in Poland and Italy where there is a lower number of beds available in long-term care facilities than in the other countries in our study[19], implying that potential residents have to wait longer to be accommodated. Another reason for later admissions in these countries might be the stronger tradition of informal instead of formal care[20-21]. The short length of stay found in this study confirms that long-term care facilities are more and more becoming places where people go to live at the very end of their lives when they are highly dependent and have complex health problems. Policy in many countries indeed aims to keep older people at home as long as possible i.e. until they reach very high levels of disability[22]. Given the short length of stay, almost all residents of these facilities can be considered to be at the end of life, making palliative care the most appropriate care approach for this population. Policies supporting these facilities to integrate a palliative care approach may bring substantial benefit to the sector.

It is vital to recognize the complexity and intensity of care that is required, especially in countries like Poland and Italy. Not only is the median length of stay extremely short in these countries (as short as 60 days in type 1 facilities in Poland), making the delivery of high-quality palliative and end-of-life care more challenging[23], but we also found the highest levels of cognitive and functional impairment as well as very high levels of advanced dementia among the residents at the time of death. At the same time, another study based on data from the PACE project shows that palliative care knowledge among Polish and Italian nurses and care assistants working in long-term care facilities is deficient[24]. There is also evidence that the integration of palliative care in long-term care facilities in Poland and Italy is minimal if not non-existent, especially compared with countries like the UK, the Netherlands and Belgium[7]. National policies focusing on enhancing palliative care development in long-term care facilities are particularly needed in Poland and Italy to ensure optimal levels of care.

The results of our study are in line with recent findings in the literature on the rise of chronic diseases[25] and increasingly complex care needs among residents of long-term care facilities[26-27]. We found that a large proportion of residents have multiple morbidities, many have considerable cognitive and functional impairment in the last month of life (reflected in high levels of dependency as shown by mean BANS-S scores ranging from 17.5 in the UK to 21.9 in Poland), and at least 60% die with dementia (table 3). This has huge implications for the care that they need. Caring for residents at the end of life entails a high burden of care for the nurses and care assistants working in this setting, and places extremely high demands on their knowledge, confidence and skills in providing palliative care[28-29]. The quality of care is thus highly contingent on staff and is a major concern of long-term care facilities[30]. Giving rising costs and demand, understanding how to meet the increasingly complex needs of residents efficiently, and determining and providing the appropriate numbers and type of staff (skill mix) and the education and training in palliative care that they need should be a high public health priority. Inadequate skill mix in staff has been linked to low-quality care[30]. Research therefore needs to investigate which staff skills contribute to high-quality palliative care. This study highlighted various complex health problems of nursing home residents (dementia, comorbidities, eating and drinking problems and poor cognitive and functional status). Education of nursing home staff should focus on learning skills to handle these health problems. Finally, given that so many residents suffer from dementia at the time of death, we also recommend that policies addressing this sector highlight the need for the integration of high-quality palliative care together with high-quality dementia care, enabling long-term care facilities to become centers of excellence in dementia end-of-life care.

Conclusion

Although there are important country differences, the population currently living and dying in long-term care facilities is very complex, displaying multiple diseases with considerable cognitive and functional impairment and high levels of dementia. Given the complex care needs of long-term care facility residents, palliative care is the most appropriate care approach for this population and education of nursing staff should include learning skills to meet these needs. Since many residents also suffer from advanced dementia at the time of death, we recommend that policies addressing this sector highlight the need for the integration of high-quality palliative care together with high-quality dementia care. This study is an excellent starting point for monitoring populations of people who die in long-term care facilities. The current challenges of dying in such facilities need adequate policy and practice responses as soon as possible.

Abbreviations

BANS-S: The Bedford Alzheimer Nursing Severity - Scale
GDS: Global Deterioration Scale

CPS: Cognitive Performance Scale

PACE : Palliative Care for Older People in Europe

Declarations

Ethics approval and consent to participate

Ethics approval from the relevant ethics committees were obtained in all participating countries. Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: NHS – NRES Committee North West-Haydock, 10/09/2015; Finland: Terveyden jahyvinvoinnin laitos, Institutet för hälsa och välfärd, 30/6/2015; Italy: Comitato Etico, Universita Cattolica del Sacro Cuore, 6/11/2017; Netherlands: Medisch Ethische Toetsingscommissie VUMedisch Centrum, 2/7/2015; Poland: Komisja Bioetycza, Uniwersytetu Jagiellonskiego, 25/6/2015; Switzerland: Commission cantonale d'éthique de la recherché scientifique de Genève (CCER), 6/8/2015.

All persons participating in the study (facility managers, care staff, GPs) have to give their prior informed consent in writing. If participants are unable to give informed consent, they will not be involved in the study. In some countries, a separate informed consent from individual participants is not required if questionnaires are filled in anonymously: for the Netherlands, the Medical Ethics Review Committee concluded that this study does not fall under the Medical Research Involving Human Subjects Act (WMO). In accordance with the Dutch code for good practice in biomedical research, a separate informed consent was not needed. The Polish Ethical Committee stated no separate informed consents were needed given the study design protected anonymous answering of individual respondents. Returning the questionnaire was regarded as consent to participate in the study.

Consent for publication

Not applicable.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Project has been co-funded by Polish Ministry of Science and Higher Education in the years 2014-2019 based on the decision no 3202/7PR/2014/2 dated on Nov. 25th, 2014. This work was supported by the European Union's Seventh Framework Programme (FP7/ 2007e2013) under grant agreement 603111 (PACE project Palliative Care for Older People). The funders had no role in study design, collection, analysis or interpretation of the data, nor in writing and the decision to submit this article for publication.

Authors' contributions

NVD, TS, NVDN, BDOP, KF, KS, MK, GG, LD and LVDB were involved in the study design. NVD, TS, NVDN, BDOP, KS, KF, MK, GG, LD and LVDB are involved in data acquisition. EH, NVD, TS, LVDB, RP, and LD were involved in developing the data analysis plan. EH, NVD, TS, NVDN, BDOP, KS, KF, MK, GG, LD and LVDB were involved in writing of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

Other PACE collaborators not in the list: Yuliana Gatsolaeva, Rose Miranda, Lara Pivodic, Marc Tanghe, Hein van Hout, Roeline H. R. W. Pasman, Mariska Oosterveld-Vlug, Ruth Piers, Anne B. Wichmann, Yvonne Engels, Myrra Vernooij-Dassen, Jo Hockley, Sheila Payne, Suvi Leppäaho, Ilona Barańska, Sophie Pautex, Catherine Bassal, Federica Mammarella, Martina Mercuri, Paola Rossi, Ivan Segat, Agata Stodolska, Eddy Adang, Paula Andreasen, Outi Kuitunen-Kaija, Danni Collingridge Moore, Agnieszka Pac, Violetta Kijowska, Maud ten Koppel, Jenny T. van der Steen, Emilie Morgan de Paula, and the European Association for Palliative Care vzw, European Forum For Primary Care, Age Platform Europe, and Alzheimer Europe.

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Table 1: Available types of facilities in six countries

Country	**Type 1** facilities with on-site physicians, nurses and care assistants	**Type 2** facilities with on-site nurses and care assistants and off-site physicians	**Type 3** facilities with on-site care assistants and off-site nurses and physicians
Belgium		X	
The Netherlands	X	X	
The United Kingdom		X	X
Finland		X	
Italy	X	X	
Poland	X	X	

Table 2: Demographic and Facility Stay Characteristics of Dying Facility Residents in Six European countries: (N=1384)

	BE N=291 N(%)	NL N=222 N(%)	UK N=91 N(%)	FI N=269 N(%)	IT N=200 N(%)	PL N=311 N(%)	P-value*
Age - yr†							
Mean (SD) years old at time of death	87 (7)	86 (9)	87 (9)	85 (9)	86 (8)	81 (11)	**<0.001**
Sex†							
Female	174 (64.0)	132 (66.7)	66 (75.0)	169 (64.3)	136 (68.3)	195 (63.5)	0.387
Male	98 (36.0)	66 (33.3)	22 (25.0)	94 (35.7)	63 (31.7)	112 (36.5)	
Type of ownership of facility†							
Public-nonprofit	135 (48.9)	211 (100.0)	2 (2.2)	211 (80.2)	66 (34.9)	201 (65.0)	**<0.001**
Private-nonprofit	124 (44.9)	NA	10 (11.0)	24 (9.1)	44 (23.3)	104 (33.7)	
Private-profit	17 (6.2)	NA	79 (86.8)	28 (10.6)	79 (41.8)	4 (1.3)	
Size of facility†							
Mean (SD) number of beds	126 (50)	124 (64)	41 (23)	41 (30)	101 (50)	72 (41)	**<0.001**
Residency before admission to facility†							
Own home (living alone or with family or others)	100 (41.8)	99 (57.9)	43 (50.6)	77 (30.0)	95 (49.7)	153 (49.8)	**<0.001**
General hospital (e.g. acute care hospital)							
Other facility	76 (31.8)	15 (8.8)	22 (25.9)	85 (33.1)	32 (16.8)	105 (34.2)	
Other residency (e.g. psychiatric or	32 (13.4)	32 (18.7)	18 (21.2)	72 (28.0)	32 (16.8)	35 (11.4)	
rehabilitation hospital)	31 (13.0)	14.6)	2 (2.4)	23 (8.9)	32 (16.8)	14 (4.6)	
Length of stay†							
Median (min-max) number of days	745 (2-9706)	710 (1-6290)	600 (2-4952)	581 (1-9218)	416 (2-10171)	145 (1-12365)	**<0.05**
Type of ward at time of death†							
Ward for residents with dementia	104 (38.1)	94 (47.5)	29 (33.3)	115 (43.7)	74 (37.9)	56 (18.4)	
Ward not specifically for dementia	169 (61.9)	104 (52.5)	58 (66.7)	148 (56.3)	121 (62.1)	249 (81.6)	**<0.01**
Place of Death†							
Facility	226 (82.2)	176 (89.3)	71 (81.6)	224 (84.8)	170 (86.7)	248 (80.0)	0.922
Other (e.g. hospital)	49 (17.8)	21 (10.7)	16 (18.4)	40 (15.2)	26 (13.3)	62 (20.0)	

* Generalized linear mixed model reporting p-value for country as a fixed effect, α =0.05. Values in bold represent significant values.

† Reported by administrator/manager of facility. For 44 out of 1,384 residents no questionnaire was returned by the administrator/manager of facility; these are not included as missing values below. Missing values age=13, sex=13, type=0, ownership=6 size=60, admission from=145, length of stay=36, type of ward dementia=19, place of death=11. Percentages may not always add up to 100 because of rounding.

Table 3: Clinical Characteristics of Dying Facility Residents in Six European Countries (N=1384)

	BE N=291 N(%)	NL N=222 N(%)	UK N=91 N(%)	FI N=269 N(%)	IT N=200 N(%)	PL N=311 N(%)	P-value*
Dementia at time of death (yes)†‡ §	183 (62.9)	135 (61.4)	53 (60.2)	222 (82.5)	154 (77.0)	207 (67.9)	**<0.001**
Stage of Dementia (based on CPS/GDS||) †‡							
Moderate or mild dementia	27 (17.1)	29 (22.3)	13 (31.0)	43 (24.2)	14 (11.7)	17 (11.3)	0.676
Severe dementia	48 (30.4)	41 (31.5)	11 (26.2)	57 (32.0)	40 (33.3)	37 (24.7)	
Very severe or advanced dementia	83 (52.5)	60 (46.2)	18 (42.9)	78 (43.8)	66 (55.0)	96 (64.0)	
Diseases at time of death‡¶							
Malignant cancer‡	30 (15.5)	27 (18.5)	9 (42.9)	41 (19.4)	26 (17.2)	10 (4.0)	**<0.001**
Severe cardiovascular disease‡	67 (34.7)	45 (30.8)	2 (9.5)	79 (37.4)	71 (47.0)	141 (55.7)	**<0.05**
Cerebrovascular accident (CVA)‡	40 (20.7)	25 (17.1)	3 (14.3)	49 (23.2)	34 (22.5)	70 (27.7)	0.483
Severe pulmonary disease‡	33 (17.1)	17 (11.6)	3 (14.3)	17 (8.1)	40 (26.5)	18 (7.1)	**<0.001**
Severe neurological disease (not dementia)‡	15 (7.8)	11 (7.5)	0 (0.0)	26 (12.3)	18 (11.9)	32 (12.6)	0.381
Severe renal disease‡	19 (9.8)	19 (13.0)	2 (9.5)	13 (6.2)	22 (14.6)	29 (11.5)	0.420
Severe diabetes‡	11 (5.7)	17 (11.6)	1 (4.8)	16 (7.6)	18 (11.9)	33 (13.0)	0.177
Other severe disease‡	31 (16.1)	4 (2.7)	3 (14.3)	51 (24.2)	33 (21.9)	33 (13.0)	**<0.001**
Multimorbidities at time of death‡							
0-1 long-term conditions	94 (48.7)	77 (52.7)	10 (47.6)	72 (34.1)	39 (25.8)	98 (38.7)	0.268
2 multimorbidities	54 (28.0)	40 (27.4)	8 (38.1)	68 (32.2)	52 (34.4)	102 (40.3)	
3 multimorbidities	30 (15.5)	25 (17.1)	2 (9.5)	49 (23.2)	37 (24.5)	40 (15.8)	
4 or more multimorbidities	15 (7.8)	4 (2.7)	1 (4.8)	22 (10.4)	23 (15.2)	13 (5.1)	
Functional/cognitive status one month before death (BANS-S)†** Mean (SD)	18.5 (4.9)	17.7 (4.7)	17.5 (4.2)	19.6 (4.3)	21.8 (3.7)	21.9 (4.6)	**<0.001**

	BE N=291 N(%)	NL N=222 N(%)	UK N=91 N(%)	FI N=269 N(%)	IT N=200 N(%)	PL N=311 N(%)	P-value*
Cognitive Performance Scale one month before death†°							
(Borderline) Intact (score 0-1)	75 (28.0)	42 (20.5)	17 (23.3)	23 (9.4)	16 (9.9)	72 (11.6)	**<0.01**
Mild to moderate impairment (score 2-3)	55 (20.5)	58 (28.2)	21 (28.7)	56 (22.9)	27 (16.7)	37 (15.9)	
Moderately severe to very severe impairment (score 4-6)	138 (51.5)	105 (51.2)	35 (47.9)	165 (67.5)	118 (73.3)	169 (72.5)	
Global Deterioration Scale Stage 7 one month before death†^	155 (57.8)	104 (47.5)	40 (50.6)	111 (48.3)	124 (66.0)	208 (73.2)	**<0.001**
Clinical complications during last month of life†¶							
Pneumonia†	64 (24.2)	75 (37.7)	16 (21.6)	76 (31.4)	45 (25.3)	62 (21.2)	**<0.01**
Febrile episode (not pneumonia) †	118 (44.2)	36 (18.4)	4 (5.4)	78 (31.1)	98 (52.4)	136 (46.6)	**<0.001**
Eating or drinking problem†	179 (65.3)	125 (60.4)	41 (51.9)	170 (66.4)	113 (60.8)	198 (66.4)	0.237
Other clinical complications (e.g. stroke)†	96 (33.0)	81 (36.5)	38 (41.8)	65 (24.2)	81 (36.5)	113 (36.3)	**<0.05**

* Generalized linear mixed model reporting p-value for country as a fixed effect, α =0.05. Values in bold represent significant values.
† Reported by staff member (nurse/care assistant) most involved in care
‡ Reported by treating physician (TP) For 397 out of 1,384 residents no questionnaire was returned by the TP, these are not included as missing values below.
§ When either the physician or the nurse (or both) considered the resident to have dementia, this was coded as yes.
||The variable stage of dementia was based on the scores on the CPS and GDS, as answered by nursing staff, after selecting residents with dementia (18).
¶ Multiple answers possible.
** Scores on BANS-S range from 7 to 28; higher scores indicate greater severity.
°Scores on CPS range from 0 to 6; higher scores indicate greater severity.
^Scores on GDS range from 0 to 6; higher scores indicate greater severity.

Percentages may not always add up to 100 because of rounding.
Missing values: dementia=11, stage of dementia=187 (419 not applicable because resident did not have dementia), diseases at time of death=12, multimorbidities=12, BANS-S=86 missing data on at least one item, CPS=182 (and 18 not applicable), GDS7=116, clinical complications=81.
Abbreviations: CPS Cognitive Performance Scale, GDS Global Deterioration Scale, BANS-S Bedford Alzheimer Nursing Severity Scale.

Table 4: Differences in characteristics of dying facility residents by facility type within countries (N=824)

	The Netherlands N=222 N(%)		**Poland** N=311 N(%)	
By facility type*	**Type 1** N=117	**Type 2** N=94	**Type 1** N=184	**Type 2** N=127
Residency before admission to facility†				
Own home (living alone or with family or others)	38 (43.2)	57 (73.1)	77 (42.3)	76 (60.8)
General hospital (e.g. acute care hospital)	11 (12.5)	3 (3.8)	93 (51.1)	12 (9.6)
Other facility	20 (22.7)	12 (15.4)	9 (4.9)	26 (20.8)
Other residency (e.g. psychiatric or rehabilitation hospital)	19 (21.6)	6 (7.7)	3 (1.6)	11 (8.8)
P-value‡	**<0.05**		**<0.001**	
Length of stay†				
Median (min-max) number of days	710 (1-5485)	980 (1-6290)	60 (1-4438)	1007 (3-12365)
P-value‡	0.742		**<0.001**	
Type of ward at time of death†				
Ward for residents with dementia	64 (59.3)	28 (32.9)	48 (26.2)	8 (6.6)
Ward not specifically for dementia	44 (40.7)	57 (67.1)	135 (73.8)	114 (93.4)
P-value‡	**<0.05**		0.160	
Place of Death†				
Facility	104 (95.4)	67 (80.7)	172 (93.5)	76 (60.3)
Other (e.g. hospital)	5 (4.6)	16 (19.3)	12 (6.5)	50 (39.7)
P-value‡	0.053		**<0.001**	
Dementia (yes) §||¶	83 (72.2)	43 (45.7)	119 (66.1)	88 (70.4)
P-value‡	**<0.01**		0.727	
Stage of Dementia (based on CPS/GDS) §||°**				
Moderate or mild dementia	17 (21.8)	10 (23.3)	3 (3.6)	14 (21.2)
Severe dementia	21 (26.9)	16 (37.2)	23 (27.4)	14 (21.2)
Very severe or advanced dementia	40 (51.3)	17 (39.5)	58 (69.0)	38 (57.6)
P-value‡	0.415		**<0.05**	
Diseases at time of death||††				
Cancer||	11 (13.1)	13 (23.6)	2 (1.2)	8 (9.9)
P-value‡	0.168		**<0.05**	
Diseases at time of death||††				
Cardiovascular disease (not CVA) ||	25 (29.8)	19 (34.5)	88 (51.2)	53 (65.4)
P-value‡	0.533		0.160	
Multimorbidities||				
0-1 multimorbidities	46 (54.8)	29 (52.7)	75 (43.6)	23 (28.4)
2 multimorbidities	22 (26.2)	15 (27.3)	71 (41.3)	31 (38.3)
3 multimorbidities	13 (15.5)	11 (20.0)	21 (12.2)	19 (23.5)
4 or more multimorbidities	3 (3.6)	0 (0.0)	5 (2.9)	8 (9.9)
P-value‡	0.967		**<0.05**	
Functional/cognitive status (BANS-S) §‡‡				
Mean (SD)	18.3 (4.7)	16.7 (4.7)	22.9 (3.8)	20.2 (5.1)
P-value‡	**<0.05**		**<0.001**	
Global Deterioration Scale Stage §^	61 (52.1)	37 (40.7)	135 (80.8)	73 (62.4)
P-value‡	0.085		**<0.01**	

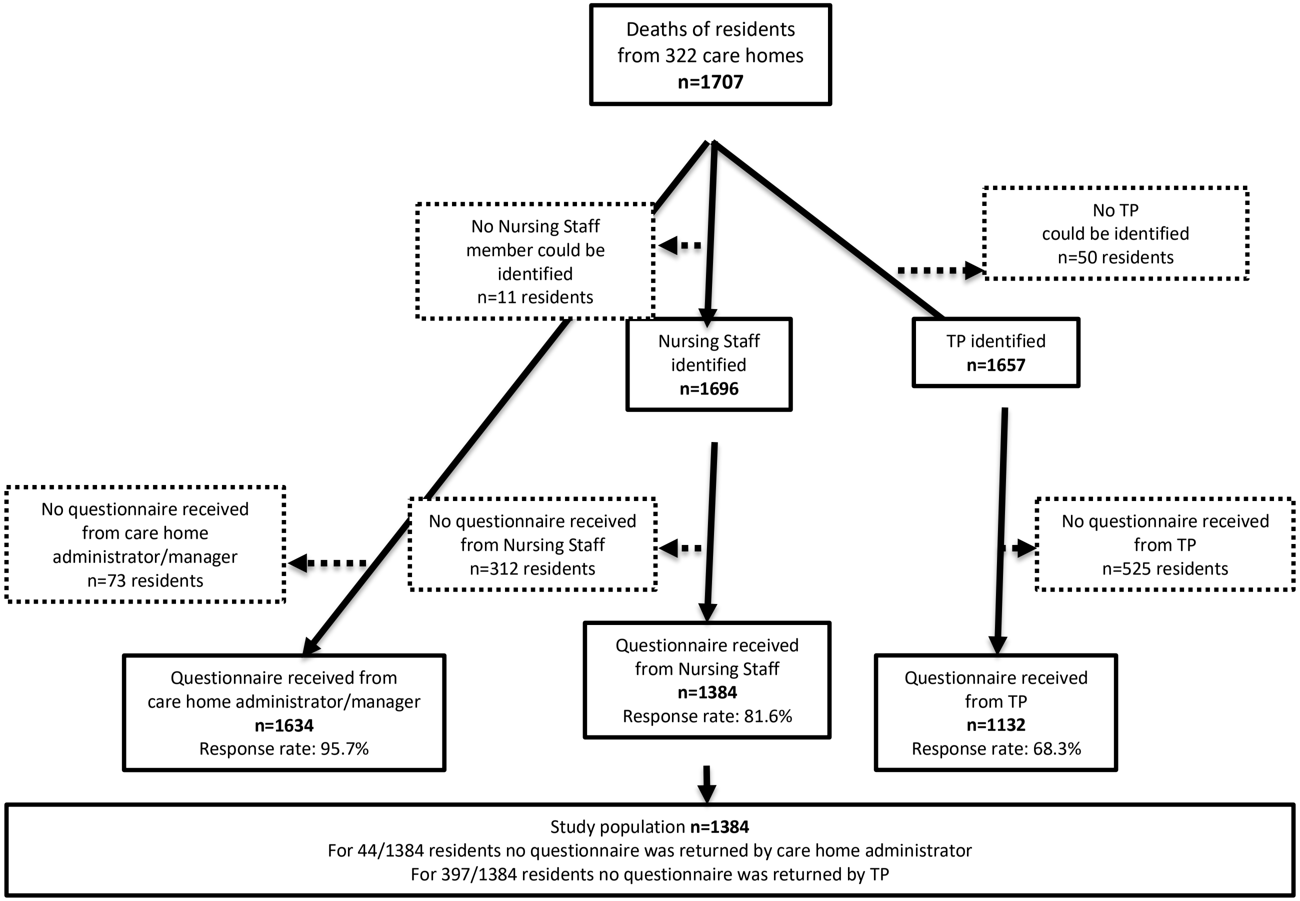
* Facility type: In this table only the Netherlands and Poland are reported, since Belgium and Finland only have type 2 facilities and almost no differences between facility types were found in England and Italy. Type 1 includes facilities with 24/7 on-site physicians, nurses and care assistants, type 2 are facilities with 24/7 on-site nurses and care assistants and off-site physicians and type 3 consists of facilities with 24/7 on-site care assistants and off-site nurses and physicians.
† Reported by administrator/manager of facility.

‡ Generalized linear mixed model per country reporting p-value for facility type as a fixed effect, α =0.05. Values in bold represent significant values.
§ Reported by staff member (nurse/care assistant) most involved in care
||Reported by treating physician (TP) For 397 out of 1,384 residents no questionnaire was returned by the TP, these are not included as missing values below.
¶ When either the physician or the nurse (or both) considered the resident to have dementia, this was coded as yes.
**The variable stage of dementia was based on the scores on the CPS and GDS, as answered by nursing staff, after selecting residents with dementia (18).
†† Multiple answers possible.
‡‡ Scores on BANS-S range from 7 to 28; higher scores indicate greater severity.
°Scores on CPS range from 0 to 6; higher scores indicate greater severity.
^Scores on GDS range from 0 to 6; higher scores indicate greater severity.

Percentages may not always add up to 100 because of rounding.

Missing values per country:
NL: Facility type=11, ownership=11 size=11, admission from=56, length of stay=31, type of ward dementia=29, place of death=30
dementia=13, stage of dementia=18 (83 not applicable because resident did not have dementia), diseases at time of death=83, multimorbidities=83.
BANS-S=21 GDS7=14
PL: Facility type=0, ownership=2 size=31, admission from=4, length of stay=4, type of ward dementia=6, place of death=1
dementia=6, stage of dementia=63 (98 not applicable because resident did not have dementia), diseases at time of death=58, multimorbidities=58.
BANS-S=28 GDS7=27

Note: Only variables for which we found a significant difference between facility types in at least one country are reported in this table. Variables for which analyses were conducted but no significant differences between facility types were found are age, gender, diseases at time of death: CVA, pulmonary disease, neurological disease, renal disease, diabetes, other severe disease, CPS and clinical complications: pneumonia, febrile episode, eating or drinking problem and other clinical complication.


Deaths of residents
from 322 care homes
n=1707
No Nursing Staff
member could be
identified
n=11 residents
Nursing Staff
identified
n=1696
TP identified
n=1657
No TP
could be identified
n=50 residents
No questionnaire received
from care home
administrator/manager
n=73 residents
No questionnaire received
from Nursing Staff
n=312 residents
No questionnaire received
from TP
n=525 residents
Questionnaire received from
care home administrator/manager
n=1634
Response rate: 95.7%
Questionnaire received
from Nursing Staff
n=1384
Response rate: 81.6%
Questionnaire received
from TP
n=1132
Response rate: 68.3%
Study population **n=1384**
For 44/1384 residents no questionnaire was returned by care home administrator
For 397/1384 residents no questionnaire was returned by TP

CHAPTER 2

AGREEMENT OF NURSING HOME STAFF WITH PALLIATIVE CARE PRINCIPLES: A PACE CROSS–SECTIONAL STUDY AMONG NURSES AND CARE ASSISTANTS IN FIVE EUROPEAN COUNTRIES

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Honinx E, Smets T, Piers R, et al. Agreement of Nursing Home Staff With Palliative Care Principles: A PACE Cross-sectional Study Among Nurses and Care Assistants in Five European Countries. Journal of Pain and Symptom Management. Published online July 2019. doi:10.1016/j.jpainsymman.2019.06.015

Abstract.

Context

To provide high-quality palliative care to nursing home residents, staff need to understand the basic principles of palliative care.

Objectives

To evaluate the extent of agreement with the basic principles of palliative care of nurses and care assistants working in nursing homes in five European countries, and to identify correlates.

Methods

Cross-sectional study in 214 homes in Belgium, England, Italy, the Netherlands and Poland. Agreement with basic principles of palliative care was measured with the Rotterdam MOVE2PC. We calculated percentages and odds ratios of agreement and an overall score between 0 (no agreement) and 5 (total agreement).

Results

Most staff in all countries agreed that palliative care involves more than pain treatment (58% Poland to 82% Belgium) and includes spiritual care (62% Italy to 76% Belgium) and care for family or relatives (56% Italy to 92% Belgium). Between 51% (Netherlands) and 64% (Belgium) correctly disagreed that palliative care should start in the last week of life and 24% (Belgium) to 53% (Poland) agreed that palliative care and intensive life-prolonging treatment can be combined. The overall agreement score ranged between 1.82 (Italy) and 3.36 (England). Older staff (0.26; 95% CI 0.09;0.43, p=0.003), nurses (0.59; 95% CI 0.43;0.75, p < 0.001), and staff who had undertaken palliative care training scored higher (0.21; 95% CI 0.08;0.34, p= 0.002).

Conclusions

The level of agreement of nursing home staff with basic principles of palliative care was only moderate and differed between countries. Efforts to improve the understanding of basic palliative care are needed.

Key Words: Palliative care, nursing homes, care homes, opinions, attitudes

Introduction

Over the past century, populations have aged; more and more people will die in older age, often after having lived with multiple chronic diseases and age-related disabilities for many years[1]. Numerous older people will move into nursing homes at some point and most of those who do will eventually die there[2]. Given the rise of chronic diseases and the increasingly complex care needs among residents of nursing homes[3-7], providing optimal palliative care in this setting is essential[2, 6-8]. Hence, nursing home staff need to be able to provide high-quality care to residents at the end of life.

Studies have shown however, that palliative care provided to nursing home residents is often inadequate, sometimes resulting in hospital transfers[9]. In a Norwegian study, up to 57% of residents were transferred to a hospital at the end of life[12]. According to a systematic review in 14 countries[13] transfers are mostly due to infections, trauma after falling and altered mental status. Otherwise, also social-structural factors such as care planning, staffing levels, lack of support and family expectations can contribute to hospital transfers[14-19]. An earlier PACE study indicated that the knowledge of end-of-life care of staff working in this setting is insufficient[17]; having adequate understanding of the principles and practices of end-of-life care and palliative care is indeed an important component of high-quality palliative care[16-19]. Studies in nursing homes demonstrated that better communication, understanding and teamwork of staff led to improved quality of care, including palliative care[9].

To help improving care, the World Health Organisation (WHO) definition of palliative care states that the skills, attitudes and competences of palliative care should be incorporated into general health care[11]. This means that staff in the nursing home setting need to be able to provide basic palliative care to residents at the end of life. This requires at least that they understand the basic principles of palliative care such as that it is applicable early in the course of a life-limiting illness, that it can be combined with life-prolonging treatments, that is holistic in nature including physical, emotional, spiritual and social aspects of care, and that it also includes care for those close to the patient[20].

Until now, it has been relatively unknown to what extent nurses and care assistants working in nursing homes in different European countries have a common understanding of these basic principles. Earlier studies in Greece, Spain and Australia assessed understanding of and attitudes towards palliative care principles using the Palliative Care Quiz for Nursing[21-23]. However, the current study is the first large-scale international study to describe and compare the extent to which staff in nursing homes in different European countries share a basic understanding of palliative care.

This study is part of the PACE (PAlliative Care for older people in care and homes in Europe) project, a European-funded project that compares palliative care in nursing homes in six European countries (Belgium, England, Italy, Finland, the Netherlands and Poland). These countries were selected to represent a diversity of geographic regions in Europe, comprising Southern, Western, Northern and Eastern Europe[24-25]. Another PACE-study conducted by Froggatt et al. showed that in England, Belgium and the Netherlands palliative care in the nursing homes is highly developed with a variety of initiatives on micro, meso and macro level, whereas, mainly in Finland and Italy, but also in Poland, palliative care development in nursing homes is limited. Also, there are few palliative care initiatives or nursing homes providing palliative care in these countries. The participating countries thus reflect different levels of development and implementation of palliative care in nursing homes, providing the optimal sample for an international comparative study[26-27]. We expect staff's understanding of the basic principles of palliative care to be insufficient and to differ between countries. We hypothesize that in countries with lower development of palliative care in nursing homes (Finland, Italy and Poland) staff less often agree with and understand the basic principles than staff in countries with higher levels of palliative care development (Belgium, the Netherlands and UK).

To test this hypothesis, the research questions of this paper are:

1) To what extent do nurses and care assistants working in nursing homes in the participating countries agree with the basic principles of palliative care?
2) Which country-, nursing home- and staff- related factors are associated with the level of agreement with the basic principles of palliative care?

Methods

Design and sampling

In 2015, a cross-sectional study among staff was conducted in nursing homes in five European countries: Belgium (Flanders), the Netherlands, England, Poland and Italy. Finland was eventually excluded from this article because in the Finnish questionnaires the term terminal care ('saattohoito') was used instead of palliative care. Even though terminal care is part of palliative care, this conceptual difference might lead to biased results. Nursing homes were selected using proportional stratified random sampling: stratified by region (province or large regions), then by bed capacity (higher or lower than the median number of beds in each country) and facility type. Subsequently, homes were sampled randomly and proportionally from each stratum, i.e. cluster sampling. If a nursing home did not want to participate, another home from the same stratum was sampled to ensure that the selected homes would be representative for the country. This method was based on publicly available lists of homes in each country. In Italy, no public lists are available and therefore a sample based on a previously constructed cluster of nursing homes, also used in earlier Italian studies like the EU SHELTER project, was used, covering all regions in Italy[24]. In England, the ENRICH research network for nursing homes was used to enhance recruitment[28].

Setting and participants

In this paper, the term nursing home refers to 'collective institutional settings where care, on-site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time'[8]. There were three types of nursing homes: type 1 with 24/7 on-site care from physicians and nurses/care assistants, type 2 with 24/7 on-site care from nurses/care assistants, but off-site from physicians, and type 3 with 24/7 on-site care from care assistants, and off-site care from nurses and physicians. Type 1 exists in Poland, Italy and the Netherlands, type 2 exists in all countries and type 3 only exists in England. In type 1 homes, dementia rates are higher, length of stay is shorter, and functional and cognitive status is poorer than in type 2 nursing homes[29]. The staff we surveyed consisted of care assistants and nurses. Care assistants provide direct personal care and work under supervision of a nurse in a team and are generally educated to a lower level than nurses[19].

Data collection

A letter introducing the PACE project and asking for voluntary participation was sent to the nursing homes. In each participating home, a contact person was appointed by the manager. This person listed all staff on duty at the time of the visit by a study researcher. The contact person distributed the paper questionnaires to these staff in a prestamped envelope together with an information leaflet, which mentioned that full anonymity was guaranteed by using unique anonymized number codes instead of names. It was also guaranteed that their answers would be treated in the strictest confidentiality not accessible by the homes, since the questionnaires were sent straight back to the researchers. The researchers registered the received questionnaires in an excel file and contacted each contact person to send up to two reminders to non-responding staff. The data collection is described in detail in the protocol of the PACE study[24]. The protocol was approved by the ethics committee in each country in 2015. In the Netherlands and Italy, no approval by an ethics committee was needed and waivers for the collection of data of deceased residents were obtained. A completed questionnaire was considered as valid informed consent.

Measurements

The following variables were used: age, gender, professional role (i.e. care assistant or nurse), having undertaken formal training in palliative care and nursing home type. Training included training in palliative care as part of the degree, additional training after the degree, or any other training in palliative care. Agreement with palliative care principles was measured by using a subscale of the validated Rotterdam MOVE2PC instrument[25,30]. The MOVE2PC (Assessment of Knowledge, and Opinions of Nurses Regarding to Palliative Care) is constructed to assess the opinions and knowledge of nurses and the perceived difficulties and educational needs regarding the provision of palliative care. It is a 66-item questionnaire, including 11 items on opinions. These are based on guidelines for palliative care in the Netherlands, which are in turn based on the WHO guidelines. Of these 11 items, five measure the extent to which nurses agree with the WHO definition of palliative care[30]. In our study, these five were used to measure the extent to which staff members of nursing homes agree with basic principles of palliative care: ‘the aim of palliative care is treatment of pain only’, ‘palliative care starts in the last weeks of life’, ‘palliative care and intensive life prolonging treatment can be combined’, ‘palliative care includes spiritual care and palliative care includes care for resident’s family/relatives’. Agreement with the principles was scored on a 3-point scale with anchors ‘disagree’, ‘neither agree nor disagree’ and ‘agree’. The MOVE2PC questionnaire was developed in the Netherlands. All items of the instrument were tested for validity regarding six measurement properties. It proved to be a valid instrument for assessing nurses’ knowledge and opinions related to palliative care[30]. For our study, we forward-backward translated the five items in all participating country languages according to EORTC guidelines with English as the source language[31]. For more details on the translation procedure, we refer to the protocol of the PACE study[24].

Statistical analyses

Multilevel models were used for the analyses because of the clustering of data in homes. To calculate the extent of agreement with each principle, the 3-point ordinal scale was converted into a 2-point dichotomous scale (‘agree with the principle’ and ‘disagree with the principle’) since we were primarily interested in staff with understanding of the principles. The neutral category ‘neither agree nor disagree’ was thus combined with the answer that was not consistent with the WHO definition, i.e. if expected to agree with a principle, the neutral answer was combined with ‘disagree’; if expected to disagree with a principle, the neutral answer was combined with ‘agree’. For each item, we accounted for the clustering at the level of nursing homes and adjusted for the following possible confounders: age, gender, professional role of the staff member and formal training. Country was entered as a fixed effect to detect differences in the extent of agreement between countries. Nursing home was entered as a random effect. Results on the extent of agreement are presented as percentages and odds ratios, based on the dichotomous scale, with Belgium as reference category.

Next, we calculated an overall score of agreement with the principles of palliative care. The individual principles were first scored 0 (disagreement or neither agree nor disagree) or 1 (agreement). Then, the scores on the five individual principles were summed. The total score of agreement ranged on a 5-point scale, between 0 and 5, with a higher score indicating more agreement with the principles.

To determine factors associated with a staff member's level of agreement (i.e. the overall score of agreement), we conducted a multiple linear mixed model analysis. Factors entered into the model were country, age, gender and professional role, formal training and type of nursing home. The associations between the overall score of agreement of staff and their characteristics were computed as estimated means. The statistical significance is presented by an alpha level of $p<0.05$. All analyses were performed with SPSS version 24.

Results

In 214 participating homes, 2719 staff members were identified and 1716 responded to the questionnaire (overall response rate 63.1%). Of these, 39.9% of the respondents were nurses and 60.1% were care assistants. Figure 1 shows the response rates per country.

Characteristics of the study sample

All characteristics, i.e. age, gender, professional role, formal training and nursing home type, differed significantly between the countries ($p<0.001$). In Belgium, England and Italy the age group 17-35 years was the largest (range between 40.4%-55.5%) (Table 1). Staff in the Netherlands and Poland were significantly older with the majority between 36 and 50 years (range between 38% - 52.9%). In all countries most of the participating staff were women, the percentage differed significantly among countries from a low of 67.3% in Italy to a high of 94.3% in the Netherlands. In Italy most of the responding staff were nurses (99.4%); in the other countries the majority were care assistants (between 53.1% and 85.8%). In most countries except England, a substantial proportion of the staff had undertaken formal training in palliative care (46.2% - 60.9%).

The extent to which staff agree with the basic principles of palliative care in the different countries

The overall score of agreement ranged between 3.36 in England and 1.82 in Italy (scale 0 to 5; table 2). Staff in Belgium, the Netherlands and Poland had overall scores of 2.91, 2.87 and 2.48 respectively.

In all countries except Italy the majority of the staff rightly disagreed that the aim of palliative care is treatment of pain only (table 2). The percentage of staff disagreeing with this statement varied from 58% in Poland to 82% in Belgium (OR: 0.12, 95% CI 0.07;0.19). Just over half of the staff in Belgium, England, Poland and Italy rightly disagreed that palliative care starts in the last weeks of life (51% – 64%). In the Netherlands only 46% disagreed with this statement (0R: 0.35, 95% CI 0.24;0.51). In all countries, the majority of staff agreed that palliative care includes spiritual care (62% – 76%, p=0.006) and that palliative care includes care for residents' family/relatives (56% – 92%, p<0.001). For these four statements, staff in Belgium showed a higher level of agreement with the palliative care principles than staff in in the other countries. With the exception of the staff in England (50%) and Poland (53%), only a minority agreed that palliative care and intensive life prolonging treatment can be combined (24% – 44%). For this statement, staff in Belgium showed the lowest level of agreement with the palliative care principles, resulting in a higher overall score for England than Belgium.

Characteristics associated with the overall score of agreement

Characteristics significantly associated with the overall score of agreement were country, professional role and formal training (Table 3). Compared with those in Belgium, staff in England more often agreed with the basic palliative care principles (estimated difference: 0.45; 95% CI 0.10; 0.81, p= 0.01), whereas staff in Poland and Italy agreed less often. No significant difference was found between Belgium and the Netherlands. Further, we found that nurses more often agreed with the basic palliative care principles than did care assistants (0.59; 95% CI 0.43;0.75, p < 0.001) and thus had higher overall scores of agreement.

Staff who had undertaken formal training were more likely to agree with the principles than those who had not (estimated difference 0.21; 95% CI 0.08;0.34, p= 0.002). Staff older than 35 years more often agreed as well (estimated difference: 0.26; 95% CI 0.09;0.43, p=0.003), also when aged between 36 and 50 years (estimated difference: 0.28; 95% CI -0.08;0.48, p=0.006). Gender and type of nursing home were not associated with agreement.

Discussion

Overall, we found large heterogeneity in the extent to which nursing home staff (nurses and care assistants) agreed with the basic principles of palliative care, but with room for improvement in all countries, especially in Italy and Poland. The level to which staff agreed with the principles was significantly associated with country, age, professional role and formal training, with older staff having a higher score of agreement than younger staff, as had nurses compared to care assistants and staff who had undertaken palliative care training compared to those who had not.

Although all countries had room to improve, the level of agreement varied greatly across countries. Staff in England more often agreed with the principles. Not surprising given that the UK ranked first in the 2015 Quality of Death Index and reached a top score in quality of palliative care globally[32]. On the other hand, the extent to which staff in Italy and Poland agreed with the principles was lower than in the other countries. This finding corroborates what was found in another PACE-study: staff working in nursing homes in these countries often lack basic knowledge of end-of-life care[17]. Froggatt et al. showed that in these countries, there are few initiatives on development of palliative care in nursing homes[26]. The extent to which nursing homes engage with palliative care initiatives and the degree of national investment in palliative care development in the nursing home setting seems to be related to the level of understanding of the basic principles of palliative care in nursing home staff.

Nevertheless, in the other countries a substantial number of staff also not completely agreed with the principles of palliative care, a finding in line with earlier studies[21-23]. This means that either they were not familiar with, or they disagreed with, the essence of palliative care. It is quite alarming that staff lack a basic level of understanding of palliative care, considering that nursing home residents spend the last months and years of their lives there and stays are becoming shorter also. The finding is in line with more general studies that found that among all types of health care professionals many are not familiar with the meaning and availability of palliative care[33-34]. Our study confirms that palliative care is in some cases (25%) still perceived as 'terminal care' (cfr. Table 4: Palliative care starts in the last week of life). Lack of understanding of the meaning of palliative care may have negative implications for the quality of care for residents with serious conditions receiving inadequate pain and symptom treatment and psycho-social support throughout their illness trajectory.

The fact that nurses agreed more often with the principles of palliative care than did care assistants is probably be due to the difference in education and expertise between the two groups. A previous PACE-paper showed that nurses have better knowledge of end-of-life care than care assistants[17]. In most countries, care assistants are responsible for direct patient care[19]. Considering budgetary constraints and shortage of personnel, this group will become more and more crucial in the future. Therefore, it is most important to train them in basic palliative care. Besides education, cultural diversity can play a role in the difference in agreement between nurses and care assistants, since cultural diversity can not only explain the difference between countries, but possibly also between professions. In the United states for example, many care assistants have a minority or immigrant background[35-36]. A cultural background influences end-of-life decision making and may result in inconsistency with values of traditional Western-based medicine[37].

Additionally, we found that staff who had undertaken training in palliative care more often agreed with the principles of palliative care than those who had not. Similar results were reported in earlier studies; taking part in training has a positive influence on the opinions of staff and a lack of training can lead to negative attitudes which can affect care outcomes[38-40]. Currently, effective palliative care training is not always included in curricula for nurses and care assistants[19]. Some training and online courses exist; however, these are often limited to certain communities[41-42]. Training elements shown to be most effective are a hands-on approach, innovative training strategies, managerial support and the use of role modelling[43-46]. More and better education and training is thus needed to promote the better understanding of palliative care and to encourage its timely use for nursing home residents. A second important strategy is to bring about a cultural shift regarding palliative care in nursing homes. Initiatives like the PACE Steps to Success Programme can contribute to making such a shift by integrating palliative care into mainstream care and can raise awareness of palliative care in nursing home staff[47].

Strength and limitations

This study has several strengths. Firstly, this is the first large-scale international study to describe and compare the extent to which nursing home staff across five European countries agree with the basic principles of palliative care. We were able to include 1716 staff members from 214 homes in five countries, providing cross-country comparable data. Secondly, this is the first international study that analyses the characteristics associated with the overall score of agreement. Thirdly, the overall response rate was 63.1%. For all countries except England (31.3%) the response rates were high, ranging from 51.7% to 93.2%.

This study also has some limitations. We must acknowledge that when speaking of levels of agreement, it is implied that people know something about the topic and agree or disagree with it. However, in this study it is also possible that staff might disagree with the principles of palliative care because of a lack of understanding. Second, staff who had undertaken formal training in palliative care might be more disposed to answer the questionnaire than those who did not, resulting in a possible response bias. Third, although response rates were high in most countries, the response rates were low in England (31.3%) and the Netherlands (51.7%), which might have caused bias. Finally, although multiple studies have linked staff attitudes to negative implications for the quality of care, it remains uncertain how attitudes regarding palliative care translate into actual care practices.

Conclusion

Given the rise of chronic diseases and complex care needs among nursing home residents, optimal palliative care in this setting is essential. To be able to provide high-quality palliative care to a growing number of nursing home residents, nursing home staff need to possess at least a basic level of understanding of palliative care. This study shows that the extent of agreement of nursing home staff with the basic principles of palliative care differs between countries, with room for improvement in all. For that reason, palliative care needs to become an integral part of all nursing school curricula and health care trainings, as well as of continuing education programme offerings. Also, a cultural shift regarding palliative care in nursing homes is needed.

Declarations

Disclosure Statement

Miss Honinx reports funding from Polish Ministry of Science and Higher Education based on the decision no 3202/7PR/2014/2, grants from European Union's Seventh Framework Programme (FP7/ 2007e2013), during the conduct of the study.

Ethics approval and consent to participate

Ethics approval from the relevant ethics committees were obtained in all participating countries. Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: NHS – NRES Committee North West-Haydock, 10/09/2015; Finland: Terveyden jahyvinvoinnin laitos, Institutet för hälsa och välfärd, 30/6/2015; Italy: Comitato Etico, Universita Cattolica del Sacro Cuore, 6/11/2017; Netherlands: Medisch Ethische Toetsingscommissie VUMedisch Centrum, 2/7/2015; Poland: Komisja Bioetycza, Uniwersytetu Jagiellonskiego, 25/6/2015; Switzerland: Commission cantonale d'éthique de la recherché scientifique de Genève (CCER), 6/8/2015.

All persons participating in the study (facility managers, care staff, GPs) have to give their prior informed consent in writing. If residents are unable to give informed consent, they will not be involved in the study. In some countries, such as Poland and the Netherlands, a separate informed consent is not required if questionnaires are filled in anonymously.

Consent for publication

Not applicable.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Project has been co-funded by Polish Ministry of Science and Higher Education in the years 2014-2019 based on the decision no 3202/7PR/2014/2 dated on Nov. 25th, 2014. This work was supported by the European Union's Seventh Framework Programme (FP7/ 2007e2013) under grant agreement 603111 (PACE project Palliative Care for Older People). The funders had no role in study design, collection, analysis or interpretation of the data, nor in writing and the decision to submit this article for publication.

Authors' contributions

EH, TS, RP, LD, SP, MK, IB, RP GG and LVDB were involved in the study design. TS, RP, LD, SP, MK, IB, RP GG and LVDB are involved in data acquisition. EH, TS, RP, LD, and LVDB were involved in developing the data analysis plan. EH, TS, RP, LD, SP, MK, IB, RP GG and LVDB were involved in writing of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

We thank all participating physicians, nurses, patients, and their families for providing data for this study; Roos Colman for her advice on data analysis; and Jane Ruthven for her language editing.

Other PACE collaborators not in the list: Yuliana Gatsolaeva, Rose Miranda, Lara Pivodic, Marc Tanghe, Hein van Hout, Nele Van Den Noortgate, Katherine Froggatt, Bregje Onwuteaka-Philipsen, Katarzyna Szczerbińska, Mariska Oosterveld-Vlug, Anne B. Wichmann, Yvonne Engels, Myrra Vernooij-Dassen, Jo Hockley, Suvi Leppäaho, Sophie Pautex, Catherine Bassal, Federica Mammarella, Martina Mercuri, Paola Rossi, Ivan Segat, Agata Stodolska, Eddy Adang, Paula Andreasen, Outi Kuitunen-Kaija, Danni Collingridge Moore, Agnieszka Pac, Violetta Kijowska, Maud ten Koppel, Jenny T. van der Steen, Emilie Morgan de Paula, and the European Association for Palliative Care vzw, European Forum For Primary Care, Age Platform Europe, and Alzheimer Europe.

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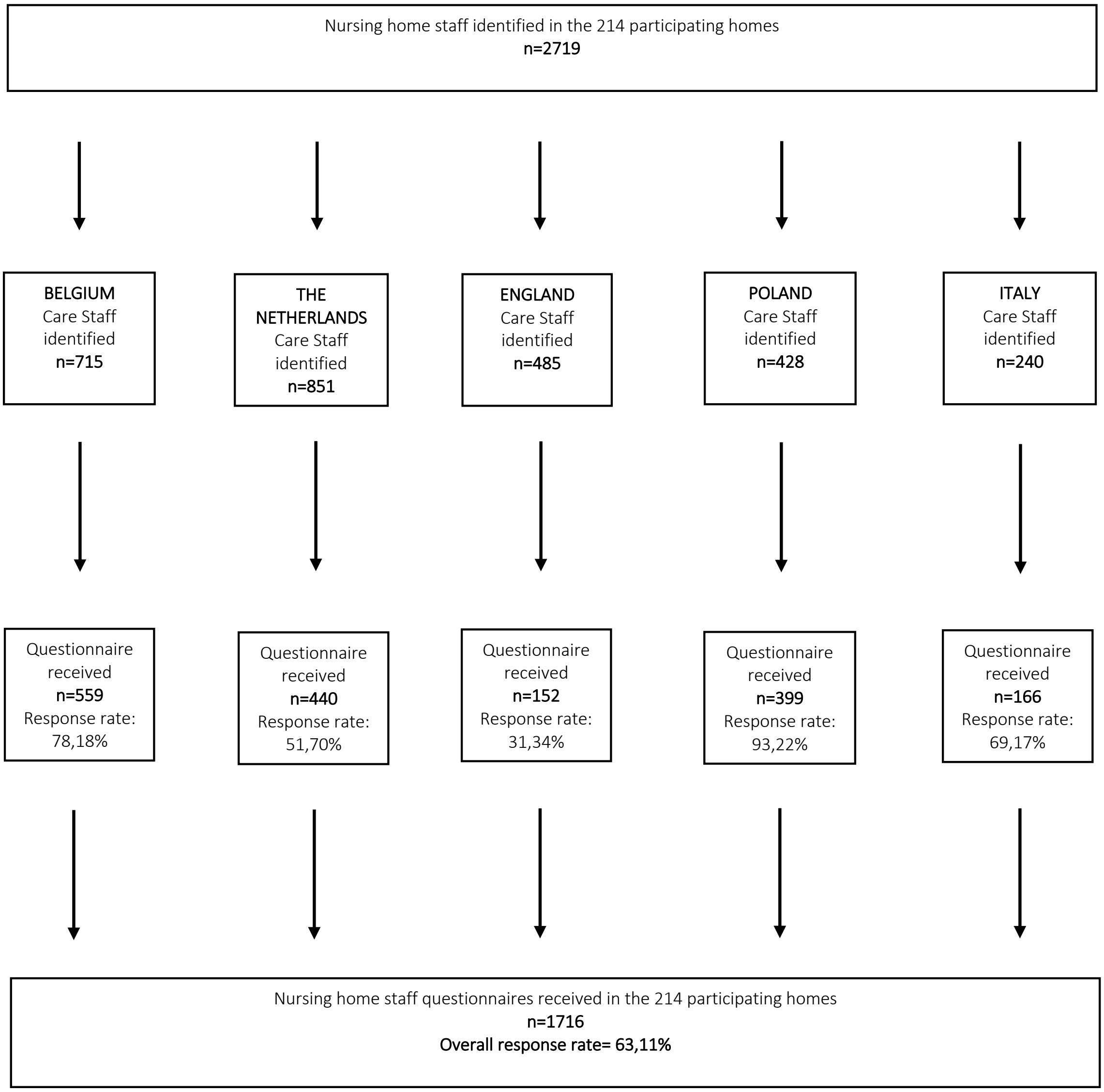
Figure 1: Flowchart of identified respondents (Nursing home care staff°) in the 6 countries



° staff = nurses and care assistants

Table 1. Characteristics of the participating nursing home staff

	Belgium n= 559 (%)	the Netherlands n= 440 (%)	England n= 152 (%)	Poland n= 399 (%)	Italy n=166 (%)	Bivariate p-value*
Age						<0.001
17-35 years	224 (40.4)	128 (29.5)	61 (41.2)	67 (17.1)	86 (55.5)	
36-50 years	201 (36.3)	165 (38)	46 (31.1)	207 (52.9)	59 (38)	
>50 years	129 (23.3)	141 (32.5)	41 (27.7)	117 (30)	10 (6.5)	
Gender						<0.001
Female	495 (88.6)	412 (94.3)	139 (92.7)	371 (94.2)	107 (67.3)	
Male	64 (11.4)	25 (5.7)	11 (7.3)	23 (5.8)	52 (32.7)	
Professional role						<0.001
Care or nursing assistant	297 (53.1)	374 (85.8)	115 (77.2)	235 (58.9)	1 (0.6)	
Nurse	262 (46.9)	62 (14.2)	34 (22.8)	164 (41.1)	156 (99.4)	
Formal training in palliative care						<0.001
No	232 (44.2)	182 (41.7)	121 (82.3)	151 (39.1)	86 (53.8)	
Yes†	293 (55.8)	254 (58.3)	26 (17.7)	235 (60.9)	74 (46.2)	
Working in which type of nursing home						<0.001
Type 1	NA	172 (42.6)	NA	130 (32.6)	63 (38)	
Type 2	537 (100)	232 (57.4)	101 (67.8)	269 (67.4)	103 (62)	
Type 3	NA	NA	48 (32.2)	NA	NA	

*Generalized linear mixed model reporting p-value for country as a fixed effect, α =0.05.
†Training in palliative care as part of degree, or as additional training after degree.
NA= not available in that particular country

Table 2. Extent to which nursing home staff agree with basic principles of palliative care (percentages and odds ratios) and overall score of agreement with the principles of palliative care.

	Belgium n= 559		**The Netherlands** n=440		**England** n= 152		**Poland** n= 399		**Italy** n=166	
	N (%)	Ref	N (%)	OR (95% CI)	N (%)	OR (95 CI%)	N (%)	OR (95% CI)	N (%)	OR (95% CI)
Opinions towards *the principles related to the WHO definition of palliative care*										
a. The aim of palliative care is treatment of pain only (DISAGREE)	450 (82)	-	344 (79)	0.74 (0.41-1.32)	119 (81)	0.83 (0.37-1.87)	226 (58)	**0.12** **(0.07-0.19)**	61 (37)	**0.08** **(0.04-0.14)**
b. Palliative care starts in the last weeks of life (DISAGREE)	353 (64)	-	201 (46)	**0.35** **(0.24-0.51)**	92 (63)	0.85 (0.5-1.44)	201 (51)	**0.41** **(0.28-0.60)**	81 (51)	**0.56** **(0.34-0.94)**
c. Palliative care and intensive life prolonging treatment can be combined (AGREE)	129 (24)	-	140 (33)	**1.51** **(1.07-2.12)**	72 (50)	**3.41** **(2.21-5.26)**	208 (53)	**3.48** **(2.49-4.86)**	73 (44)	**3.25** **(2.07-5.10)**
d. Palliative care includes spiritual care (AGREE)	415 (76)	-	297 (68)	0.81 (0.56-1.77)	104 (73)	1.16 (0.70-1.90)	292 (75)	0.91 (0.62-1.34)	100(62)	**0.32** **(0.19-0.53)**
e. Palliative care includes care for resident's family/relatives (AGREE)	503 (92)	-	372 (86)	**0.58** **(0.34-0.99)**	112 (80)	**0.39** **(0.21-0.75)**	245 (63)	**0.11** **(0.07-0.18)**	92 (56)	**0.06** **(0.03-0.11)**
Overall score of agreement with the principles of palliative care	2.91		2.87		3.36		2.48		1.82	

Generalized linear mixed model reporting p-value for country as a fixed effect, α =0.05
The model accounted for the clustering at the level of homes and adjusted for age, gender, professional role and training in palliative care
CI, confidence interval; OR, odds ratio; Ref., reference category.
Numbers in bold represent statistically significant differences with Belgium

Table 3. Association between overall score of agreement with principles of palliative care ° of nursing home staff and their characteristics

	**Agreement with the principles of palliative care*	
	Estimated difference (95% CI)	Adjusted p-Value
	Predictors	
Intercept	2.91 (2.55 – 3.28)	**<0.001**
Country		
Belgium	REF	
The Netherlands	-0.04 (-0.30; 0.22)	0.75
England	0.45 (0.10; 0.81)	**0.01**
Poland	-0.43 (-0.69; -0.17)	**0.001**
Italy	-1.09 (-1.42; -0.75)	**<0.001**
Age		
17-35 years	REF	
36-50 years	0.26 (0.09; 0.43)	**0.003**
>50 years	0.28 (-0.08; 0.48)	**0.006**
Gender		
Male	REF	
Female	-0.12 (-0.33; 0.10)	0.28
Professional role		
Care or nursing assistant	REF	
Nurse	0.59 (0.43; 0.75)	**<0.001**
Training in palliative care		
No	REF	
Yes‡	0.21 (0.08; 0.34)	**0.002**
Nursing home Type		
Type 1	Ref	
Type 2	0.07 (-0.17;0.30)	0.58
Type 3	-0.27 (-0.83;0.29)	0.35
	Variances	
Residual effect	1.38 (1.27- 1.49)	**<0.001**
Random effect- Nursing home	0.14 (0.08-0.24)	**0.001**
ICC	0.09	

* Multiple linear mixed model analysis with nursing home as random effect and country, age, gender, professional role, type of nursing home and training in palliative care as covariates.

‡Training in palliative care as part of degree or additional training after degree.

ICC= intraclass correlation coefficient

Missing data in analysis: 219 (9.6%)

Table 4. Extent to which long-term care nursing home nurses and care assistants agree or disagree with the principles of palliative care (percentages)

	Belgium n= 559			**The Netherlands** n=440			**England** n= 152			**Poland** n= 399			**Italy** n=166			**Total** N = 1716		
	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)	D (%)	N (%)	A (%)
Opinions towards *the principles related to the WHO definition of palliative care*																		
a. The aim of palliative care is treatment of pain only	82	13	5	79	15	7	81	13	6	58	10	32	37	33	30	71	15	14
b. Palliative care starts in the last weeks of life	64	20	16	46	21	33	63	17	18	51	18	30	51	25	22	55	20	25
c. Palliative care and intensive life prolonging treatment can be combined	42	32	24	34	32	33	16	31	72	19	27	53	18	37	44	31	32	37
d. Palliative care includes spiritual care	3	20	76	7	25	68	6	19	73	8	17	75	8	30	62	6	22	72
e. Palliative care includes care for resident's family/relatives	2	5	92	4	10	86	8	11	80	15	21	63	11	33	56	7	14	79

D= disagree
N= neither agree nor disagree
A= agree

CHAPTER 3

LARGE DIFFERENCES IN THE ORGANIZATION OF PALLIATIVE CARE IN NURSING HOMES IN SIX EUROPEAN COUNTRIES: FINDINGS FROM THE PACE CROSS–SECTIONAL STUDY

Honinx, E., Van den Block, L., Piers, R., Onwuteaka-Philipsen BD, Payne, S., Szczerbińska, K., Gambassi, G., Kylänen, M., Deliens, L. and Smets T, on behalf of PACE.

Honinx E, Van den Block L, Piers R, et al. Large differences in the organization of palliative care in nursing homes in six European countries: findings from the PACE cross-sectional study (*submitted*).

Abstract

Background.
To be able to provide high-quality palliative care, there need to be a number of organizational structures available in the nursing homes. It is unclear to what extent such structures are actually present in nursing homes in Europe. We aim to examine structural indicators for quality of palliative care in nursing homes in Europe and to evaluate the differences in terms of availability of and access to palliative care, infrastructure for residents and families, multidisciplinary meetings and quality improvement initiatives.

Methods.
A PACE cross-sectional study (2015) of nursing homes in Belgium, England, Finland, Italy, the Netherlands and Poland. Nursing homes (N=322) were selected in each country via proportional stratified random sampling. Nursing home administrators (N=305) filled in structured questionnaires on nursing home characteristics. Organization of palliative care was measured using 13 of the previously defined IMPACT structural indicators for quality of palliative care covering four domains: availability of and access to palliative care, infrastructure for residents and families, multidisciplinary meetings and quality improvement initiatives. We calculated structural indicator scores for each country and computed differences in indicator scores between the six countries. Pearson's Chi-square test was used to compute the p-value of each difference.

Results.
The availability of specialist palliative care teams in nursing homes was limited (6.1%-48.7%). In Finland, Poland and Italy, specialist advice was also less often available (35.6% - 46.9%). Up to 49% of the nursing homes did not provide a dedicated contact person who maintained regular contact with the resident and relatives. The 24/7 availability of opioids for all nursing home residents was low in Poland (37.5%).

Conclusions.
This study found a large heterogeneity between countries in the organization of palliative care in nursing homes, although a common challenge is ensuring sufficient structural access to specialist palliative care services. Policymakers and health and palliative care organizations can use these structural indicators to identify areas for improvement in the organization of palliative care.

Key words
Organization, structural indicators, palliative care, nursing home, Europe, PACE.

What is known on this topic:

- To be able to provide high-quality palliative care, there need to be a number of organizational structures available in the nursing homes

- It is unclear to what extent such structures are actually present in nursing homes in Europe.
- Gaining insight into these structures, via the IMPACT structural indicators for quality of palliative care, would help policymakers in identifying areas for improvement and in developing policy measures.

What this study adds:

- European nursing homes lack dedicated palliative care functions, specialist palliative care teams, and a contact person who maintains regular contact with the resident and relatives.
- The availability of opioids is low in nursing homes in Poland.
- Policymakers should invest in the availability of adequate general and specialist palliative care for all nursing home residents in need of this kind of support, either via internal or external services, with attention to minimal equipment and the necessary financial resources.

Introduction

Delivering high-quality palliative care is of utmost importance in nursing homes given the complex needs of the residents living and dying in these facilities. Information about the quality of care can be drawn from care process and outcomes, but also from structure or organizational characteristics[1]. A recent EU study, the European IMPACT project (IMplementation of quality indicators for PAlliative Care sTudy)[2] developed structural indicators for quality of palliative care. The IMPACT structural indicators were developed for several palliative care settings including nursing homes and cover different domains such as access to specialist palliative care, availability of specialized equipment for residents in need of palliative care, multidisciplinary team meetings, availability of opioids and the assessment of experiences of the relatives with the care provided[2]. To be able to provide high-quality palliative care, there need to be a number of organizational structures available in the nursing homes[3].

To date, these structural indicators for quality of palliative care have not been used to measure quality in nursing homes, nor to compare countries via appropriate international samples, making it unclear to what extent such structures are actually present in nursing homes in Europe[4,5]. Given the regulatory differences between nursing homes and between European countries, one can also expect differences in the way palliative care is organized in the nursing homes in these countries[6]. Insight into the organizational structures for palliative care in nursing homes in Europe will help policy and other decision-makers in identifying areas for improvement and in developing policy measures. To provide these insights, comparable data sets on structural indicators for quality of palliative care across different European countries are needed.

Within PACE, a European funded project that compared palliative care in nursing homes in six European countries, we conducted a large-scale survey of nursing homes to describe how they are organized with regard to palliative care, and to study differences in organizational structures[7]. The aim of the current study is to examine structural indicators for quality of palliative care in nursing homes in Belgium, England, Finland, Italy, the Netherlands and Poland and to evaluate the differences in terms of availability of and access to palliative care, infrastructure for residents and families, multidisciplinary meetings and quality improvement initiatives.

Methods

Study design

In 2015, we performed the PACE cross-sectional study of nursing homes in Belgium (Flanders), England, Finland, Italy, the Netherlands and Poland. Proportional stratified random sampling was used to select a representative sample of nursing homes in each country. Nursing homes were first stratified by region, then by nursing home type and bed capacity (higher or lower than the median number of beds in the country). They were sampled randomly and proportionally from each stratum. Where a nursing home declined to participate, another from the same stratum was sampled. For recruitment, national (or regional) lists of nursing homes were used, except for Italy, where no such list was available. In that country, a previously constructed cluster of nursing homes interested in research was used. To enhance recruitment of nursing homes in England, we relied on the ENRICH (Enabling Research In Care Homes) network[8]. The PACE protocol provides more details about the study[7].

Setting and participants

We define nursing homes as 'collective institutional settings where care, on-site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time'[9]. We distinguished three types of nursing homes: type 1 with 24/7 care from on-site physicians and nurses/care assistants, type 2 with 24/7 care from on-site nurses/care assistants and off-site physicians, and type 3 with 24/7 care from on-site care assistants, and off-site nurses and physicians[10]. The administrator of each participating nursing home was asked to fill in a structured questionnaire on nursing home characteristics.

Data collection

A letter that introduced the PACE project was sent to the nursing home administrator inviting participation in the study. Upon agreement, a researcher visited the nursing home. During the visit, the administrator was asked to fill in a questionnaire about the nursing home.

Measurements

The sample of nursing homes was described based on type of nursing home (care from on-site physicians and nurses / care from on-site nurses and off-site physicians / care from off-site physicians and nurses), type of ownership of the nursing home (public-nonprofit/private-nonprofit/private-profit) and size of nursing home (number of beds). The organization of palliative care in the nursing homes was measured using the IMPACT structural indicators for quality of palliative care[2]. The IMPACT Indicators were previously developed in a European study to monitor and improve the organization of palliative care in a variety of settings[11]. The final set consists of 23 indicators, covering seven organizational domains: 1) access to palliative care, 2) infrastructure, 3) assessment tools, 4) personnel, 5) documentation of clinical data, 6) quality, and 7) education. From this set, 13 indicators, covering four domains (1, 2, 4 and 6), are applicable to nursing homes and were used in the PACE questionnaire for nursing home administrators. These indicators were included in a feasibility testing of the questionnaires in several nursing homes in each country. Based on the feedback of the feasibility testing, the PACE consortium made minor adjustments to the wording of the domains and indicators that required clarification. The final four domains were: availability of and access to palliative care, infrastructure for residents and families, multidisciplinary meetings and quality improvement initiatives. The original thirteen IMPACT indicators and the adapted thirteen structural indicators for quality of palliative care can be found in Table 1.

The indicators were measured in all six countries. However, their implementation may differ between countries since the availability of in-house and external palliative care services in the nursing homes varies between countries. Table 2 gives an overview of the palliative care services available to nursing homes in the six countries, which can be used as a framework for the implementation of the indicators within the specific context of each country.

Statistical analysis

All analyses were performed with IBM SPSS version 23[12]. For each country, the types and mean size of nursing homes and types of nursing home ownership were determined. Then, we calculated indicator scores for each country, based on the structural indicators in the nursing homes, reported as counts and percentages. Next, we computed differences in indicator scores between the six countries. Pearson’s Chi-square test was used to compute the p-value of each difference; Fisher’s exact test was applied for frequencies below 5. An alpha level of $p<0.05$

defined statistical significance. Because all countries, except Belgium and Finland, had several types of nursing homes, we additionally calculated indicator scores by nursing home type within those four countries. Due to convergence problems because of low numbers of cases, the significance of these differences could not be tested.

Ethical aspects

In 2015, the PACE protocol was approved by the ethics committees of each country. If no ethical approval was required, which was the case in Italy and the Netherlands, waivers for data collection were obtained. Completed questionnaires were regarded as informed consents.

Results

In this study, 322 nursing homes from Belgium, England, Finland, Italy, the Netherlands and Poland were initially recruited. Of these 322 homes, a total of 305 (95%) nursing homes – for which the nursing home administrator returned the questionnaire on nursing home characteristics – were eventually included.

Characteristics of the participating nursing homes

Table 3 shows that type 1 nursing homes (care from on-site physicians and nurses) existed in Italy, the Netherlands and Poland (24.2% - 38.6%). Type 2 nursing homes (care from on-site nurses and off-site physicians) were the most common type in all countries (55.1% - 100%) except in England (45.8%), where type 3 nursing homes (care from off-site physicians and nurses) were most common (54.2%; p<0.001). In almost all countries, the majority of the nursing homes were public non-profit facilities, except for England and Italy where more private for-profit facilities (86.8% and 41.8% respectively) existed (p<0.001). Nursing home size differed significantly between a mean of 37 beds in Finland to 110 beds in Belgium (p<0.001).

Availability of and access to palliative care in nursing homes

Specialist palliative care teams employed by the nursing home were rarely present, with a prevalence rate ranging from 6.1% in England up to 48.7% in Belgium (p<0.001; Table 4). Specialist palliative care advice for professionals delivering palliative care in the nursing home was mainly available in Belgium (92.7%), England (87.2%) and the Netherlands (65.1%). In the other countries, specialist advice was less often available (35.6% in Finland - 46.9% in Italy;

p<0.001). The majority of the nursing homes in England, Finland and Italy had a procedure in place regarding bereavement support for relatives (respectively 68.2%, 59.8% and 59.4%); whereas in Belgium (26.2%), the Netherlands (22%) and Poland (20.4%) this was the case to a lesser extent (p<0.001). Opioids were available 24/7 to all residents in the majority of the nursing homes in all countries (69.7% in Italy – 83.3% in England), except for Poland, where they were available 24/7 to all residents in only 37.7% of the nursing homes (p<0.001). In Poland, in 27.1% of the homes, opioids were not available 24/7 to any of residents. In most nursing homes an assigned contact person who maintains a regular contact with the resident and relatives was available for each resident (51.2% in Belgium – 82.6% in England; p<0.001), except for Poland and Italy where such a contact person was often not present at all (not available: Poland 57.1%; Italy 48.5%). When comparing indicator scores of the different nursing home types (Table 1A in Appendix), a large difference was found in Poland regarding the availability of specialist palliative care advice for professionals delivering palliative care between type 1 homes (care from on-site physicians and nurses) and type 2 homes (care from on-site nurses and off-site physicians) (25% and 61.5% respectively).

Infrastructure for residents and families in nursing homes

Pressure relieving matrasses (90.9% in Finland – 100% in Italy; p<0.001), hospital beds (78.8% in Italy – 98.9% in Finland; p<0.01) and oxygen delivery (66.7% in England – 97.7% in Belgium and the Netherlands; p<0.001) were available in nearly all nursing homes. Suction equipment was present in nursing homes in all countries (77.3% in the Netherlands – 100% in Italy) but to a lesser extent in nursing homes in England (39.6%; p<0.01). The same applied to stoma care supplies (50% in England – 86.4% in the Netherlands; p<0.001). Syringe drivers were mainly available in nursing homes in England (83.8%), the Netherlands (72.7%) and Belgium (65.1%) but less frequently in the other countries (36.4% in Italy – 42.9% in Poland; p<0.001). Additional analyses (Table 1A in Appendix) indicated a lesser supply of syringe drivers (3.7%) and oxygen delivery (48.1%) in type 2 homes (care from on-site nurses and off-site physicians) in Poland compared with type 1 homes (care from on-site physicians and nurses; 90.9% and 95.5% respectively). In England, suction equipment and stoma care supplies were less available in type 3 homes (care from off-site physicians and nurses; 11.5% and 30.8%) than in type 2 homes (72.7% for both indicators). In most countries, the nursing homes had single bedrooms available for dying residents who wished for one (78.4% in Finland – 93.5% in England;

p<0.001). This was usually not the case in Poland (27.1%) and Italy (50%). The large majority of nursing homes in the six countries permitted unrestricted visiting hours (87% in England – 100% in Belgium and Finland; p<0.01) and overnight stays (59.2% in Poland – 90.9 in Italy; p=0.001) for relatives of dying residents.

Multidisciplinary meetings in nursing homes

Multidisciplinary meetings were held in the majority of nursing homes in all countries (50.6% in Finland – 97.7% in the Netherlands; p<0.001) although the frequency of the meetings differed significantly between countries (Weekly: 9.4% in Italy – 39.4 in Finland; p<0.01). There were no substantial differences between the different nursing home types within countries.

Quality improvement initiatives in nursing homes

For 33.7% - 64.4% of the nursing homes, the experiences of the relatives of all residents regarding the care provided were assessed (p<0.001). In Poland, this percentage was considerably lower (10.2%) with 65.3% of nursing homes never assessing relatives' experiences. In the Netherlands, Italy and Poland, the assessment was carried out less often in type 2 nursing homes (care from on-site nurses and off-site physicians) than in type 1 homes (care from on-site physicians and nurses; Table 1A in Appendix). Guidelines for the last three days of life were often not used (Not used: 48.8% in England – 90.3% in Italy; p<0.001).

Discussion

Main findings

Using previously defined quality indicators for the organization of palliative care, this study identified several areas of improvement for the organization of palliative care in nursing homes in six European countries. Dedicated palliative care functions, specialist palliative care teams, and a dedicated contact person who maintained regular contact with the resident and relatives were often not structurally embedded in the organization of nursing home care in most countries, in particular in Finland and Poland. There was little structural availability of specialist advice for professionals delivering palliative care in Finland, Italy and Poland. The availability of opioids was low in nursing homes in Poland. Almost all structural indicators for quality of palliative care differed significantly between countries. Differences between nursing home types were limited to the availability of specialist palliative care advice, the regular assessment of relatives' care experiences and the availability of certain specialized equipment.

Strengths and limitations

This study has several strengths. It is the first study to measure and compare the structural indicators for quality of palliative care in nursing homes in representative samples of nursing homes that cover different European regions. Also, the overall response rate was very high (95%). We were able to include data from 305 nursing homes in six countries to make cross-country comparisons.

This study has some limitations. Firstly, we cannot exclude the risk of nursing homes with a strong interest in palliative care being more inclined to participate in the study. Secondly, we were unable to test the statistical significance of the differences in indicator scores between nursing home types within the countries due to low number of cases, but this is likely to account for some of the variance. Lastly, these structural indicators are mainly valuable for policymaking, to map the organization of palliative care and compare it on a macro-level. They do not guarantee high-quality palliative care for each individual resident, and a low score on an indicator does not necessarily indicate suboptimal palliative care for an individual resident. This was confirmed in a previous PACE study that found that even in countries with high levels of palliative care integration, the quality of dying and of end-of-life care of nursing home residents was poor[13].

What this paper adds

Although we found heterogeneity in the way palliative care is organized in the different countries, one area that appears to need improvement in all countries is the availability and access to specialist palliative care support. We found that there is low access to specialist palliative care teams in all countries and there is little availability of specialist advice for professionals delivering palliative care in nursing homes in Finland, Italy and Poland. Belgium had the highest number of nursing homes indicating that a specialist palliative care team was present in the facility (49%) and that specialist advice (93%) was available. However, these results should be interpreted cautiously; in Belgium the number of employed staff is 0.5 FTE per resident which is not enough to provide adequate care to heavily care-dependent residents[14]. The availability and amount of specialist palliative care in a country also depends on the health care system of each country. However, although all nursing and care staff in nursing homes should be able to provide general palliative care to residents, research shows that a general palliative care approach is not always sufficient to meet the needs of certain nursing home residents; these residents may benefit from specialist palliative care, especially when needs become complex[15–17]. Our study shows that specialist palliative care is often not available in nursing homes, and there is thus clearly room for improvement in this area.

Aside from similarities, there were also apparent differences between countries, an important one being the low levels of access to opioids in nursing homes in Poland. The low opioid availability we found in nursing homes in Poland is not surprising as other research has shown that use and prescription of opioids was lowest in Poland compared with other European countries[18–21]. Another PACE study on opioid use at the end of life suggested that the low opioid prescription rate and use during the last days of life in nursing homes in Poland probably reflects the low opioid use in Poland in general [22,23]. Opioids are important to treat pain at the end of life in nursing home residents and they are considered essential to providing adequate palliative care[17,23,24]. However, fear of opioid addiction, or analgesic tolerance, possible side-effects or the belief that opioids would hasten death might hinder access to and use of opioids[25,26]. Our finding may be an incentive for policymakers in Poland to make opioids available 24/7 for all nursing home residents when they need them. To do this, the report of the Access To Opioid Medication in Europe (ATOME) group suggests that legal barriers that hinder the use of opioids in Poland need to be addressed, and that the misconception of opioids as being a life-shortening drug need to be corrected through adequate information and training for health care providers[27,28].

Countries like Italy, Finland and Poland appear to have more areas for organizational improvement of palliative care (e.g. access to palliative care, availability of a contact person for residents or relatives and specialized equipment) than Belgium, England and the Netherlands. These results are in line with earlier findings from a report of the European Association of Palliative Care Taskforce on Long-term Care Facilities on the development of palliative care in nursing homes in Europe. In Poland, and especially in Italy and Finland, fewer initiatives to develop palliative care in nursing homes and less engagement by and within nursing homes with palliative care initiatives or care provision existed than in Belgium, the Netherlands, and the UK[6,29]. Policy choices (e.g. regarding health care organization or funding) in a country affect the possibilities available to palliative care in that country[30]. Our findings confirm that the basic requirements for palliative care on a macro level are better guaranteed in Belgium, the Netherlands and the UK than in the other three countries. The differences in palliative care organization between countries may also reflect country-specific differences in culture, regulatory mechanisms and legislation[30,31]. Specially in countries with room for improvement of palliative care organization, such as Italy, Poland and Finland, extra initiatives should be considered, while drawing lessons from other countries. Policymakers should invest in dedicated functions for palliative care and the availability of adequate general and specialist palliative care for all nursing home residents in need of this kind of support, either via internal or external services.

Nevertheless, the organization of palliative care in nursing homes remains a common challenge. This is due to the slow development of and limited attention given to palliative care in nursing homes[29]. Earlier research has shown that, regarding palliative care, focus was and still is mainly on hospitals, hospices and home care[32,33]. Also with regard to general care and wellbeing, the nursing home setting remains underinvested[34]. The current study highlights the need for a model within the healthcare sector that guarantees equal access to palliative care for all healthcare settings, with detailed information on minimal equipment that should be available in nursing homes and the financial resources needed to provide it.

Conclusions

This study found a large heterogeneity between countries in the organization of palliative care in nursing homes, although a common challenge is ensuring sufficient structural access to specialist palliative care services. Policymakers and health and palliative care organizations can use these structural indicators to identify areas for improvement in the organization of palliative care.

Declarations

Ethics approval and consent to participate

Ethics approval from the relevant ethics committees were obtained in all participating countries. Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: NHS – NRES Committee North West-Haydock, 10/09/2015; Finland: Terveyden jahyvinvoinnin laitos, Institutet för hälsa och välfärd, 30/6/2015; Italy: Comitato Etico, Universita Cattolica del Sacro Cuore, 6/11/2017; Netherlands: Medisch Ethische Toetsingscommissie VUMedisch Centrum, 2/7/2015; Poland: Komisja Bioetycza, Uniwersytetu Jagiellonskiego, 25/6/2015; Switzerland: Commission cantonale d'éthique de la recherché scientifique de Genève (CCER), 6/8/2015.

All persons participating in the study (facility managers, care staff, GPs) have to give their prior informed consent in writing. If participants are unable to give informed consent, they will not be involved in the study. In some countries, a separate informed consent from individual participants is not required if questionnaires are filled in anonymously: for the Netherlands, the Medical Ethics Review Committee concluded that this study does not fall under the Medical Research Involving Human Subjects Act (WMO). In accordance with the Dutch code for good practice in biomedical research, a separate informed consent was not needed. The Polish Ethical Committee stated no separate informed consents were needed given the study design protected anonymous answering of individual respondents. Returning the questionnaire was regarded as consent to participate in the study.

Consent for publication

Not applicable.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Project has been co-funded by Polish Ministry of Science and Higher Education in the years 2014-2019 based on the decision no 3202/7PR/2014/2 dated on Nov. 25th, 2014. This work was supported by the European Union's Seventh Framework Programme (FP7/ 2007e2013) under grant agreement 603111 (PACE project Palliative Care for Older People). The funders had no role in study design, collection, analysis or interpretation of the data, nor in writing and the decision to submit this article for publication.

Authors' contributions

EH, LVDB, RP, BDOP, SP, KS, GG, MK, LD and TS were involved in the study design. LVDB, RP, BDOP, SP, KS, GG, MK, LD and TS are involved in data acquisition. EH, LVDB, RP, LD and TS were involved in developing the data analysis plan. EH, LVDB, RP, BDOP, SP, KS, GG, MK, LD and TS were involved in writing of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

Other PACE collaborators not in the list: Yuliana Gatsolaeva, Rose Miranda, Lara Pivodic, Marc Tanghe, Hein van Hout, Roeline H. R. W. Pasman, Mariska Oosterveld-Vlug, Ruth Piers, Anne B. Wichmann, Yvonne Engels, Myrra Vernooij-Dassen, Jo Hockley, Sheila Payne, Suvi Leppäaho, Ilona Barańska, Sophie Pautex, Catherine Bassal, Federica Mammarella, Martina Mercuri, Paola Rossi, Ivan Segat, Agata Stodolska, Eddy Adang, Paula Andreasen, Outi Kuitunen-Kaija, Danni Collingridge Moore, Agnieszka Pac, Violetta Kijowska, Maud ten Koppel, Jenny T. van der Steen, Emilie Morgan de Paula, and the European Association for Palliative Care vzw, European Forum For Primary Care, Age Platform Europe, and Alzheimer Europe.

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Table 1 Overview of the wording of the original IMPACT structural Indicators for palliative care and adjustments made in the PACE questionnaire

IMPACT indicators		PACE indicators
1. Access to palliative care		*1. Availability of and access to palliative care*
1.	A **specialist palliative care team** is available 24/7.	Is there a **specialist palliative care team** present in your facility (employed in your facility)? If yes, do you **use this specialist palliative** care team?
2.	**Specialist palliative care** advice is available 24/7 to professionals delivering palliative care.	Is **specialist palliative care advice** available to professionals delivering palliative care in your facility? If yes, do you **use this advice**?
3.	Bereaved relatives and/or professionals involved in care of a person in need of palliative care are offered support during the **bereavement** process if they need or wish to have support.	Do you have a procedure in place to ensure that relatives of residents are offered **bereavement support**, if they need or wish to have support?
4.	**Opioids** are accessible and available for persons in need of palliative care 24/7.	Are **opioids** available 24/7 for residents in need of palliative care in your facility?
5.	Persons in need of palliative care have an assigned **contact person** who maintains regular contact with the person and their families and ensures coordinated delivery of health and social care.	Does your facility offer residents in need of palliative care an **assigned contact person** (e.g. care manager, case manager or key worker) who maintains a regular contact with the resident and his or her relatives, in order to ensure coordinated health and social care?
2. Infrastructure		*2. Infrastructure for residents and families*
6.	**Specialized equipment** (e.g. anti-decubitus mattresses, suction equipment, stoma care, oxygen delivery, drug administration pumps, hospital beds, etc.) is available to persons in need of palliative care.	What **specialized equipment** is available for residents in need of palliative care in your facility? (pressure relieving mattresses, suction equipment, stoma care supplies, oxygen delivery, syringe driver, hospital beds)
7.	**Single bedrooms** are available for persons who are dying and who wish to have one.	Are **single bedrooms** available in your facility for ALL residents who are dying and who wish to have one?

8.	Family members and friends are able to **visit** the dying person without restrictions of visiting hours.	Are there unrestricted **visiting hours** for relatives of residents who are dying, if they wish?
9.	There are facilities for relatives to **stay overnight** with their dying relative.	Are there facilities for relatives to **stay overnight** with their dying relative?
3. Personnel		*3. Multidisciplinary meetings*
10.	The multidisciplinary **team** that delivers palliative care services consists of at least:	Is there a **regular multidisciplinary meeting** (with at least a physician and a nurse) to review treatment and care plans organized in your facility?
	a) a physician and nurse;	
11.	There is a **weekly multidisciplinary meeting** with at least the physician and nurse in charge of the person in need of palliative care to review treatment and care plans.	If yes, **how frequently** is this meeting organized? (**weekly**, monthly, other frequency)
4. Quality		*4. Quality improvement initiatives*
12.	**Family and caregiver experiences** of the palliative care service are assessed/evaluated/recorded.	Does your facility systematically **assess the experiences of relatives** of residents regarding provided care?
13.	An end-of-life care **pathway** (such as the Liverpool Care Pathway) was used for the **last 3 days of life** of a person in need of palliative care.	Are **specific guidelines** used for the last 3 days of life of a resident in need of palliative care in your facility?

Table 2 Classification of in-house and external palliative care services available in nursing homes in six countries.

Belgium	Netherlands	England	Finland	Italy	Poland
In-house palliative care service in a nursing home					
NH staff (nurse/care assistants) trained in palliative care Palliative care support team per facility, consisting of: - Coordinating advisory physician (a GP who is responsible for nunrsing home medical management incl. palliative care; however, s/he does not function as a GP of the residents (they have their own GP) -Palliative care reference nurse (to support GPs and nurses operating in the nursing homes)	Type 1: Elderly care physician (also provides general palliative care) and nurse/care assistants trained in palliative care Type 2: Nurse/care assistants trained in palliative care	NH staff (nurse/care assistants) trained in palliative care Palliative care team (specialist nurse and palliative medicine doctor, sometimes other professionals) advise and assess residents, no hands-on care. Some palliative care nurses are linked to the nursing home	Elderly care physicians and registered and licensed practical nurses trained in palliative care	General practitioner and NH staff (nurse/care assistants) trained in palliative care	Type 1: General practitioner and NH staff (nurse/care assistants) trained in palliative care Type 2: no internal palliative care service Difference in availability specialist palliative care advice between type 1 and 2 because of financial contracting law regulation. Type 1 is obliged to provide palliative care in the frame of internal service (call on palliative care specialist is an exception). Type 2 calls on external palliative care specialists.

External palliative care service in a nursing home					
External palliative home care team (provides advice or training to nursing home staff) External general physician	Type 1: Access to consultant or consultation team palliative care Type 2: External elderly care physician (also provides general palliative care) Access to consultant or consultation team palliative care	External physicians linked to the nursing home District nurses (deliver hands-on care to older people and provide general palliative care) sometimes linked to the nursing home External specialist palliative care team and care home liaison specialist palliative care nurse	External general physician External elderly care physician or external palliative care team.	Palliative care services of the health care district in isolated cases Palliative care services from collaborating not-for-profit organizations	Type 1: no use of external palliative care service Type 2: Hospice team (palliative care specialist physician and palliative care specialist nurse) visiting a resident at residential home

Table 3: Description of sample of nursing homes in six European countries (N=305)

	BE N=43 N(%)	**NL** N=44 N(%)	**EN** N=48 N(%)	**FI** N=88 N(%)	**IT** N=33 N(%)	**PL** N=49 N(%)	P-value*
Type of nursing home							**<0.001**
Type 1 with on-site care from physicians, nurses and care assistants	NA	17 (38.6)	NA	NA	8 (24.2)	22 (44.9)	
Type 2 with on-site care from nurses and care assistants, but off-site care from physicians	43 (100.0)	27 (61.4)	22 (45.8)	88 (100.0)	25 (75.8)	27 (55.1)	
Type 3 with on-site care from care assistants, but off-site care from nurses and physicians	NA	NA	26 (54.2)	NA	NA	NA	
Type of ownership of nursing home							**<0.001**
Public-nonprofit	21 (48.8)	44 (100.0)	1 (2.1)	66 (75.9)	10 (30.3)	30 (62.5)	
Private-nonprofit	19 (44.2)	NA	5 (10.4)	10 (11.5)	8 (24.2)	17 (35.4)	
Private-profit	3 (7.0)	NA	42 (87.5)	11 (12.6)	15 (45.5)	1 (2.1)	
Size of nursing home							**<0.001**
Mean (SD) number of beds	110 (49)	88 (54)	39 (22)	37 (28)	82 (56)	72 (41)	

Missing values: Type of nursing home=0, type of ownership=2, size=5

Table 4: Structural indicators in nursing homes in six European countries (N=305)

	BE N=43 N(%)	**NL** N=44 N(%)	**EN** N=48 N(%)	**FI** N=88 N(%)	**IT** N=33 N(%)	**PL** N=49 N(%)	P-value*
Availability of specialist palliative care							
Specialist PC team present in the facility (employed by facility)?							
Yes	19 (48.7)	13 (29.5)	3 (6.5)	8 (9.5)	4 (12.1)	3 (6.1)	<0.001
If present, use specialist PC team?							
Yes, for all residents in need of SPC	11 (61.1)	1 (7.7)	2 (66.7)	4 (50.0)	2 (66.7)	2 (66.7)	
Yes, for most residents in need of SPC	3 (16.7)	1 (7.7)	0 (0.0)	0 (0.0)	1 (33.3)	0 (0.0)	<0.05
Yes, for some residents in need of SPC	4 (22.2)	7 (53.8)	1 (33.3)	4 (50.0)	0 (0.0)	1 (33.3)	
No, never	0 (0.0)	4 (30.8)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	
Specialist PC advice available to professionals delivering PC in your facility?							
Yes	38 (92.7)	28 (65.1)	41 (87.2)	31 (35.6)	15 (46.9)	21 (45.7)	<0.001
If available, use specialist PC advice?							
Yes, for all residents in need of SPC	14 (38.9)	5 (19.2)	30 (81.1)	11 (40.7)	8 (57.1)	11 (57.9)	
Yes, for most residents in need of SPC	6 (16.7)	2 (7.7)	2 (5.4)	3 (11.1)	1 (7.1)	0 (0.0)	<0.001
Yes, for some residents in need of SPC	16 (44.4)	15 (57.7)	5 (13.5)	10 (37.0)	4 (28.6)	5 (26.3)	
No, never	0 (0.0)	4 (15.4)	0 (0.0)	3 (11.1)	1 (7.1)	3 (15.8)	
Procedure bereavement support relatives?							
Yes	11 (26.2)	9 (22.0)	30 (68.2)	52 (59.8)	19 (59.4)	10 (20.4)	<0.001
Opioids available 24/7 for residents with PC?							
Yes, for all residents	33 (78.6)	32 (72.7)	35 (83.3)	70 (80.5)	23 (69.7)	18 (37.5)	<0.001
Yes, for most residents	1 (2.4)	4 (9.1)	4 (9.5)	6 (6.9)	3 (9.1)	1 (2.1)	
Yes, for some residents	7 (16.7)	4 (9.1)	2 (4.8)	7 (8.0)	4 (12.1)	16 (33.3)	
No, never	1 (2.4)	4 (9.1)	1 (2.4)	4 (4.6)	3 (9.1)	13 (27.1)	
Contact person for residents/relatives to ensure coordinated health and social care?							
Yes, for all residents	21 (51.2)	32 (72.7)	38 (82.6)	63 (71.6)	15 (45.5)	19 (38.8)	<0.001
Yes, for most residents	5 (12.2)	1 (2.3)	2 (4.3)	5 (5.7)	0 (0.0)	0 (0.0)	
Yes, for some residents	4 (9.8)	0 (0.0)	4 (8.7)	3 (3.4)	2 (6.1)	2 (4.1)	
No, never	11 (26.8)	11 (25.0)	2 (4.3)	17 (19.3)	16 (48.5)	28 (57.1)	
Facilities for residents and families							
Specialized equipment available†							
Pressure relieving mattresses	42 (97.7)	43 (97.7)	46 (95.8)	80 (90.9)	33 (100.0)	47 (95.9)	0.377

Suction equipment	34 (79.1)	34 (77.3)	19 (39.6)	70 (79.5)	33 (100.0)	45 (91.8)	<0.001
Stoma care supplies	29 (67.4)	38 (86.4)	24 (50.0)	67 (76.1)	25 (75.8)	35 (71.4)	<0.01
Oxygen delivery	42 (97.7)	43 (97.7)	32 (66.7)	61 (69.3)	30 (90.9)	34 (69.4)	<0.001
Syringe driver	28 (65.1)	32 (72.7)	40 (83.8)	34 (38.6)	12 (36.4)	21 (42.9)	<0.001
Hospital beds	37 (86.0)	40 (90.9)	43 (89.6)	87 (98.9)	26 (78.8)	47 (95.9)	<0.01
Single bedrooms in facility for ALL dying residents who wish to have one?							
Yes	34 (79.1)	40 (93.0)	43 (93.5)	69 (78.4)	16 (50.0)	13 (27.1)	<0.001
Unrestricted visiting hours for relatives of dying residents if they wish?							
Yes	43 (100.0)	40 (93.0)	40 (87.0)	88 (100.0)	31 (96.9)	47 (95.9)	<0.01
Relatives can stay overnight with dying relative							
Yes	36 (87.8)	38 (88.4)	36 (90.0)	72 (81.8)	30 (90.9)	29 (59.2)	0.001
Multidisciplinary approaches							
Regular multidisciplinary meeting (with at least a physician and a nurse) to review treatment and care plans organized in your facility?							
Yes	37 (88.1)	43 (97.7)	29 (64.4)	44 (50.6)	26 (78.8)	35 (72.9)	<0.001
If yes, how frequently is this meeting organized?							
Weekly	8 (19.0)	12 (27.3)	11 (28.2)	8 (9.4)	13 (39.4)	12 (25.5)	<0.01
Monthly or less often	34 (81.0)	32 (72.7)	28 (71.8)	77 (90.6)	20 (60.6)	35 (74.5)	
Quality improvement initiatives							
Systematic assessment of relatives' experiences regarding provided care?							
Yes, for all residents	18 (45.0)	18 (40.9)	29 (64.4)	29 (33.7)	20 (62.5)	5 (10.2)	<0.001
Yes, for most residents	7 (17.5)	4 (9.1)	5 (11.1)	21 (24.4)	1 (3.1)	7 (14.3)	
Yes, for some residents	6 (15.0)	6 (13.6)	2 (4.4)	25 (29.1)	4 (12.5)	5 (10.2)	
No, never	9 (22.5)	16 (36.4)	9 (20.0)	11 (12.8)	7 (21.9)	32 (65.3)	
Specific guidelines used for the last 3 days of life of a resident in need of palliative care in your facility?							
Yes	15 (36.6)	18 (40.9)	21 (51.2)	36 (40.9)	3 (9.7)	7 (14.9)	<0.001

* χ2 test for differences between countries or Fisher's exact test in case cells with frequency below 5, α =0.05

† Multiple answers possible

Missing values: Specialist PC team=10, use specialist PC team=2 (255 not applicable because no specialist PC team present), specialist PC advice=9, use specialist PC advice=24 (122 not applicable because no specialist PC advice available), procedure bereavement=10, opioids=9, contact person=4, specialized equipment=0, single bedrooms=5, unrestricted visiting hours=4, relatives overnight=11, multidisciplinary meeting= 6, weekly multidisciplinary meeting=15, systematic assessment relatives=9, guidelines=13.
Abbreviations: PC=Palliative Care, SPC=Specialist Palliative Care

Appendix Chapter 3

Table 1A: Structural indicators in nursing homes by nursing home type within countries

	NL N=44 N(%)		**EN** N=48 N(%)		**IT** N=33 N(%)		**PL** N=49 N(%)	
By nursing home type*	Type 1 N = 17	Type 2 N = 27	Type 2 N = 22	Type 3 N = 26	Type 1 N = 8	Type 2 N = 25	Type 1 N = 22	Type 2 N = 27
Availability of specialist palliative care								
Specialist PC team present in the facility (employed by facility)?								
Yes	6 (35.4)	7 (25.9)	0 (0)	3 (12)	0 (0)	4 (16)	2 (9.1)	1 (3.7)
If present, use specialist PC team?								
Yes, for all residents in need of SPC	1 (16.7)	0 (0)	N.A.	2 (66.7)	N.A.	2 (66.7)	1 (50)	1 (100)
Yes, for most residents in need of SPC	0 (0)	1 (14.3)	N.A.	0 (0)	N.A.	1 (33.3)	0 (0)	0 (0)
Yes, for some residents in need of SPC	2 (33.3)	5 (71.4)	N.A.	1 (33.3)	N.A.	0 (0)	1 (50)	0 (0)
No, never	3 (50)	1 (14.3)	N.A.	0 (0)	N.A.	0 (0)	0 (0)	0 (0)
Specialist PC advice available to professionals delivering PC in your facility?								
Yes	12 (70.6)	16 (61.5)	20 (90.9)	21 (84)	3 (37.5)	12 (50)	5 (25)	16 (61.5)
If available, use specialist PC advice?								
Yes, for all residents in need of SPC	4 (33.3)	1 (7.1)	14 (73.7)	16 (88.9)	1 (33.3)	7 (63.6)	2 (40)	9 (64.3)
Yes, for most residents in need of SPC	0 (0)	2 (14.3)	2 (10.5)	0 (0)	0 (0)	1 (9.1)	0 (0)	0 (0)
Yes, for some residents in need of SPC	4 (33.3)	11 (78.6)	3 (15.8)	2 (11.1)	1 (33.3)	3 (27.3)	2 (40)	3 (21.4)
No, never	4 (33.3)	0 (0)	0 (0)	0 (0)	1 (33.3)	0 (0)	1 (20)	2 (14.3)
Procedure bereavement support relatives?								
Yes	6 (35.3)	3 (12.5)	15 (71.4)	15 (65.2)	6 (75)	13 (54.2)	4 (18.2)	6 (22.2)
Opioids available 24/7 for residents with PC?								
Yes, for all residents	15 (88.2)	17 (63)	17 (81)	18 (85.7)	5 (62.5)	18 (72)	9 (40.9)	9 (34.6)
Yes, for most residents	2 (11.8)	2 (7.4)	3 (14.3)	1 (4.8)	1 (12.5)	2 (8)	1 (4.5)	0 (0)
Yes, for some residents	0 (0)	4 (14.8)	1 (4.8)	1 (4.8)	1 (12.5)	3 (12)	4 (18.2)	12 (46.2)
No, never	0 (0)	4 (14.8)	0 (0)	1 (4.8)	1 (12.5)	2 (8)	8 (36.4)	5 (19.2)

Contact person for residents/relatives to ensure coordinated health and social care?								
Yes, for all residents	15 (88.2)	17 (63)	17 (81)	21 (84)	3 (37.5)	12 (48)	7 (31.8)	12 (44.4)
Yes, for most residents	0 (0)	1 (3.7)	2 (9.5)	2 (8)	0 (0)	0 (0)	0 (0)	0 (0)
Yes, for some residents	0 (0)	0 (0)	2 (9.5)	2 (8)	1 (12.5)	1 (4)	2 (9.1)	0 (0)
No, never	2 (11.8)	9 (33.3)	0 (0)	2 (8)	4 (50)	12 (48)	13 (59.1)	15 (55.6)
Facilities for residents and families								
Specialized equipment available†								
Pressure relieving mattresses	17 (100)	26 (96.3)	21 (95.5)	25 (96.2)	8 (100)	25 (100)	21 (95.5)	26 (96.3)
Suction equipment	17 (100)	17 (63)	16 (72.7)	3 (11.5)	8 (100)	25 (100)	21 (95.5)	24 (88.9)
Stoma care supplies	15 (88.2)	23 (85.2)	16 (72.7)	8 (30.8)	4 (50)	21 (84)	16 (72.7)	19 (70.4)
Oxygen delivery	17 (100)	26 (96.3)	19 (86.4)	13 (50)	7 (87.5)	26 (96.3)	21 (95.5)	13 (48.1)
Syringe driver	13 (76.5)	19 (70.4)	20 (90.9)	20 (76.9)	2 (25)	10 (40)	20 (90.9)	1 (3.7)
Hospital beds	15 (88.2)	25 (92.6)	20 (90.9)	23 (88.5)	7 (87.5)	19 (76)	21 (95.5)	26 (96.3)
Single bedrooms in facility for ALL dying residents who wish to have one?								
Yes	16 (94.1)	24 (92.3)	19 (90.5)	24 (96)	4 (50)	12 (50)	6 (28.6)	7 (25.9)
Unrestricted visiting hours for relatives of dying residents if they wish?								
Yes	16 (94.1)	24 (92.3)	18 (85.7)	22 (88)	8 (100)	23 (95.8)	21 (95.5)	26 (96.3)
Relatives can stay overnight with dying relative								
Yes	17 (100)	21 (80.8)	17 (89.5)	19 (90.5)	7 (87.5)	23 (92)	13 (59.1)	16 (59.3)
Multidisciplinary approaches								
Regular multidisciplinary meeting (with at least a physician and a nurse) to review treatment and care plans organized in your facility?								
Yes	17 (100)	26 (96.3)	16 (76.2)	13 (54.2)	8 (100)	18 (72)	15 (68.2)	20 (76.9)
If yes, how frequently is this meeting organized?								
Weekly	3 (17.6)	9 (33.3)	5 (29.4)	6 (27.3)	4 (50)	9 (36)	5 (23.8)	7 (26.9)
Monthly or less often	14 (82.4)	18 (66.7)	12 (70.6)	16 (72.7)	4 (50)	16 (64)	16 (76.2)	19 (73.1)
Quality improvement initiatives								
Systematic assessment of relatives' experiences regarding provided care?								
Yes, for all residents	8 (47.1)	10 (37)	11 (52.4)	18 (75)	8 (100)	12 (50)	4 (18.2)	1 (3.7)

Yes, for most residents	1 (5.9)	3 (11.1)	4 (19)	1 (4.2)	0 (0)	1 (4.2)	5 (22.7)	2 (7.4)
Yes, for some residents	2 (11.8)	4 (14.8)	1 (4.8)	1 (4.2)	0 (0)	4 (16.7)	1 (4.5)	4 (14.8)
No, never	6 (35.3)	10 (37)	5 (23.8)	4 (16.7)	0 (0)	7 (29.2)	12 (54.5)	20 (74.1)
Specific guidelines used for the last 3 days of life of a resident in need of palliative care in your facility?								
Yes	8 (47.1)	10 (37)	12 (52.2)	21 (51.2)	2 (28.6)	1 (4.2)	2 (9.1)	5 (20)

*Nursing home type: In this table Belgium and Finland are not reported since they only have type 2 homes. Type 1 includes nursing homes with 24/7 on-site physicians, nurses and care assistants, type 2 are nursing homes with 24/7 on-site nurses and care assistants and off-site physicians and type 3 consists of nursing homes with 24/7 on-site care assistants and off-site nurses and physicians.

Due to convergence problems because of low numbers of cases the significance of these differences could not be tested.

PART II

INAPPROPRIATE TREATMENTS AND HOSPITALIZATIONS AT THE END OF LIFE

CHAPTER 4

POTENTIALLY INAPPROPRIATE TREATMENTS AT THE END OF LIFE IN NURSING HOME RESIDENTS FROM SIX EUROPEAN COUNTRIES

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Honinx E, Van den Block L, Piers R, et al. Potentially inappropriate treatments at the end of life in nursing home residents: Findings from the PACE cross-sectional study in 6 European countries. Journal of Pain and Symptom Management. Published online September 2020. doi:10.1016/j.jpainsymman.2020.09.001

Abstract

Context

Certain treatments are potentially inappropriate when administered to nursing homes residents at the end of life and should be carefully considered. An international comparison of potentially inappropriate treatments allows insight into common issues and country-specific challenges of end-of-life care in nursing homes and helps direct health care policy in this area.

Objectives

To estimate the prevalence of potentially inappropriate treatments in the last week of life in nursing home residents, and analyze the differences in prevalence between countries.

Methods

A cross-sectional study of deceased residents in nursing homes (2015) in six European countries: Belgium (Flanders), England, Finland, Italy, the Netherlands and Poland. Potentially inappropriate treatments included: enteral administration of nutrition, parental administration of nutrition, artificial fluids, resuscitation, artificial ventilation, blood transfusion, chemotherapy/radiotherapy, dialysis, surgery, antibiotics, statins, antidiabetics, new oral anticoagulants. Nurses were questioned about whether these treatments were administered in the last week of life.

Results

We included 1384 deceased residents from 322 nursing homes. In most countries, potentially inappropriate treatments were rarely used, with a maximum of 68.2% of residents receiving at least one treatment in Poland. Exceptions were antibiotics in all countries (between 11.3% in Belgium and 45% in Poland), artificial nutrition and hydration in Poland (54.3%) and Italy (41%) and antidiabetics in Poland (19.7%).

Conclusion

Although the prevalence of potentially inappropriate treatments in the last week of life was generally low, antibiotics were frequently prescribed in all countries. In Poland and Italy, the prevalence of artificial administration of food/fluids in the last week of life was high, possibly reflecting country differences in legislation, care organization and culture, and the palliative care competences of staff.

Key words: potentially inappropriate treatments, nursing homes, end-of-life care, Europe.

Key message:

Potentially inappropriate treatments in the last week of life of nursing homes residents are uncommon in most countries except for the use of antibiotics. In Italy and Poland these treatments are more prevalent, especially artificial nutrition and fluid treatments and antibiotics, possibly due to country differences in legislation, organization, culture and staff competence.

Introduction

In Europe, an increasing number of older people spend their last months in nursing homes and up to 38% of people over 65 years die there[1]. We conducted the PACE (Palliative Care for Older People) cross-sectional study in nursing homes in Belgium, England, Finland, Italy, the Netherlands and Poland[2], and demonstrated that residents in these countries die at a mean age of 85 years, often with advanced dementia, multiple comorbidities and clinical complications[1,3,4]. This makes them a particularly vulnerable population for whom providing appropriate treatments at the end of life is crucial, albeit challenging[1,3–8].The difficulty of predicting death in older people complicates the decision on whether a treatment or medication is still appropriate[9]; staff are sometimes too optimistic about the benefits of such treatments[10,11], and residents are often poorly informed of the possible complications[12].

Recent studies show that certain treatments are potentially inappropriate when administered to older people at the end of life, in particular those with dementia and those living in nursing homes, and should therefore be carefully considered[13–15]. Antibiotics and medications like anti-diabetics, statins or oral anticoagulants have no or questionable benefit in short-term use in the last week of life[13]. In long-term use, polypharmacy, comorbidities and age-related alterations in drug metabolism can result in side-effects that cause functional and cognitive impairment in older adults[16–18]. Artificial nutrition and hydration[19–21], resuscitation[22,23] and artificial ventilation[24–26] can have deleterious effects on quality of life when used in the last week and can complicate the dying process while blood transfusion, chemo/radiotherapy, dialysis or surgery can be futile and burdensome with low survival rates and resulting in poor quality of life[10–12,14].

Earlier studies on potentially inappropriate treatments are limited to describing prevalence in one country or comparison between countries in specific settings such as home care[27] or during the last month of life[28]. So far, there are no studies that have compared prevalence of potentially inappropriate treatments in the last week of life between European countries. An international comparison would allow deeper insight into common issues and country-specific challenges in nursing homes and could help direct health care policy and decision-makers. The aim of the current study was to estimate the prevalence of potentially inappropriate treatments in the last week of life in nursing home residents in six European countries and to study the differences in prevalence of these treatments between countries.

Methods

Study design and sampling

A cross-sectional study of deceased residents in nursing homes was conducted in 2015 in six European countries: Belgium (Flanders), England, Finland, Italy, the Netherlands and Poland[2], using proportional stratified random sampling. In each country, nursing homes were stratified by region (provinces or other large regions), by type and by bed capacity (above/below country median), and sampled randomly to cover the entire country. For each one that declined participation, another from the same stratum was sampled. Available national (or regional in Belgium) lists were used for recruitment. In England, we also used the ENRICH (Enabling Research in Care Homes) network[29]. In Italy, a previously created cluster interested in research was used as the basis for the sample since no national list was available. We aimed to include at least 48 nursing homes per country, to identify a minimum of 192 residents per country or 1152 in total[2]. The PACE protocol provides more details[2].

Setting and participants

The term nursing home in this paper refers to 'collective institutional settings where care, on-site provision of personal assistance with activities of daily living, and on-site or off-site provision of nursing and medical care, is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time' [30]. Participating nursing homes reported on all deceased residents over the preceding three months. Questionnaires on each were sent to the nurse/care assistant most involved in their care, the manager, and the resident's general practitioner (GP); the manager was asked to fill in a questionnaire about the nursing home.

Data collection

Nursing homes received a letter presenting the PACE project and a call for participation. Further contact was made via phone or email. The manager nominated an internal contact who provided an overview of all deceased residents in the preceding three months and a list of the key respondents for each (staff member, i.e. nurse/care assistant most involved in care, manager/administrator, GP); these received a paper questionnaire with an anonymous code and an attached document that guaranteed full anonymity and confidentiality with questionnaires returned directly to the researchers who monitored them using excel files. In case of non-response, up to two reminders were sent after three and six weeks.

Measurements

Questionnaires from all three key respondents were used to report on the characteristics of the resident: age, gender, length of stay in the nursing home, place of death, presence and stage of dementia at time of death, diseases at time of death and functional and cognitive status during last month of life (Table 1). Presence of dementia was based on the estimation of the GP, nurse or both; stage was based on the Global Deterioration Scale and the Cognitive Performance Scale, as estimated by nursing staff[3] with CPS scores of 5-6 and GDS stage 7 considered as advanced dementia. The score for functional and cognitive status during last month of life was computed with the Bedford Alzheimer Nursing Severity Scale (BANS-S)[31], ranging between 7 and 28. Higher scores indicated greater severity.

In this study, we refer to inappropriate treatments as treatments and/or medication for which 'the negative consequences (such as mortality and symptom burden) outweigh the expected health benefits (such as increased life expectancy or pain relief)'[32]. We first performed an extensive literature search. Next, during multiple meetings with the PACE consortium (i.e. geriatricians, nurses, psychologists) and palliative care researchers, we discussed the list of potentially inappropriate treatments and made a final selection based on the following criteria: 1) used as a standard treatment for older people, 2) considered potentially life-prolonging, and 3) can be easily recalled by a nurse filling in the questionnaire. The final selection agreed by the consortium partners, was: artificial enteral administration of nutrition (e.g. tube feeding, percutaneous endoscopic gastrostomy i.e. PEG), parenteral administration of nutrition, artificial fluids, resuscitation, artificial ventilation, blood transfusion, chemotherapy/radiotherapy, dialysis, surgery, antibiotics, statins, antidiabetics, new oral anticoagulant [33–38]. Nurses were asked whether, to their knowledge, these were administered in the last week of life or not (meaning either ‘not at all’ or ‘in the last month except the last week’). The treatments were then subdivided into five categories: artificial nutrition and hydration treatments (enteral administration nutrition, parental administration nutrition, artificial fluid), critical treatments (resuscitation and artificial ventilation), antimicrobial treatments (antibiotics), medications (statins, antidiabetics, new oral anticoagulants) and other (blood transfusion, chemotherapy/radiotherapy, dialysis, surgery).

Statistical analysis

Analyses were conducted for deceased residents for whom an assessment by the nurse was made retrospectively, using IBM SPSS version 25[39]. To investigate the effect of missing data (up to 24% missing values for some treatments), sensitivity analyses were conducted via imputation of incomplete cases with fully conditional specification (shown in Results and Table 2) and complete cases (Table 1A in Appendix). The imputation method estimates each missing value based on associations with other covariates from the dataset using regression analysis (age of resident, gender of resident, availability and number of visits by GP, comorbidity and cause and place of death). Demographic and clinical characteristics are reported as mean and standard deviation (SD) for continuous variables, or median and range in case of skewness, and count and percentage for categorical variables. Generalized linear mixed models were used to compute differences in demographic characteristics of residents between countries. These models were used for the analyses because of the clustering of data (in countries and nursing homes). Country was included as a fixed effect and nursing home as a random effect in each model (Table 1).

To determine differences in the prevalence between countries, we conducted logistic mixed-effects regression analyses (Table 2). Country was again included as a fixed effect and nursing home as a random effect in each model. To correct for differences in demographic and clinical characteristics, we included age, length of stay, place of death, dementia at time of death, diseases (cancer, cardiovascular, pulmonary and others) and functional/cognitive status as fixed effects. This allowed for a fair comparison between countries. We exlucded missing values for each characteristic from the analysis. We present frequencies and total numbers for all potentially inappropriate treatments in each country. An alpha level of $p<0.05$ represents statistical significance.

Ethical aspects

The relevant ethics committee of each country approved the study protocol [2], except for Italy and the Netherlands, where no additional ethical approval was needed since retrospective data of deceased residents was used.

Results

In 322 participating nursing homes, 1707 deaths were reported. For 11 cases, no staff member could be identified (Figure 1). Of the 1696 staff members sent a questionnaire, 1384 responded (overall response rate 81.6%). Response rates per country are reported in the footnotes of Figure 1. Sensitivity analyses using only complete cases (Table 1A in Appendix) did not result in different conclusions.

Characteristics of the study sample

At the time of death, mean age ranged between 81 years in Poland and 87 years in Belgium and England (Table 1). Residents were mostly female, ranging from 63.5% in Poland to 75% in England. The shortest median stay (145 days) was found in Poland, the longest (745 days) in Belgium. Residents died mainly in the nursing home (80% in Poland – 89.3% in the Netherlands). Dementia was most prevalent in Finland (82.5%) and least in England (60.2%), with between 42.9% (England) and 64% (Poland) being advanced. Severe cardiovascular disease was most often reported as the disease at time of death in all countries (34.7% in Belgium – 55.7% in Poland) except England, where this was malignant cancer (42.9%). The poorest functional and cognitive status was found in Poland (BANS-S mean score of 21.9) and the best in England (BANS-S mean score of 17.5).

Differences in the prevalence of potentially inappropriate treatments in the last week of life in six countries

Use of at least one potentially inappropriate treatment in the last week ranged from 19.9% in Belgium to 68.2% in Poland (p<0.001). Artificial nutrition and/or hydration were most frequent in Poland (54.3%) and least in the Netherlands (2.7%; p<0.001). In advanced dementia, use was low in England (0%), the Netherlands (1.7%), Finland (3.8%) and Belgium (4.8%) but higher in Italy (43.9%) and Poland (59.4%; not in tables). Artificial fluids were being used most (p<0.001), in particular in Poland (48.6%) and Italy (24.5%). Artificial enteral nutrition was administered mainly in Poland (17%; p>0.001) whereas parenteral nutrition was more prevalent in Italy (21.5%; p>0.001). Use of critical care treatments was limited, ranging from 8.7% in Poland to 1.4% in Belgium (p<0.001), with resuscitation being most frequent in England (5.5%; p=0.05) and artificial ventilation in Poland (7.1%; p>0.001). Of all treatments, antibiotics were the most commonly used in all countries, from 11.3% in Belgium to 45% in Poland (p<0.001). At least one of antibiotics, antidiabetics, statins, and anticoagulants was used in 18.3% of residents in Poland and 4.8% in Belgium (p<0.001). Antidiabetic medications were administered from 2.2% in England to 13.2% in Poland (p<0.001) and statins from 1% in Belgium to 4.4% in England (p=0.23). No use of oral anticoagulants was reported in England while in Poland use was reported for 5.5% of residents (p<0.001). Other treatments like blood transfusions, chemotherapy or radiotherapy, dialysis and surgery were rarely used, from England where no usage was reported to Poland where 3.2% of residents underwent at least one of these treatments (p<0.001). Dialysis was rarely used (p<0.001) ranging between 0% (England and Finland) and 1.6% (Poland). Surgery was performed on none of the residents in England and on up to 1.4% in the Netherlands (p<0.001). No blood transfusions were reported in England with 1% in Poland (p<0.001). Chemotherapy and radiotherapy were almost never used in the last week of life in any country, ranging from 0% in Belgium, England, the Netherlands and Poland to 1% in Italy. The risk adjustment procedure ruled out these differences being due to resident characteristics, implying they reflected differences in appropriate care between countries.

Results of the complete case analysis were similar to the results from the imputed data (Table 1A in Appendix).

Discussion

Main findings

Artificial ventilation, resuscitation, blood transfusions, chemotherapy or radiotherapy, dialysis and surgery were rarely used in the last week of life of nursing home residents in most of the studied countries. However, the prevalence of most treatments differed statistically significantly between countries. Poland had the highest percentage of residents receiving at least one potentially inappropriate treatment in the last week of life. Artificial nutrition and/or hydration were common in Poland and Italy, in particular the administration of artificial fluids, even in residents with advanced dementia. Antibiotics were frequently administered in all countries, albeit with the highest rates in Poland and Italy, and antidiabetics were most often administered in Poland.

Strengths and limitations

This study is the first to compare the use of potentially inappropriate treatments in the last week of life of nursing home residents in representative samples of nursing homes in different countries. We were able to include data on 1384 residents from 322 nursing homes in six European countries with different healthcare systems[6] and palliative care cultures[40]. The risk adjustment procedure assured that our results reflected differences in prevalence between countries and were not influenced by differences in resident characteristics.

This study also has important limitations. Firstly, it is not possible to infer from survey data when a particular treatment is 'inappropriate'. The data may lead to the assumption that, in retrospect, all treatments administered in the last week of life were inappropriate. However, death is difficult to predict[41] so at the time it was given, a treatment may not have been considered inappropriate. Nevertheless, this study compares the use of treatments on a country level and does not aim to evaluate their appropriateness on an individual level. Secondly, the data were collected from nurses rather than directly from resident files. There is a possibility of recall bias, though nurses were instructed to consult patient records where necessary. Thirdly, we did not collect information about when treatments were initiated or the clinical indications for them, which would have provided a more detailed understanding. Fourthly, we were dealing with high quantities of missing data for some treatments (up to 24%). Therefore, sensitivity analyses were conducted via regression imputation of incomplete and complete cases. These showed mainly similar results, indicating that the missing data influence was small. Finally, when a resident died in hospital, the nursing home may not have had information on hospital treatments in the last week of life, leading to a possible underestimation. However, given that only 15% of the residents died in-hospital, the possible bias caused by this is likely to be small.

What this paper adds

This study showed that the prevalence of most potentially inappropriate treatments in the last week of life was low in nursing home residents in Belgium, England, Finland and the Netherlands and particularly low compared with earlier studies in the United States and Canada. For instance, up to 23% of residents with severe cognitive impairment in Canada received statins in their last week of life, and anticoagulants were used in 52% of nursing home residents with dementia. However, comparison of data is difficult when study designs and data collection are different (data from medical records and administrative databases using prospective samples)[42–45]. Besides the variation in data collection and study design, differences might be explained by the North American medical culture that tends to favor more aggressive treatments for terminally ill people[46].

The use of antibiotics in the last week of life was high in all countries, from one in ten in Belgium to four in ten in Poland. There is an ongoing debate on the indications for antibiotics at the end of life[47,48] and guidelines on antimicrobial stewardship in palliative care do not yet exist[48]. While some researchers consider antibiotic treatment in the last days of life to be pointless[49–51], others consider it part of symptom control[52]. Earlier research on the use of antibiotics in nursing homes revealed a similar prevalence at the end of life[53–58]. It is challenging to predict when someone will die[41] and whether an antimicrobial treatment will have a positive effect on symptom control, which complicates the decision[47], particularly in residents with cognitive impairments for whom expressing symptoms is difficult[48]. Better recognition of the terminal phase might help with these decisions. Finally, more research is needed to guide the use of antibiotics at the end of life of nursing home residents.

The low prevalences in Belgium, England and the Netherlands might be partly explained by the culture of palliative care. In those countries many nursing homes provide palliative care and have more palliative care implementation activities [6], with high regional and national activity at policy, finance, legislation and regulation levels and a longer tradition of advance care planning than in Poland and Italy, making nursing home staff more aware of the resident's preferences at the end of life.

In contrast with other countries, the prevalence of most potentially inappropriate treatments was highest in Poland and Italy, especially for enteral and parenteral administration of nutrition and artificial fluid administration, even with advanced dementia. There are several possible explanations for this. Firstly, the high rate in Italy might be related to law enforcement. In 2009, a bill was passed[59] mandating that hydration and nutrition must always be provided, and by any means, because they are considered basic support measures and fundamental to life. In Poland, artificial feeding is considered an admission criterion for nursing homes [60]. Nevertheless, their appropriateness is questionable [61], especially for those with advanced dementia[15]. Taking into account the relatively high numbers with advanced dementia in our sample, with the highest rates in Poland and Italy (64% and 55%), our findings are particularly striking.

Secondly, care culture in these countries rarely includes advance care planning, leaving the administration or discontinuation of certain treatments undiscussed[62]. This may lead to more pressure from family members to use all possible treatments[62,63]. The decision about discontinuation may also cause ethical problems when there is no advance care planning in place. In addition, because of the greater taboo about death and dying in these countries, nursing home staff may not feel competent to discuss end-of-life issues with residents and family members[5,64,65].

A third possible explanation may be the low level of basic knowledge of end-of-life care among nursing home staff. An earlier report of the PACE study[7] showed that knowledge of the basic physical aspects of end-of-life care among nurses and care assistants in nursing homes was lowest in Poland and Italy, particularly of indications for the use of feeding tubes[7]. Fourthly, GPs in Poland

and Italy recognize the terminal phase less often than in Belgium, England, Finland and the Netherlands[66]. Nursing home residents in Poland and Italy also least often had palliative care as their main treatment goal in the last week of life, indicating a focus on life-sustaining treatments. This might lead to negative consequences such as more futile or invasive treatments, more 'in bed' time and higher healthcare costs[67]. At the same time, one could argue that treatment choices also have to be culturally sensitive to be appropriate. Although ESPEN (European Society of Clinical Nutrition and Metabolism) has elaborated European nutrition recommendations[68], there are country-specific approaches to artificial nutrition, which not only depend on legislation or health care policy and organization, but also on culture. It is also plausible that a difference in prescribing habits between countries is responsible for difference in treatments. However, this was not examined in this study and should be included in future research

Implications

Our findings are a potential starting point for the improvement of end-of-life care treatments in nursing homes. Practices where there is more room for improvement (e.g. artificial nutrition and hydration treatments), require particular attention. Substantial country differences call for the development of guidelines to assist nursing home staff and GPs in treatment decision-making – taking into account cultural differences – and in recognizing the terminal phase. Further, greater attention needs to be paid to advance care planning in nursing homes as this may help residents, relatives and caregivers to discuss goals and preferences for future care. Finally, there is a need for staff training in end-of-life care conversations and the physical aspects of end-of-life care. Our results can be used by policy and other decision-makers to develop public health policies and interventions to improve the appropriateness of end-of-life care in nursing homes and allow the exchange of good practices across national borders.

Conclusion

The prevalence of potentially inappropriate treatments in the last week of life of nursing home residents was low in most studied countries, except for the use of antibiotics which was common. In Italy and Poland, all treatments were more prevalent, specially the administration of artificial nutrition and fluids and antibiotics. These differences may reflect country-specific differences in legislation, care organization, culture and the knowledge and skills of nursing home staff regarding palliative care.

Declarations

Disclosure Statement

Miss Honinx reports funding from Polish Ministry of Science and Higher Education based on the decision no 3202/7PR/2014/2, grants from European Union's Seventh Framework Programme (FP7/ 2007e2013), during the conduct of the study.

Ethics approval and consent to participate

Ethics approval from the relevant ethics committees were obtained in all participating countries. Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: NHS – NRES Committee North West-Haydock, 10/09/2015; Finland: Terveyden jahyvinvoinnin laitos, Institutet för hälsa och välfärd, 30/6/2015; Italy: Comitato Etico, Universita Cattolica del Sacro Cuore, 6/11/2017; Netherlands: Medisch Ethische Toetsingscommissie VUMedisch Centrum, 2/7/2015; Poland: Komisja Bioetycza, Uniwersytetu Jagiellonskiego, 25/6/2015; Switzerland: Commission cantonale d'éthique de la recherché scientifique de Genève (CCER), 6/8/2015.

All persons participating in the study (facility managers, care staff, GPs) have to give their prior informed consent in writing. If participants are unable to give informed consent, they will not be involved in the study. In some countries, such as Poland and the Netherlands, a separate informed consent is not required if questionnaires are filled in anonymously.

Consent for publication

Not applicable.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Project has been co-funded by Polish Ministry of Science and Higher Education in the years 2014-2019 based on the decision no 3202/7PR/2014/2 dated on Nov. 25th, 2014. This work was supported by the European Union's Seventh Framework Programme (FP7/ 2007e2013) under grant agreement 603111 (PACE project Palliative Care for Older People). The funders had no role in study design, collection, analysis or interpretation of the data, nor in writing and the decision to submit this article for publication.

Authors' contributions

EH, TS, RP, SVK, BDOP, SP, KS, GG, HFS, DL and LVDB were involved in the study design. TS, BDOP, SP, KS, GG, HFS, DL and LVDB are involved in data acquisition. EH, TS, RP, SVK, LD, and LVDB were involved in developing the data analysis plan. EH, TS, RP, SVK, BDOP, SP, KS, GG, HFS, DL and LVDB were involved in writing of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

We thank all participating physicians, nurses, patients, and their families for providing data for this study; and Jane Ruthven for her language editing.

Other PACE collaborators not in the list: Yuliana Gatsolaeva, Rose Miranda, Lara Pivodic, Marc Tanghe, Hein van Hout, Nele Van Den Noortgate, Katherine Froggatt, H. Roeline W. Pasman, Ilona Baranska, Mariska Oosterveld-Vlug, Anne B. Wichmann, Yvonne Engels, Myrra Vernooij-Dassen, Jo Hockley, Suvi Leppäaho, Sophie Pautex, Catherine Bassal, Federica Mammarella, Martina Mercuri, Paola Rossi, Ivan Segat, Agata Stodolska, Eddy Adang, Marika Kylänen, Paula Andreasen, Outi

Kuitunen-Kaija, Danni Collingridge Moore, Agnieszka Pac, Violetta Kijowska, Maud ten Koppel, Jenny T. van der Steen, Emilie Morgan de Paula, and the European Association for Palliative Care vzw, European Forum For Primary Care, Age Platform Europe, and Alzheimer Europe.

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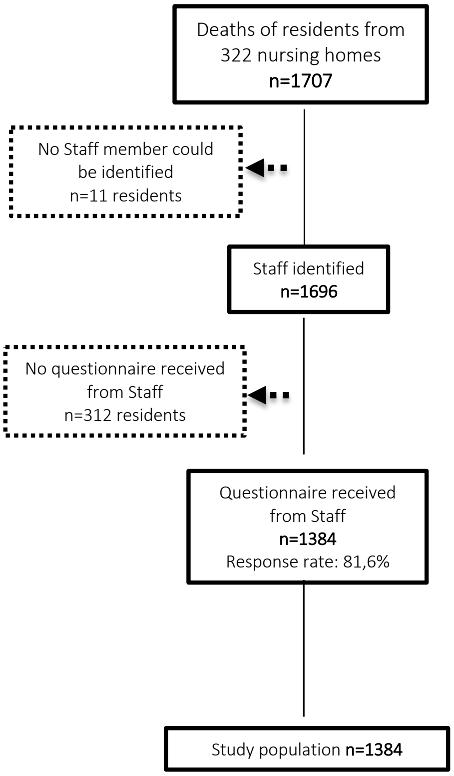
Figure 1: Flowchart of identified deceased residents for whom an assessment by staff° was made in six countries



° staff = nurse or care assistant most involved in resident's care
Response rates per country: Belgium (85.1% (N=291/342)); England (54.2% (N=91/168)); Finland (95.1% (N=269/283)); Italy (91.7% (N=200/229)); the Netherlands (67.5% (N=222/329)); Poland 87.4% (N=311/356).

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Table 1: Demographic and clinical characteristics of deceased residents for whom an assessment by staff° was made in six countries: (N=1384)

	BE (N=291)	**EN** (N=91)	**FI** (N=269)	**IT** (N=200)	**NL** (N=222)	**PL** (N=311)	P-value*
Age – years ||							
Mean (SD) years old at time of death	87 (7)	87 (9)	85 (9)	86 (8)	86 (9)	81 (11)	**<0.001**
Gender ||							
Female Count (%)	174 (64.0)	66 (75.0)	169 (64.3)	136 (68.3)	132 (66.7)	195 (63.5)	
Male Count (%)	98 (36.0)	22 (25.0)	94 (35.7)	63 (31.7)	66 (33.3)	112 (36.5)	0.387
Length of stay ||							
Median (min-max) number of days	745 (2-9706)	600 (2-4952)	581 (1-9218)	416 (2-10171)	710 (1-6290)	145 (1-12365)	**<0.05**
Place of Death ||^							
Nursing home Count (%)	226 (82.2)	71 (81.6)	224 (84.8)	170 (86.7)	176 (89.3)	248 (80.0)	
Hospital Count (%)	48 (17.5)	16 (8.6)	24 (9.1)	26 (13.3)	12 (6.1)	60 (19.4)	**<0.001**
Dementia at time of death (yes) †‡ §							
Count (%)	183 (62.9)	53 (60.2)	222 (82.5)	154 (77.0)	135 (61.4)	207 (67.9)	**<0.001**
Advanced dementia							
Count %	83 (52.5)	18 (42.9)	78 (43.8)	66 (55.0)	60 (46.2)	96 (64.0)	0.676
Diseases at time of death‡¶							
Malignant cancer‡	30 (15.5)	9 (42.9)	41 (19.4)	26 (17.2)	27 (18.5)	10 (4.0)	**<0.001**
Severe cardiovascular disease‡	67 (34.7)	2 (9.5)	79 (37.4)	71 (47.0)	45 (30.8)	141 (55.7)	**<0.05**
Cerebrovascular accident (CVA)‡	40 (20.7)	3 (14.3)	49 (23.2)	34 (22.5)	25 (17.1)	70 (27.7)	0.483
Severe pulmonary disease‡	33 (17.1)	3 (14.3)	17 (8.1)	40 (26.5)	17 (11.6)	18 (7.1)	**<0.001**
Severe neurological disease (not dementia) ‡	15 (7.8)	0 (0.0)	26 (12.3)	18 (11.9)	11 (7.5)	32 (12.6)	0.381
Severe renal disease‡	19 (9.8)	2 (9.5)	13 (6.2)	22 (14.6)	19 (13.0)	29 (11.5)	0.420
Severe diabetes‡	11 (5.7)	1 (4.8)	16 (7.6)	18 (11.9)	17 (11.6)	33 (13.0)	0.177
Other severe disease‡	31 (16.1)	3 (14.3)	51 (24.2)	33 (21.9)	4 (2.7)	33 (13.0)	**<0.001**
Functional/cognitive status one month before death (BANS-S) † ¶							
Mean (SD)	18.5 (4.9)	17.5 (4.2)	19.6 (4.3)	21.8 (3.7)	17.7 (4.7)	21.9 (4.6)	**<0.001**

* Logistic regression mixed model reporting p-value for differences between countries, **α** =0.05

|| Reported by administrator/manager of nursing home. For 44 out of 1384 residents no questionnaire was returned by the administrator/manager of care home; these are not included as missing values reported below.

† Reported by staff member (nurse/care assistant) most involved in care.

‡ Reported by general practitioner (GP). For 397 out of 1384 residents no questionnaire was returned by the GP, these are not included as missing values below.
§ When either the physician or the nurse (or both) considered the resident to have dementia, this was coded as yes.
° staff = nurse or care assistant most involved in resident's care
^Other categories: facility hospice/ PC unit or other
¶ Scores on BANS-S range from 7 to 28; higher scores indicate greater severity.
Percentages may not always add up to 100 because of rounding.
Abbreviations: BANS-S = Bedford Alzheimer Nursing Severity Scale, SD = Standard Deviation
Missing values: age=13, sex=13, size=60, length of stay=36, place of death=11, dementia =11, stage of dementia=187 (419 not applicable because resident did not have dementia), diseases at time of death=12, BANS-S=86 missing data on at least one item.

Table 2. Prevalence of potentially inappropriate treatments in the last week of life in six countries°

	BE (N=291) Count (%)	**EN** (N=91) Count (%)	**FI** (N=269) Count (%)	**IT** (N=200) Count (%)	**NL** (N = 222) Count (%)	**PL** (N=311) Count (%)	Country range (%)	Corrected p-value*
Artificial nutrition and hydration treatments								
Enteral administration of nutrition	2 (0.7%)	1 (1.1%)	2 (0.7%)	13 (6.5%)	3 (1.4%)	53 (17%)	*0.7% - 17%*	<0.001
Parenteral administration of nutrition	3 (1%)	1 (1.1%)	4 (1.5%)	43 (21.5%)	0 (0.0%)	40 (12.9%)	*0.0% - 21.5%*	<0.001
Artificial (non-oral) fluid administration	17 (5.8%)	6 (6.6%)	19 (7.1%)	45 (24.5%)	5 (2.3%)	151 (48.6%)	*2.3% - 48.6%*	<0.001
At least one artificial nutrition and hydration treatment	*19 (6.5%)*	*7 (7.7%)*	*22 (8.2%)*	*82 (41%)*	*6 (2.7%)*	*169 (54.3%)*	*2.7% - 54.3%*	<0.001
Critical care treatment								
Resuscitation	2 (0.7%)	5 (5.5%)	4 (1.5%)	2 (1%)	1 (0.5%)	7 (2.3%)	*0.5% - 5.5%*	0.05
Artificial ventilation	3 (1%)	4 (4.4%)	7 (2.6%)	7 (3.6%)	3 (1.4%)	22 (7.1%)	*1% - 7.1%*	<0.001
At least one critical care treatment	*4 (1.4%)*	*8 (8.8%)*	*11 (4.1%)*	*9 (4.9%)*	*4 (1.8%)*	*27 (8.7%)*	*1.4% - 8.7%*	<0.001
Antimicrobial treatment								
Antibiotics of any type	33 (11.3%)	18 (19.8%)	48 (17.8%)	74 (37%)	38 (17.1%)	140 (45%)	*11.3% - 45%*	<0.001
At least one medication								
Statins	3 (1%)	4 (4.4%)	10 (3.7%)	4 (2%)	9 (4.1%)	13 (4.2%)	*1% - 4.4%*	0.23
Antidiabetics	12 (4.1%)	2 (2.2%)	18 (6.7%)	7 (3.5%)	14 (6.3%)	41 (13.2%)	*2.2% - 13.2%*	<0.001
Oral anticoagulants	1 (0.3%)	0 (0.0%)	3 (1.1%)	4 (2%)	7 (3.2%)	17 (5.5%)	*0.0% - 5.5%*	<0.001
At least one medication	*14 (4.8%)*	*5 (5.5%)*	*28 (10.4%)*	*11 (5.5%)*	*20 (9%)*	*57 (18.3%)*	*4.8% - 18.3%*	<0.001
Other treatments								
Blood transfusion	1 (0.3%)	0 (0.0%)	1 (0.4%)	2 (1%)	1 (0.5%)	3 (1%)	*0.0% - 1%*	<0.001
Chemotherapy/radiotherapy	0 (0.0%)	0 (0.0%)	1 (0.4%)	2 (1%)	0 (0.0%)	0 (0.0%)	*0.0% - 1%*	0.01
Dialysis	1 (0.3%)	0 (0.0%)	0 (0.0%)	2 (1%)	1 (0.5%)	5 (1.6%)	*0.0% - 1.6%*	<0.001
Surgery	1 (0.3%)	0 (0.0%)	1 (0.4%)	1 (0.5%)	3 (1.4%)	2 (0.6%)	*0.0% - 1.4%*	<0.001
At least one of the other treatments	*3 (1%)*	*0 (0.0%)*	*3 (1.1%)*	*7 (3.5%)*	*5 (2.3%)*	*10 (3.2%)*	*0.0% - 3.5%*	<0.001
At least one potentially inappropriate treatment	*58 (19.9%)*	*28 (30.8%)*	*75 (27.9%)*	*106 (53%)*	*51 (23%)*	*212 (68.2%)*	*19.9% - 68.2%*	<0.001

Logistic regression mixed model reporting p-value for differences between countries, **α** =0.05
All treatments are reported by staff member (nurse/care assistant) most involved in care.
°Results from regression imputation.
* To correct for differences in demographic and clinical characteristics, we included age, length of stay, place of death, dementia at time of death, diseases at time of death (cancer, cardiovascular, pulmonary and other diseases) and functional/cognitive status as fixed effects.

Appendix Chapter 4

Table 1A Prevalence of potentially inappropriate treatments in the last week of life in six countries (complete case analysis)

	BE (N=291) Count (%)	**EN** (N=91) Count (%)	**FI** (N=269) Count (%)	**IT** (N=200) Count (%)	**NL** (N = 222) Count (%)	**PL** (N=311) Count (%)	Country range (%)	Corrected p-value*
Artificial nutrition and hydration treatments								
Enteral administration of nutrition	2 (0.7%)	1 (1.4%)	2 (0.8%)	13 (7.7%)	3 (1.4%)	53 (24.9%)	*0.7% - 24.9%*	**<0.001**
Parenteral administration of nutrition	3 (1.1%)	1 (1.4%)	4 (1.7%)	43 (25.6%)	0 (0.0%)	40 (19.8%)	*0.0% - 19.8%*	**<0.001**
Artificial (non-oral) fluid administration	16 (6%)	6 (8.1%)	19 (8%)	45 (26.8%)	4 (2%)	125 (52.1%)	*6% - 52.1%*	**<0.001**
At least one artificial nutrition and hydration treatment	*18 (6.8%)*	*7 (9.5%)*	*22 (9.6%)*	*81 (49.7%)*	*6 (2.9%)*	*163 (66.3%)*	*2.9% - 66.3%*	**<0.001**
Critical care treatment								
Resuscitation	2 (0.8%)	5 (6.7%)	4 (1.7%)	2 (1.3%)	1 (0.5%)	7 (4%)	*0.5% - 4%*	0.16
Artificial ventilation	3 (1.1%)	4 (5.4%)	7 (3%)	7 (4.6%)	3 (1.5%)	22 (11.8%)	*1.1% - 11.8%*	**<0.001**
At least one critical care treatment	*4 (1.5%)*	*8 (10.8%)*	*11 (4.7%)*	*9 (5.9%)*	*4 (1.9%)*	*27 (14.8%)*	*1.5% - 14.8%*	**<0.001**
Antimicrobial treatment								
Antibiotics of any type	33 (12%)	18 (22%)	46 (18.5%)	71 (38.4%)	35 (17%)	107 (44.2%)	*12% - 44.2%*	**<0.001**
At least one medication								
Statins	3 (1.2%)	4 (6.1%)	10 (4.4%)	4 (2.7%)	9 (4.5%)	13 (8.1%)	*1.2% - 8.1%*	0.22
Antidiabetics	12 (4.6%)	2 (2.9%)	18 (7.8%)	7 (4.5%)	14 (7%)	38 (19.7%)	*2.9% - 19.7%*	**<0.001**
Oral anticoagulants	1 0.4%	0 (0.0%)	3 (1.3%)	4 (2.7%)	7 (3.5%)	17 (9.6%)	*0.0% - 9.6%*	**<0.001**
At least one medication	*14 (5.8%)*	*5 (7.9%)*	*28 (12.4%)*	*11 (7.5%)*	*20 (10.2%)*	*57 (31%)*	*5.8% - 31%*	**<0.001**
Other treatments								
Blood transfusion	1 (0.4%)	0 (0.0%)	1 (0.4%)	2 (1.3%)	1 (0.5%)	3 (1.7%)	*0.0% - 1.7%*	**<0.001**
Chemotherapy/radiotherapy	0 (0.0%)	0 (0.0%)	1 (0.4%)	2 (1.3%)	0 (0.0%)	0 (0.0%)	*0.0% - 1.3%*	0.07
Dialysis	1 (0.4%)	0 (0.0%)	0 (0.0%)	2 (1.3%)	1 (0.5%)	5 (2.9%)	*0.0% - 2.9%*	**<0.001**
Surgery	1 (0.4%)	0 (0.0%)	1 (0.4%)	1 (0.7%)	3 (1.5%)	2 (1.3%)	*0.0% - 1.5%*	**<0.001**
At least one of the other treatments	*3 (1.2%)*	*0 (0.0%)*	*3 (1.3%)*	*7 (4.8%)*	*5 (2.6%)*	*10 (6.5%)*	*0.0% - 6.5%*	**<0.001**

Generalized linear mixed model reporting p-value for differences between countries, α =0.05

All treatments are reported by staff member (nurse/care assistant) most involved in care.

* To correct for differences in demographic and clinical characteristics, we included age, length of stay, place of death, dementia at time of death, diseases at time of death (cancer, cardiovascular, pulmonary and other diseases) and functional/cognitive status as fixed effects.

Percentages may not correspond with count due to missing values.

Missing values for each treatment: enteral administration: 214, parenteral administration: 233, artificial fluid: 194, resuscitation: 272, ventilation: 261, antibiotics: 146, statins: 328, antidiabetics: 274, anticoagulants: 317, blood transfusion: 274, chemotherapy/radiotherapy: 278, dialysis: 285, surgery: 329

CHAPTER 5

HOSPITALIZATION IN THE LAST MONTH OF LIFE AND IN–HOSPITAL DEATH OF NURSING HOME RESIDENTS: AN ANALYSIS OF SIX EUROPEAN COUNTRIES

Honinx, E., Piers, R., Onwuteaka-Philipsen, B.D., Payne, S., Szczerbińska, K., Gambassi, G., Kylänen, M., Deliens, L., Van den Block, L.*, Smets T*, on behalf of PACE.

Honinx E, Piers R, Onwuteaka-Philipsen BD, et al. Hospitalization in the last month of life and in-hospital death of nursing home residents: an analysis of six European countries (*submitted*).

Abstract.

Objectives

We aim to examine hospitalizations of nursing home residents in the last month of life and place of death, identifying related country, resident, care processes and facility factors in six European countries.

Setting: A cross-sectional study (2015) of deceased residents in 322 nursing homes (Belgium, England, Finland, Italy, the Netherlands and Poland).

Participants: The nursing home manager, physician and primary nurse completed questionnaires (N= 1384) on demographic, clinical, nursing home stay and care process characteristics.

Outcome measures: Hospitalization and place of death were analyzed using generalized linear and logistic mixed models. Multivariate analyses were conducted to determine associated factors.

Results

Twelve to 26% of residents were hospitalized in the last month of life, up to 19% died in-hospital ($p<0.001$). Belgian residents were more likely to be hospitalized than those in Italy, the Netherlands and Poland. For those dying in-hospital, the main reason for admission was acute change in health status. Residents with a better functional status were more likely to be hospitalized or to die in-hospital. The likelihood of hospitalization and in-hospital death increased if no conversation on preferred care with a relative was held. Not having an advance directive regarding hospitalizations increased the likelihood of hospitalization.

Conclusions

Although participating countries vary in hospitalization and in-hospital death rates, a minority of nursing home residents were hospitalized in the last month of life. Close monitoring of acute changes in health status and adequate equipment seem critical to avoiding unnecessary hospitalizations. Strategies to increase discussion of preferences need to be developed. Our findings can be used by policymakers at governmental and nursing home level.

Keywords: hospitalization, hospital death, nursing home, Europe, PACE.

Strengths and limitations of this study

- A large-scale retrospective study on the hospitalization of nursing home residents in the last month of life and on place of death
- Identifying the country-, resident-, care processes-, and facility- related factors associated with hospitalization in the final month and in-hospital death
- Enables to hypothesize about which palliative care practices may result in better nursing home outcomes
- Data from 1384 residents from 322 representative nursing homes in six European countries with a high response rate
- Hospital records or hospital medical and nursing staff were not consulted about hospitalization-related factors

Introduction

In Europe up to 38% of people over 65 years die in a nursing home[1]. Older people living in nursing homes have a high level of comorbidity, frailty and complex health needs[2]. Their hospitalization comes with a number of drawbacks like low satisfaction with care, rapid functional decline, low survival rates and a suboptimal quality of end-of-life care and should thus be avoided without strong clinical indication[3–7]. Nevertheless, in many countries hospitalization of nursing home residents at the end of life is not infrequent and some die there, even if they would had preferred not to [8–13].

Most studies on hospitalization of nursing home residents in the last month of life have been conducted in the US and many focused on place of death[14]; only a few looked at associated factors, mainly limited to resident-level factors such as age or gender, and reported inconsistent results, with highly variable hospitalization rates[15]. The PAlliative Care for older people in Europe (PACE) project, which studied palliative care in nursing homes in six European countries (Belgium, England, Finland, Italy, the Netherlands and Poland), conducted a large-scale representative, cross-national survey of deceased nursing home residents to study the characteristics of hospitalizations in the last month of life, place of death, and the country-, resident-, care processes-, and facility-related factors associated with them and with in-hospital death. Studying cross-national variation can provide useful information for the development of end-of-life care policies and targeted interventions to meet the needs of nursing home residents, their relatives, and society as a whole.

Thus, the aims of this study were to provide an answer to two different research questions:

(1) What are the characteristics of hospitalizations of nursing home residents in the last month of life and what is the place of death in Belgium, England, Finland, Italy, the Netherlands and Poland?

(2) Which factors are associated with hospitalizations of nursing home residents in the last month of life and with in-hospital death?

Methods

Study design and sampling

A cross-sectional study of deceased residents in nursing homes was conducted in 2015 in six European countries: Belgium, England, Finland, Italy, the Netherlands and Poland[9]. A proportional stratified random sampling procedure was applied in each country which included a stratification of the nursing homes by type, region/province and number of beds. Homes were proportionally and randomly sampled from each stratum resulting in representative samples. Publicly available regional or national lists were used as a basis for recruitment. In Italy, no such lists were available, and therefore a previously composed cluster of eligible homes was used that reflected the three main regions and different types and sizes of nursing homes[16]. To enhance recruitment in England, we collaborated with the ENRICH research network for nursing homes[17]. If a nursing home declined participation, another from the same stratum was selected. All homes reported on the deaths, both inside and outside the home (e.g. in hospital), of residents over the preceding three months. More details about the study design and protocol have been published elsewhere[9]. We used the STROBE cross sectional checklist when writing our report[18].

Setting and participants

In this paper we define nursing homes as 'collective institutional settings where care and on-site personal assistance with activities of daily living, and on-site or off-site nursing and medical care, is provided for older people who live there, 24 hours a day, seven days a week, for an undefined period of time'[19]. We distinguish between three types: 24/7 care from on-site physicians and nurses/care assistants (type 1), 24/7 care from on-site nurses/care assistants and off-site physicians (type 2), and 24/7 care from on-site care assistants and off-site physicians and nurses (type 3). Type 2 nursing homes are present in all countries, whereas type 1 is only present in Italy, the Netherlands and Poland and type 3 only in England[2]. Structured questionnaires were sent to the staff member who was most involved in the care of the resident (nurse/care assistant), the physician and the nursing home administrator for each identified deceased resident.

Patient and public involvement

No patient involved.

Data collection

A letter introducing the PACE project and inviting participation was sent to every sampled nursing home. If one agreed to participate, a contact person was appointed by the manager. He/she listed all deceased residents in the preceding three months and their attending physician and staff member i.e. nurse or care assistant most involved in their care. The contact person also distributed pre-coded envelopes containing a paper questionnaire and a document guaranteeing full anonymity to those identified, ensuring strict confidence through direct return of the completed questionnaires to the researchers who registered the returned envelopes in an excel file. Up to two reminders were sent in case of non-response, after three and six weeks.

Measurements

For each resident, information on demographic, clinical, nursing home stay and care process characteristics was collected.

The administrator of each participating home provided information on age, gender and nursing home characteristics: type of ownership (public-nonprofit/private-nonprofit/private-profit), type and size (number of beds) of nursing home and length of stay of the resident (in days). The administrator also reported whether or not the nursing home included 24/7 availability of opioids, and an assigned contact person who maintained regular contact with the residents and relatives to ensure coordinated delivery of health and social care.

The physician reported on the presence of illness at time of death and whether or not they had expected the death.

The nurse provided data on the functional and cognitive status of the resident during the last month of life, measured with the Bedford Alzheimer Nursing Severity Scale (BANS-S)[20], with scores ranging between 7 (low) and 28 (high). Presence of dementia at time of death was estimated by the physician, the nurse or both and coded as ‘yes’ if either indicated its presence. The nurse also reported on care processes: presence of a written ‘do not transfer to hospital’ advance directive and whether there had been – prior to a decision – a conversation with a relative about the resident's preferred medical treatment and course of care in the last phase of life.

To describe the characteristics of hospitalization and place of death, we included questions on hospital use in the last month of life and place of death. We surveyed: the number of visits to the emergency room (ER), hospital admissions, total days spent in hospital if admitted, admission to the intensive care unit (ICU), whether the hospital palliative care team was involved, place of death and, if death occurred in hospital, the reason for the final admission and at whose request it took place.

To analyze which factors related to hospitalization during the last month of life and in-hospital death, variables from all three questionnaires were selected based on the authors' clinical experience and extensive literature search [14,21–24].

Statistical analysis

All variables were calculated at the level of the resident; we included only those for whom a questionnaire was filled in by the nurse. Demographic, clinical, nursing home stay and care process characteristics are presented as count and percentages for categorical variables and mean and standard deviation (SD) for continuous variables (Table 1). Generalized linear and logistic mixed models were used to calculate the differences in these characteristics between countries, with country as a fixed effect and nursing home as a random effect in each model to account for data clustering at country and nursing home level.

To analyze the characteristics of hospitalization and place of death, generalized linear and logistic mixed models were conducted. Country was again included as a fixed effect. Nursing home was included as a random effect in each model. We also included age, dementia at time of death, diseases at time of death (cancer, cardiovascular, pulmonary and other diseases), functional/cognitive status, length of stay, type of ownership and type nursing home and nursing home size as fixed effects to correct for differences in demographic, clinical and nursing home stay characteristics. With this risk adjustment procedure, a fair comparison between countries was made possible. We excluded missing values for each characteristic from the analyses.

To analyze which factors related to hospitalization in the last month and in-hospital death, selected variables (demographic, country, resident, nursing home and care process characteristics) were first included in univariate analyses. Next, variables that proved to be significantly associated with hospitalization during the final month and in-hospital death were subsequently included as fixed effects into two multivariate logistic mixed regression models with nursing home as random factor and either hospitalization in the final month (yes/no) or in-hospital death (yes/no) as dependent variable (table 3). Due to low numbers of complete cases in England, we excluded data from England from the multivariate analyses. Statistical significance was represented by an alpha level of $p<0.05$. All analyses were performed with IBM SPSS version 25[25].

Ethical aspects

The ethics committee of each country approved the study protocol in 2015. If no approval for collection of data of deceased residents was needed, which was the case for Italy and the Netherlands, waivers were acquired. All participants took part on a voluntary basis, meaning that completed (anonymous) questionnaires were regarded as valid informed consents.

Results

In 322 participating nursing homes, 1707 deceased residents were identified. For eleven, no nurse could be contacted (Figure 1). From the 1696 nurse questionnaires that were sent out, 1384 were completed and returned (overall response rate 81.6%). Response rates per country are reported in the footnotes of Figure 1.

Demographic, clinical, nursing home stay and care process characteristics of deceased nursing home residents

Residents' mean age at time of death ranged from 81 years in Poland to 87 years in Belgium and England (Table 1). Most residents were female (64% in Poland – 75% in England) and the majority had dementia (60.2% in England – 82.5% Finland). Polish residents had the poorest functional and cognitive status (BANS-S mean score of 21.9), whereas those in England had the highest (BANS-S mean score of 17.5). Between 40.8% (Poland) and 100% (Belgium) of residents were in type 2 nursing homes (care from on-site nurses and off-site physicians). The size of the nursing homes varied, ranging between 41 beds (England and Finland) to 126 beds (Belgium). The majority of deceased residents resided in nursing homes where opioids were available 24/7 for *all* residents with palliative care needs (68.8% in Italy – 88.1% in Belgium and England), except in Poland (48.4%; p=0.002). For most residents (60.7% – 85.2%) a contact person was available to ensure coordinated health and social care (p<0.001). However, in Italy and Poland, such a person was not available for 36.5% and 53.1% of residents respectively. In the majority of cases across the countries (51.6% in Poland – 72.1% in Finland; p=0.001), the physician expected the resident's death. A third of residents in Belgium (33%) had a 'do not transfer to hospital' advance directive while barely anyone had in Italy (0.5%; p<0.001). In most countries, the resident's primary nurse had discussed with a relative the resident's preferred medical treatments or course of care in the last phase of life (58.2% in Italy –75.2% in the Netherlands), but that happened less often in Poland (27.8%; p<0.001).

Hospitalizations and place of death of nursing homes residents

Between 7.9% (the Netherlands) and 20.2% (England) of the residents visited the emergency room – for less than 24 hours – in the last month of life (p<0.001). Up to 26% were hospitalized in the last month of life (11.6% in Italy – 25.8% in Belgium; p<0.001), most of them only once. Nevertheless, up to 33.3% (Poland) of those were hospitalized multiple times. The average length of stay ranged between seven days in Poland and Italy and 14 days in Finland. The hospital palliative care team was involved in the care of 3.6% of those admitted in Italy and 15.4% in England. The percentage of residents dying in-hospital ranged from 6.1% in the Netherlands to 19.4% in Poland (p>0.001). Among those who died during hospitalization, the reason for the final admission was in the majority of cases a sudden onset or an exacerbation of symptoms or a life-threatening situation (64.7% in the Netherlands – 92.3% in England). For these, the decision to hospitalize was made by the physician (25% in Italy – 65.9% in Belgium) and the nurses (18.8% in the Netherlands – 68.8% in Italy). The rate of hospitalization in the last month of life was highest for residents in type 3 nursing homes and more for type 2 than for type 1 (table A1 in Appendix). A similar pattern was observed for in-hospital deaths. The highest rates were found in Polish type 2 nursing homes: 33.3% was hospitalized and 38.1% died in-hospital.

Factors associated with hospitalization during the last month of life

In Belgium, residents had a significantly greater likelihood of being hospitalized at the end of life than those in Italy (OR = 0.36; p=0.02), the Netherlands (OR = 0.27; p=0.002) or Poland (OR = 0.39; p=0.04) (Table 3). Those with higher functional status one month before death (lower BANS-S score) were more likely to be hospitalized then those with a high BANS-S score (OR = 0.90; p<0.001). Although dementia was not associated with hospitalization, additional analysis (not in tables) showed that residents with early stage dementia were more likely to be hospitalized than those with very severe or advanced dementia. In nursing homes where opioids were available to *most* residents, the odds of hospitalization increased (OR = 2.73; p=0.01) compared with those where they were available to *all* residents. Not having a 'do not transfer to hospital' advance directive increased the likelihood of hospitalization compared with having one (OR = 0.17; p=0.001). It was also more likely if there had been no conversation between the nurse and a relative about preferred medical treatments and course of care in the last phase of life than if there had (OR = 0.47; p<0.001).

Factors associated with in-hospital death

Residents were more likely to die in-hospital if the nursing home physician did not expect the death (OR = 5.21; p<0.001), if it was sooner than they expected (OR = 2.82; p=0.002) or if it was neither expected nor unexpected (OR = 3.90; p=0.001). A resident was more likely to die in-hospital if they had a good functional status than a poor one (OR = 0.89; p<0.001) (Table 3). Again, in-hospital deaths were also more likely if the nurse had not had a conversation with a relative about medical treatments or the preferred course of care in the last phase of life than if they had (OR = 0.54; p=0.03). No significant additional association was found.

Discussion

Main findings

Between 12% (Italy) and 26% (Belgium) of residents were hospitalized at least once in the last month of life. Besides country differences, residents were also more likely to be hospitalized if they had a high functional status, no advance directive regarding hospitalization, and if there had been no conversation with a relative about preferences at the end of life. Between 6% (the Netherlands) and 19% (Poland) died while in hospital. For these residents, the reason for the last hospital admission was in the majority of cases the acute onset or exacerbation of symptoms or the sudden appearance of a life-threatening situation. Residents were more likely to die in-hospital than in the nursing home if they had a better functional status, if the physician did not expect the death and if no end-of-life conversations had been held with a relative.

Strengths and limitations

We conducted a large-scale study on the hospitalization of nursing home residents in the last month of life and on place of death, identifying the country-, resident-, care processes-, and facility-related factors associated with such events in six European countries. We were able to include data from 1384 residents from 322 representative nursing homes (Figure 1). Overall response rate across all countries was high (Figure 1). Earlier studies included only resident-level variables, whereas our study went beyond resident-level and included variables related to the care process and to the nursing home[14]. The analysis of associations on different levels enables us to hypothesize about which palliative care practices may result in better nursing home outcomes. Further, the retrospective character of this study is most suitable to examine hospitalizations of nursing home residents in the last month of life and place of death. Nevertheless, it is important to mention some limitations: the physician response rate for England was low so data from England were not considered in the multivariate analyses; we did not review hospital records or interview hospital medical and nursing staff about hospitalization-related factors, which could have been a useful addition to the information provided by nursing home staff, specially where they were little involved in the hospitalizations.

Hospitalizations in the last month of life

Our finding that 12% to 26% of nursing home residents are hospitalized at least once in the last month of life is comparable with numbers found in previous studies from European countries. Two systematic reviews on hospitalizations in the last month of life of nursing home residents in Europe reported a range from 8% to 34%, with up to 50% in Germany[17,28]. Studies from the US reported higher rates of hospitalization in the last month of life than ours, ranging between 25% and 35%[26,27], which might be partly attributable to a more cure-oriented culture for terminally ill people there than in most European countries, in combination with the Medicare fee-for-service system that offers financial incentives to nursing homes for hospitalizing residents[3,28].

We found that residents in Belgium were more likely to be hospitalized than those in Italy, the Netherlands and Poland; the rate in Poland was almost as high as in Belgium. Across all countries, type of nursing home was not significantly related to hospitalization, though additional analysis showed that type 2 nursing homes – the only type in Belgium – had more hospitalizations and in-hospital deaths than type 1, suggesting nursing home organization could be a possible explanation for Belgium's high hospitalization rate and the high rate in type 2 nursing homes in Poland. Another reason could be that Belgian family physicians usually coordinate the end-of-life care of their patients, which would make them essential in avoiding hospitalizations in the last month of life[29]; this gate-keeping role is however limited so that hospitalization can be requested more easily by family members without consulting them[30,31]. On top of that, there is the institutionalized nature of the final phase in Belgium[32]; in the Netherlands, where hospitalization in the last month of life was least common, care in nursing homes is not managed by the family physician but by the elderly care physician in the nursing home[4,33]. This model is less hospital-centric and has the potential to decrease hospitalization in the last month of life.

Apart from country, other factors increased the likelihood of hospitalization. Residents were more likely to be hospitalized in the last month of life if they had a better functional status and were not suffering from very severe or advanced dementia. This suggests that primarily residents with a better state of health and a better prognosis are hospitalized. This finding seems plausible and was confirmed by a US study on hospitalizations of dying nursing home residents[34]. Hospitalizations were also more likely if no conversation on medical treatments and the course of care had been held between the nurse and a relative and if residents did not have a written 'do not transfer to hospital' advance directive. A study on avoiding hospitalizations of nursing home residents identified both having advance directives and discussing residents' preferences as two strategies for reducing hospital transfers[35]. In general, very few of the residents had such an advance directive (0.5% – 33%). Since many suffer from dementia and thus do not have the capacity to make decisions themselves, written advance directives would be crucial. In the United States, written advance directives are more common (72%), possibly due to support from governments, healthcare providers and insurers in completing them[36,37]. Hospitalization is however sometimes needed and is not always avoidable; even though a resident prefers not to be transferred, nursing home staff may not feel equipped to provide the care required. Sometimes, high-quality medical care cannot be provided in the nursing home, which can be a reason for referral to another setting.

In-hospital death

The percentage of residents dying in-hospital ranged between 6% in the Netherlands and 19% in Poland. The average number of in-hospital deaths in our study lies well below that in other studies from Europe, the US, Asia and Canada which reported a median of one in five residents dying in-hospital[12,14,27]. In Belgium and Poland, the percentage of in-hospital deaths was highest. For Poland, this was especially the case in type 2 nursing homes with off-site physicians (38%). In the Netherlands, in-hospital deaths were less common, in all types, and happened more often at a resident's request than in the other countries. Earlier studies also report lower in-hospital deaths and more residents with a palliative care goal on the day of death in the Netherlands than in other countries[36,38,39]. These findings might suggest that in the Netherlands close attention is paid to the preferences of the resident regarding place of death. Further, discontinuing life-prolonging medical treatments is accepted practice there and quality of life is an important aspect of end-of-life decisions and often outweighs prolongation of life[40]. Hendriks et al. found that there were several contact moments during a nursing home stay between physicians, nursing staff and relatives in which care goals and treatment decisions were discussed[41,42]. This implies an organizational focus on facilitating end-of-life discussions. We found that in the majority of cases, the main reason for the last hospital admission was a sudden onset or exacerbation of symptoms or a life-threatening situation and that admission had usually been requested by a physician or nurse. This suggests that most last hospitalizations were a reaction to what staff perceived as an urgent medical situation. Furthermore, physicians indicated they usually expected the resident to die. Not expecting death increased the likelihood of in-hospital death. Which suggest that staff are more inclined to transfer residents to the hospital (for a treatment or diagnosis) if they assume the residents is not dying. In-hospital deaths were also more likely if the conversation about preferences on medical treatments and the course of care between a nurse and a relative had not taken place. These findings suggest that involvement of staff and their knowledge of a resident's preferences might have a strong impact on place of death. Interestingly, not having an advance directive regarding do not transfer to hospital was associated with a higher likelihood of hospitalization in the last month, but not with a higher likelihood of dying in-hospital. Given that the main reason for the final hospitalization was an acute medical situation, having an advance directive appears not to make a difference in such a case. This seems to indicate that in such situations very complex decision-making takes place, with hospitalization as the default option.

Implications

Not having a do not transfer to hospital advance directive increased the likelihood of hospitalizations in the last month of life. In addition to a continuing commitment to advance care planning, our findings indicate the need to improve management of acute changes in symptoms – through staff training and support – before they worsen and require hospital stays. Hospitalizations also increased if the physician did not expect a resident's death, which highlights the importance of recognition of the terminal phase.

Conclusions

In the European countries participating in the PACE project, between 12% and 26% of nursing home residents were hospitalized in the last month of life and up to 19% died in-hospital. This indicates that although the participating countries vary in hospitalization and in-hospital death, a minority of the residents were hospitalized in the last month of life. For those who died in-hospital, the main reason for hospital admission was an acute change in health status, those with a higher functional status being more likely to be hospitalized or to die in-hospital. The likelihood of hospitalization in the last month of life and of in-hospital death increased if no conversation about the preferred course of care was held with a relative. Having no advance directive regarding hospitalizations increased the likelihood of hospitalization in the last month of life but not of in-hospital death. Close monitoring of acute changes in a resident's health status – reinforced by staff training and support – and adequate equipment to manage these changes are critical in the nursing home setting to avoid unnecessary hospitalizations. In addition, strategies to increase discussion about individual preferences and advance care planning need to be developed and adapted locally. Our findings can be used by policymakers – at government and nursing home level – to follow up on the effects of their policies.

List of abbreviations

US	United States
ENRICH	ENabling Research In Care Homes
PACE	PAlliative Care for older people in Europe
BANS-S	Bedford Alzheimer Nursing Severity - Scale
ER	Emergency Room
ICU	Intensive Care Unit
OR	Odds Ratio
NH	Nursing Home
NA	Not Applicable
SD	Standard Deviation
PC	Palliative Care

Declarations

Ethics approval and consent to participate

Ethics approval from the relevant ethics committees were obtained in all participating countries. Belgium: Commissie Medische Ethiek UZBrussel, 27/05/2015; England: NHS – NRES Committee North West-Haydock, 10/09/2015; Finland: Terveyden jahyvinvoinnin laitos, Institutet för hälsa och välfärd, 30/6/2015; Italy: Comitato Etico, Universita Cattolica del Sacro Cuore, 6/11/2017; Netherlands: Medisch Ethische Toetsingscommissie VUMedisch Centrum, 2/7/2015; Poland: Komisja Bioetycza, Uniwersytetu Jagiellonskiego, 25/6/2015; Switzerland: Commission cantonale d'éthique de la recherché scientifique de Genève (CCER), 6/8/2015.

All persons participating in the study (facility managers, care staff, GPs) have to give their prior informed consent in writing. If participants are unable to give informed consent, they will not be involved in the study. In some countries, a separate informed consent from individual participants is not required if questionnaires are filled in anonymously: for the Netherlands, the Medical Ethics

Review Committee concluded that this study does not fall under the Medical Research Involving Human Subjects Act (WMO). In accordance with the Dutch code for good practice in biomedical research, a separate informed consent was not needed. The Polish Ethical Committee stated no separate informed consents were needed given the study design protected anonymous answering of individual respondents. Returning the questionnaire was regarded as consent to participate in the study.

Consent for publication

Not applicable.

Availability of data and material

The datasets used and/or analyzed during the current study are available from the corresponding author on reasonable request.

Competing interests

The authors declare that they have no competing interests.

Funding

Project has been co-funded by Polish Ministry of Science and Higher Education in the years 2014-2019 based on the decision no 3202/7PR/2014/2 dated on Nov. 25th, 2014. This work was supported by the European Union’s Seventh Framework Programme (FP7/ 2007e2013) under grant agreement 603111 (PACE project Palliative Care for Older People). The funders had no role in study design, collection, analysis or interpretation of the data, nor in writing and the decision to submit this article for publication.

Authors' contributions

EH, RP, BDOP, SP, KS, GG, MK, LD, LVDB and TS were involved in the study design. RP, BDOP, SP, KS, GG, MK, LD, LVDB and TS are involved in data acquisition. EH, RP, LD, LVDB and TS were involved in developing the data analysis plan. EH, RP, BDOP, SP, KS, GG, MK, LD, LVDB and TS were involved in writing of the manuscript. All authors read and approved the final manuscript.

Acknowledgements

Other PACE collaborators not in the list: Yuliana Gatsolaeva, Rose Miranda, Lara Pivodic, Marc Tanghe, Hein van Hout, Roeline H. R. W. Pasman, Mariska Oosterveld-Vlug, Ruth Piers, Anne B. Wichmann, Yvonne Engels, Myrra Vernooij-Dassen, Jo Hockley, Sheila Payne, Suvi Leppäaho, Ilona Barańska, Sophie Pautex, Catherine Bassal, Federica Mammarella, Martina Mercuri, Paola Rossi, Ivan Segat, Agata Stodolska, Eddy Adang, Paula Andreasen, Outi Kuitunen-Kaija, Danni Collingridge Moore, Agnieszka Pac, Violetta Kijowska, Maud ten Koppel, Jenny T. van der Steen, Emilie Morgan de Paula, and the European Association for Palliative Care vzw, European Forum For Primary Care, Age Platform Europe, and Alzheimer Europe.

References chapter 5

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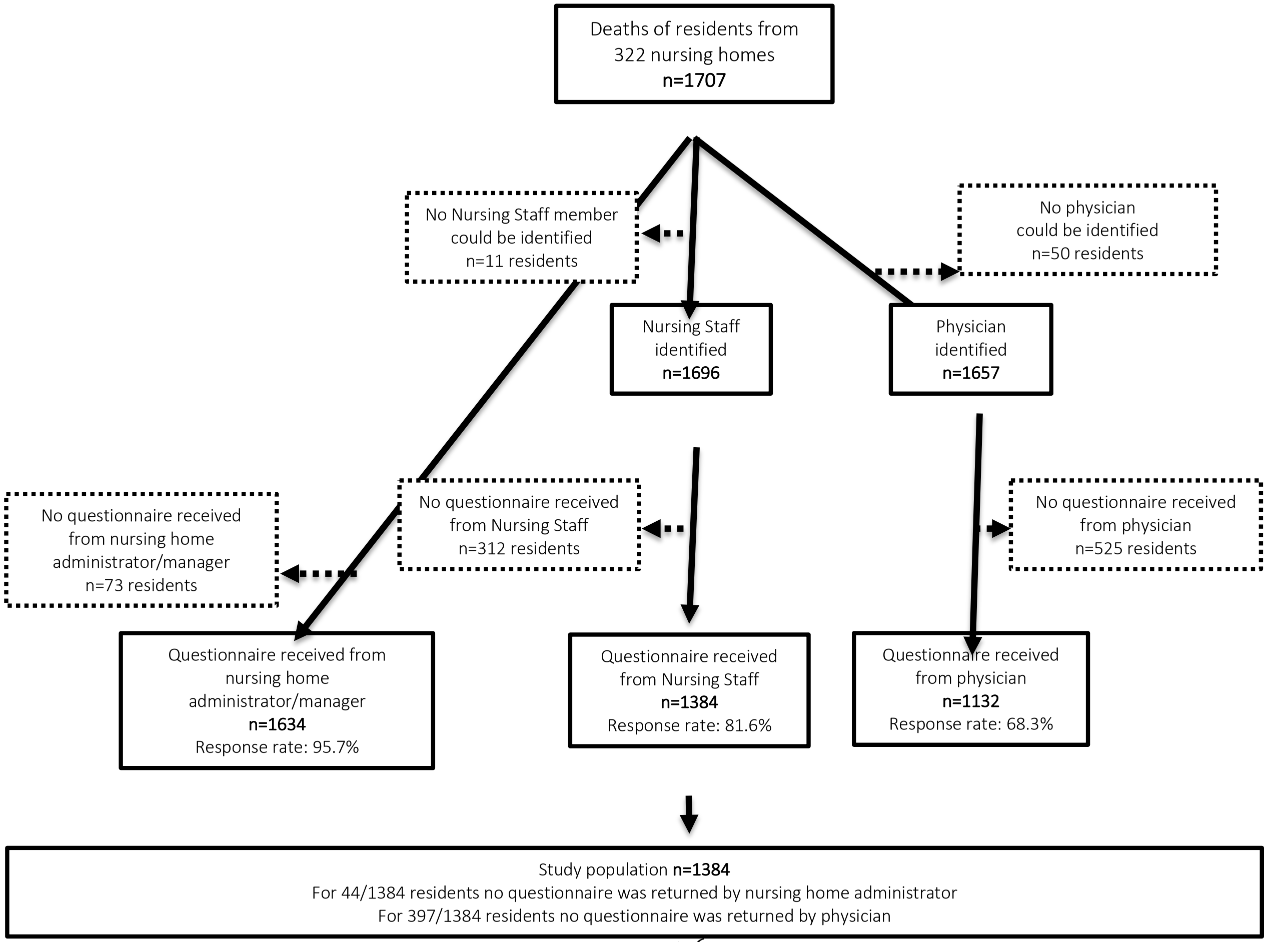
Figure 1. Numbers of questionnaires (distributed and returned) regarding residents per respondent in 6 countries.



Average response rates per country
Administrator/manager: Belgium 94.2%, the Netherlands 90.6%, England 96.4%, Finland 98.6%, Italy 96.5%, Poland 98.9%
Nursing staff: Belgium 85.1%, the Netherlands 67.5%, England 54.2%, Finland 95.1%, Italy 91.7%, Poland 87.4% for Treating physicians: Belgium 66.9%, the Netherlands 63.1%, England 23.8%, Finland 80.2%, Italy 88.4%, Poland 75.6%

Table 1. Demographic, clinical and nursing home stay characteristics of deceased residents in six countries: (N=1384)

	BELGIUM (N=291)	ENGLAND (N=91)	FINLAND (N=269)	ITALY (N=200)	THE NETHERLANDS (N=222)	POLAND (N=311)	P-value*
Demographic characteristics							
Age – years || Mean (SD) years old at time of death	87 (7)	87 (9)	85 (9)	86 (8)	86 (9)	81 (11)	**<0.001**
Gender ||							
Female Count (%)	174 (64.0)	66 (75.0)	169 (64.3)	136 (68.3)	132 (66.7)	195 (63.5)	
Male Count (%)	98 (36.0)	22 (25.0)	94 (35.7)	63 (31.7)	66 (33.3)	112 (36.5)	0.387
Clinical characteristics							
Dementia at time of death (yes) †‡ § Count (%)	183 (62.9)	53 (60.2)	222 (82.5)	154 (77.0)	135 (61.4)	207 (67.9)	**<0.001**
Functional/cognitive status one month before death (BANS-S) † ¶** (Mean (SD))	18.5 (4.9)	17.5 (4.2)	19.6 (4.3)	21.8 (3.7)	17.7 (4.7)	21.9 (4.6)	**<0.001**
Diseases at time of death‡¶							
Malignant cancer‡	30 (15.5)	9 (42.9)	41 (19.4)	26 (17.2)	27 (18.5)	10 (4.0)	**<0.001**
Severe cardiovascular disease‡	67 (34.7)	2 (9.5)	79 (37.4)	71 (47.0)	45 (30.8)	141 (55.7)	**<0.05**
Severe pulmonary disease‡	33 (17.1)	3 (14.3)	17 (8.1)	40 (26.5)	17 (11.6)	18 (7.1)	**<0.001**
Other severe disease‡	31 (16.1)	3 (14.3)	51 (24.2)	33 (21.9)	4 (2.7)	33 (13.0)	**<0.001**
Nursing home stay characteristics							
Type of ownership ||							
Public-nonprofit	135 (48.9)	2 (2.2)	211 (80.2)	66 (34.9)	211 (100.0)	201 (65.0)	
Private-nonprofit	124 (44.9)	10 (11.0)	24 (9.1)	44 (23.3)	NA	104 (33.7)	
Private-profit	17 (6.2)	79 (86.8)	28 (10.6)	79 (41.8)	NA	4 (1.3)	**<0.001**
Type of nursing home ||							
Type 1 (care from on-site physicians and nurses)	NA	NA	NA	48 (25.4)	117 (55.5)	184 (59.2)	
Type 2 (care from on-site nurses and off-site physicians)	276 (100)	49 (53.8)	267 (100)	141 (74.6)	94 (44.5)	127 (40.8)	
Type 3 (care from off-site physicians and nurses)	NA	42 (46.2)	NA	NA	NA	NA	0.960
Nursing home size || (Mean (SD) number of beds)	126 (50)	41 (23)	41 (30)	101 (50)	124 (64)	72 (41)	**<0.001**

Length of stay || Median (min-max) number of days	745 (2-9706)	600 (2-4952)	581 (1-9218)	416 (2-10171)	710 (1-6290)	145 (1-12365)	**<0.05**
Opioids available 24/7 for residents with PC? ||							
Yes, for all residents	236 (88.1)	73 (88)	224 (84.2)	130 (68.8)	171 (81)	149 (48.4)	
Yes, for most residents	9 (3.4)	4 (4.8)	17 (6.4)	36 (19)	26 (12.3)	2 (0.6)	
Yes, for some residents	21 (7.8)	4 (4.8)	20 (7.5)	6 (3.2)	9 (4.3)	66 (21.4)	
No, never	2 (0.7)	4 (2.4)	5 (1.9)	17 (9)	5 (2.4)	91 (29.5)	**<0.001**
Care process characteristics							
Resident had a written advance directive with regard to 'do not transfer to a hospital'	96 (33)	18 (19.8)	21 (7.8)	1 (0.5)	N.A.	6 (1.9)	**<0.001**
Conversation between nurse and relative about preferred course of care was held	215 (74.9)	52 (63.4)	158 (60.5)	114 (58.2)	167 (75.2)	81 (27.8)	**<0.001**
Contact person for residents/relatives to ensure coordinated health and social care							
Yes, for all residents	159 (60.7)	75 (85.2)	194 (72.7)	86 (45.5)	162 (76.8)	133 (42.8)	
Yes, for most residents	31 (11.8)	1 (1.1)	17 (6.4)	0 (0.0)	4 (1.9)	0 (0.0)	
Yes, for some residents	25 (9.5)	8 (9.1)	10 (3.7)	34 (18)	0 (0.0)	13 (4.2)	
No, never	47 (17.9)	4 (4.5)	46 (17.2)	69 (36.5)	45 (21.3)	165 (53.1)	**0.002**
Physician's level of expectation about death							
Death was expected	107 (55.7)	14 (63.6)	155 (72.1)	105 (68.2)	97 (66)	130 (51.6)	
Death was expected, yet sooner than anticipated	42 (21.9)	4 (18.2)	43 (20)	23 (14.9)	29 (19.7)	55 (21.8)	
Death was neither expected nor unexpected	16 (8.3)	4 (18.2)	12 (5.6)	20 (13)	10 (6.8)	35 (13.9)	
Death was unexpected	27 (14.1)	0 (0)	5 (2.3)	6 (3.9)	11 (7.5)	32 (12.7)	**0.001**

We only included residents for whom a questionnaire was filled in by a nurse (total N = 1384).

All variables are calculated at the level of the resident.

* Generalised linear and logistic mixed models reporting p-value for country as a fixed effect and nursing home as random effect in each model, α < 0.05

† Reported by the nurse/care assistant most involved in care.

|| Reported by administrator/manager of nursing home. For 44 out of 1384 residents no questionnaire was returned by the nursing home administrator; these are not included as missing values below.

‡ Reported by the physician. For 397/1384 residents no questionnaire was returned by physician; these are not included as missing values below.

§ When either the physician or the nurse (or both) considered the resident to have dementia, this was coded as yes.

¶ Multiple answers possible.

** Scores on BANS-S range from 7 to 28; higher scores indicate greater severity.

Percentages may not always add up to 100 because of rounding.
Missing values: age= 13, gender = 13, dementia=11, BANS-S=86 (missing data on at least one item), diseases=12, type of ownership=2, type of nursing home=0, size=5, length of stay=15, advance directive=66, contact person=4, physician's expectation = 7.
Abbreviations: NA Not Applicable, BANS-S Bedford Alzheimer Nursing Severity Scale, SD Standard Deviation, PC Palliative Care.

Table 2. Hospitalization and place of death of nursing homes residents in six countries.

	BELGIUM (N=291)	ENGLAND (N=91)	FINLAND (N=269)	ITALY (N=200)	THE NETHERLANDS (N=222)	POLAND (N=311)	P-value*
Hospitalization in the last month of life							
Did the resident visit the emergency room in the last month of life (for less than 24 hours)? † Yes (total)	37 (13.3)	17 (20.2)	40 (15.4)	31 (16.7)	17 (7.9)	25 (9.2)	**<0.001**
Once	35 (94.6)	15 (88.2)	28 (70)	28 (90.3)	12 (70.6)	19 (76)	
Twice or more	2 (5.4)	2 (11.8)	12 (30)	3 (9.7)	5 (29.4)	6 (24)	**0.02**
Was the resident admitted to a hospital for more than 24 hours during the last month of life? † Yes (total)	72 (25.8)	20 (23.3)	58 (22.2)	22 (11.6)	34 (15.7)	66 (25.1)	**0.001**
Once	67 (93.1)	18 (90)	44 (75.9)	17 (77.3)	24 (70.6)	44 (66.7)	
Twice or more	5 (6.9)	2 (10)	14 (24.1)	5 (22.7)	10 (29.4)	22 (33.3)	**<0.001**
If admitted to hospital in last month of life, average length of stay in hospital in days† mean	10.5	6.4	14.4	7	7	8.4	0.35
If admitted to the hospital, was the resident admitted to an ICU in the last month of life? †§ (yes)	6 (75)	0 (0)	2 (28.6)	2 (33.3)	2 (12.5)	4 (16.7)	0.93
Was the Hospital Palliative Care Team involved in the care of the resident in the hospital? † (yes)	11 (14.5)	10 (15.4)	36 (15.1)	6 (3.6)	2 (3.8)	29 (15.5)	0.08
Place of death							
Place of Death ||^							
Nursing home (%)	226 (82.2)	71 (81.6)	224 (84.8)	170 (86.7)	176 (89.3)	248 (80.0)	
Hospital (%)	48 (17.5)	16 (8.6)	24 (9.1)	26 (13.3)	12 (6.1)	60 (19.4)	**<0.001**
If the resident died in hospital, what were the medical reasons for the last hospital admission? †°							

A specific diagnosis was required for further decisions	3 (7.5)	0 (0)	1 (2.4)	0 (0)	3 (17.6)	7 (10.9)	
For specific treatment	5 (12.5)	1 (7.7)	9 (22)	4 (18.2)	3 (17.6)	8 (12.5)	
Sudden onset or exacerbation symptoms or a life-threatening situation	32 (80)	12 (92.3)	31 (75.6)	18 (81.8)	11 (64.7)	49 (76.6)	0.93
If the resident died in the hospital, at whose request did the last admission to the hospital take place? †°							
Resident	2 (4.5)	1 (6.7)	2 (4.2)	0 (0)	3 (18.8)	2 (3.1)	
Relatives	3 (6.8)	0 (0)	6 (12.5)	1 (6.3)	0 (0)	7 (10.8)	
Physician	29 (65.9)	6 (40)	18 (37.5)	4 (25)	10 (62.5)	25 (38.5)	
Nurses/carers NH	10 (22.7)	8 (53.3)	22 (45.8)	11 (68.8)	3 (18.8)	31 (47.7)	0.99

We only included residents for whom a questionnaire was filled in by a nurse (total N = 1384)
All variables are calculated at the level of the resident
* Generalised linear and logistic mixed models reporting p-value with country as a fixed effect and nursing home as a random effect in each model. Age, length of stay, place of death, dementia at time of death, diseases at time of death (cancer, cardiovascular, pulmonary and other diseases) and functional/cognitive status were also included as fixed effects to correct for differences in demographic, clinical and nursing home stay characteristics, α < 0.05.
§ Total number of answers to this question per country: 8 (Belgium), 2 (England), 7 (Finland), 6 (Italy), the Netherlands (16), Poland (24)
† Reported by the nurse/care assistant most involved in care.
||Reported by administrator/manager of nursing home. For 44 out of 1384 residents no questionnaire was returned by the nursing home administrator.
^Other places not in table include: LTCF/hospice/Pall care unit/other
°Multiple answers possible
Abbreviations: ICU Intensive Care Unit, NH Nursing Home

Table 3. Factors associated with (1) hospitalization of nursing home residents in last month of life and (2) in-hospital death.

	HOSPITALIZATION §		IN-HOSPITAL DEATH §	
Country, resident and nursing home characteristics (independent variables)	Exp(Coefficient)°; (95% CI)	*p*-value for factor	Exp(Coefficient)°; (95% CI)	*p*-value for factor
Intercept^	8.02 (1.90 to 33.8)	**0.005**	1.37 (0.19 to 9.82)	0.75
Country ||				
Belgium (reference)	Ref		ref	Ref
Finland	0.51 (0.24 to 1.11)	0.09	0.35 (0.11 to 1.23)	0.08
Italy	0.36 (0.16 to 0.85)	**0.02**	1.55 (0.50 to 4.81)	0.45
The Netherlands	0.27 (0.12 to 0.62)	**0.002**	0.33 (0.10 to 1.17)	0.09
Poland	0.39 (0.16 to 0.97)	**0.04**	1.33 (0.40 to 4.43)	0.64
Clinical characteristics				
Dementia at time of death†	0.86 (0.55 to 1.37)	0.53	0.78 (0.43 to 1.41)	0.41
Functional/cognitive status one month before death (BANS-S) †	0.90 (0.86 to 0.95)	**<0.001**	0.89 (0.84 to 0.95)	**<0.001**
Nursing home stay characteristics				
Type of nursing home||				
Type 1 (reference)	Ref	ref	Ref	ref
Type 2	0.91 (0.47 to 1.75)	0.77	1.90 (0.73 to 4.94)	0.19
Nursing home size||	1.00 (0.99 to 1.00)	0.23	0.99 (0.99 to 1.00)	0.10
Opioids available 24/7 for residents with PC needs||				
Yes, for all residents	Ref	Ref	ref	Ref
Yes, for most residents	2.73 (1.25 to 5.95)	**0.01**	1.85 (0.49 to 6.92)	0.36
Yes, for some residents	1.84 (0.84 to 3.99)	0.13	1.30 (0.44 to 3.86)	0.64
No, never	1.01 (0.43 to 2.38)	0.98	0.40 (0.10 to 1.55)	0.18
Care process characteristics				

Conversation between nurse and relative about preferred course of care was held†	0.47 (0.31 to 0.72)	**<0.001**	0.54 (0.31 to 0.95)	**0.03**
Resident had a written advance directive with regard to 'do not transfer to a hospital'†	0.17 (0.06 to 0.50)	**0.001**	0.40 (0.12 to 1.34)	0.14
Contact person for residents/relatives to ensure coordinated health and social care ||				
Yes, for all residents	ref	Ref	ref	Ref
Yes, for most residents	0.87 (0.29 to 2.62)	0.80	0.73 (0.12 to 4.64)	0.74
Yes, for some residents	0.43 (0.13 to 1.39)	0.16	0.94 (0.22 to 4.00)	0.93
No, never	1.24 (0.73 to 2.11)	0.42	0.90 (0.40 to 2.00)	0.74
Physician's level of expectation about death‡				
Death was expected	Ref	Ref	Ref	Ref
Death was expected, yet sooner than anticipated	1.18 (0.73 to 1.93)	0.50	2.82 (1.48 to 5.39)	**0.002**
Death was neither expected nor unexpected	1.04 (0.53 to 2.03)	0.91	3.90 (1.78 to 8.55)	**0.001**
Death was unexpected	0.45 (0.19 to 1.04)	0.06	5.21 (2.22 to 12.23)	**<0.001**

* Multivariate logistic mixed-effects regression models reporting p-value with hospitalization in the last month of life and place of death as independent variables and nursing home as random factor, $\alpha < 0.05$.

°Exponentiation of the coefficient, which is an odds ratio.

^Expected mean value of the dependent variables (hospitalization and in-hospital death) when all factors equal zero.

|| Reported by administrator/manager of nursing home. For 44 out of 1384 residents no questionnaire was returned by the nursing home administrator.

† Reported by the nurse/care assistant most involved in care.

‡ Reported by the physician. For 397/1384 residents no questionnaire was returned by physician.

§ Hospitalization 'no' and in-hospital death 'no' are reference categories

We were able to include 790 residents for analysis of hospitalization and 814 residents for analysis of in-hospital death in the complete-case multivariate analysis.

Due to low numbers of complete cases in England, we excluded data from England from the multivariate analyses. Therefore, also type 3 nursing homes were not included.

Abbreviations: PC Palliative care, BANS-S Bedford Alzheimer Nursing Severity Scale.

Appendix

Table A1. Hospitalizations and in-hospital deaths by nursing home type for each country

		HOSPITALIZATION	IN-HOSPITAL DEATH
Country	Type of nursing home ‖	Yes Count (%)	Yes Count (%)
Belgium	Type 2: On-site nurses and off-site physicians	68 (25.8%)	48 (17.5%)
Finland	Type 2: On-site nurses and off-site physicians	57 (22.0%)	24 (9.1%)
Italy			
	On-site physicians and nurses	8 (16.7%)	11 (23.9%)
	On-site nurses and off-site physicians	12 (9.1%)	14 (10%)
Netherlands			
	On-site physicians and nurses	10 (8.7%)	3 (2.8%)
	On-site nurses and off-site physicians	24 (26.4%)	9 (10.8%)
Poland			
	On-site physicians and nurses	28 (18.8%)	12 (6.5%)
	On-site nurses and off-site physicians	38 (33.3%)	48 (38.1%)
England	On-site nurses and off-site physicians	6 (13.3%)	7 (14.6%)
	Off-site physicians and nurses	14 (34.1%)	9 (23.1%)
Total			
	On-site physicians and nurses	46 (14.7%)	26 (7.7%)
	On-site nurses and off-site physicians	205 (22.7%)	150 (16%)
	Off-site physicians and nurses	14 (34.1%)	9 (23.1%)

We only included residents for whom a questionnaire was filled in by a nurse (total N = 1384)
All variables are calculated at the level of the resident
‖ Reported by administrator/manager of nursing home. For 44 out of 1384 residents no questionnaire was returned by the nursing home administrator.

PART III

EVALUATION OF A PALLIATIVE CARE PROGRAMME IN NURSING HOMES IN EUROPE

CHAPTER 6

EVALUATION OF A PALLIATIVE CARE PROGRAMME FOR NURSING HOMES IN SEVEN COUNTRIES: THE PACE CLUSTER–RANDOMIZED CLINICAL TRIAL

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Van den Block L, Honinx E, Pivodic L, et al. Evaluation of a Palliative Care Program for Nursing Homes in 7 Countries. JAMA Internal Medicine. Published online 2020. doi:10.1001/jamainternmed.2019.5349

Abstract

Importance

High-quality evidence on how to improve palliative care in nursing homes is lacking.

Objectives

To investigate the effect of the PACE Steps to Success Programme on resident and staff outcomes.

Design

Cluster-randomized controlled trial (2015-17) comparing PACE Steps to Success Programme (intervention) with usual care (control). Randomization was stratified by country and median number of beds in each country in a 1:1 ratio.

Setting, participants

Seventy eight nursing homes in seven countries.

Intervention

PACE Steps to Success is an multi-component intervention to integrate basic non-specialist palliative care in nursing homes. Using a train-the-trainer approach, an external trainer supports staff in nursing homes to introduce a palliative care approach over the course of one year following a six-steps programme. The steps are 1) advance care planning with residents and family, 2) assessment, care planning, and review of needs and problems, 3) co-ordination of care via monthly multidisciplinary review meetings, 4) delivery of high-quality care focusing on pain and depression, 5) care in the last days of life, 6) care after death.

Primary outcomes, measures

Primary resident outcome was comfort in the last week of life measured after death by staff using the End-of-Life in Dementia Scale Comfort Assessment while Dying (EOLD-CAD, range, 14-42). Primary staff outcome was knowledge of palliative care reported by staff using the Palliative Care Survey (PCS, range 0-1).

Results

Concerning deceased residents, we collected 551/610 questionnaires from staff at baseline and 984/1178 post-intervention in 37 intervention and 36 control homes. Residents' comfort in the last week of life did not differ between intervention and control groups (baseline-adjusted mean difference -0.55, 95%CI -1.71;0.61;p=0.35).

Concerning staff, we collected 2680/3638 questionnaires at baseline and 2437/3510 post-intervention in 37 intervention and 38 control homes. Staff in the intervention group had significantly better knowledge of palliative care than staff in the control group, but the difference was minimal (baseline-adjusted mean difference 0.04, 95%CI 0.02;0.05;p<0.001).

Conclusions

Residents' comfort in the last week of life did not improve after introducing the PACE Steps to Success Programme. Improvements in staff knowledge of palliative care were clinically not important.

Trial registration

The trial is closed; registered as ISRCTN14741671.

Introduction

In many countries more than one in four people die in a nursing home[1,2] and this is expected to increase substantially in future[3,4]. Research has consistently shown that the quality of end-of-life care and dying is suboptimal in many nursing homes. An important proportion of residents die with unrecognized, undertreated symptoms and after multiple hospitalizations and/or burdensome life-prolonging treatments in the final months[3-9], yet access to palliative care services is usually low[10,11] as is staff palliative care knowledge[12].

While palliative care has been advocated as the preferred approach in nursing homes in many countries[3], very few initiatives aimed at implementing it exist and available evidence is weak. Previous studies have used existing data[13,14], but no large scale clinical trials have been conducted. A 2011 Cochrane review[7] on effectiveness of multi-component palliative care interventions for nursing homes found only two RCTs and one before-after study and highlighted the critical need for high-quality studies. A few trials focusing on evaluating single-component interventions[15,16] have been performed since, and two trials evaluating the impact of a multicomponent palliative care programme found no effects[1,17].

Current research[18-21] suggests that education alone is insufficient to change practice in nursing homes. Achieving effective change seems to require a whole-setting approach[18-21]. Based on these premises, the UK Six Steps to Success for Care Homes was developed[22,23] and adapted to the PACE Steps to Success Programme for multi-country evaluation. It consists of a one-year palliative care programme for nursing homes, aimed at implementing a basic, non-specialist palliative care approach.

The research questions for this cluster-randomized controlled trial across nursing homes in seven European countries were:

1. Does the PACE Steps to Success Programme have an effect on resident outcomes as reported by staff i.e. comfort in the last week of life (primary resident outcome), and quality of care in the last month of life (secondary resident outcome)?
2. Does the Programme have an effect on staff outcomes i.e. knowledge of palliative care (primary staff outcome), self-efficacy, educational needs, and opinions on palliative care (secondary staff outcomes).

Methods

Trial design

We conducted the multi-facility cluster-randomized controlled PACE trial (2015-17) in Belgium, England, Finland, Italy, the Netherlands, Poland and Switzerland, to compare the PACE Steps to Success Programme (intervention) with usual care (control). We randomized at nursing home level (cluster) level because the intervention involved the training of all staff in each nursing home.

There were no deviations from the methods in the protocol after trial commencement. We followed CONSORT guidelines for cluster trials to design and report the study registered at www.isrctn.com – ISRCTN14741671 (FP7-HEALTH-2013-INNOVATION-1 603111) July 30, 2015. The full protocol of this trial has previously been published[24].

Participating nursing homes

Nursing homes were approached randomly from a list of all nursing homes in a predefined geographical location in each country by phone or e-mail to enquire interest in participating in the study, and to evaluate inclusion and exclusion criteria using a standardized checklist. If a nursing home did not respond, was excluded or declined to participate, another one from the list was randomly approached until a sufficient number agreed to participate in each country.
Inclusion criteria were:

- on-site provision of nursing care and personal assistance with activities of daily living and off-site GPs responsible for medical care
- at least 30 beds and 15 or more residents dying in or outside the nursing home over the last year (to obtain sufficient power[24])
- consent of management to participation in writing before randomization and agreed allocation of time for staff to act as PACE coordinators for approximately 0.5 days per week.

Nursing homes were excluded if they:

- already used detailed palliative care guidelines or planning tools or were accredited users of the Gold Standards Framework[23] or InterRAI-PC[25]
- were involved in the pilot testing of the intervention materials preceding the trial.

Randomization and blinding

Randomization was done for each country separately. Randomization was stratified by country and median number of beds in a 1:1 ratio using a computer-generated random sequence i.e. in each country all participating nursing homes were divided into two groups based on the median number of beds in the country; half were randomized to the intervention group, half to the control group delivering care as usual. The randomization procedure was repeated per country if the number of beds was unbalanced i.e. if the difference in number of beds between the control and intervention groups was greater than 15%. Randomization was blinded and performed by independent statisticians. Due to the nature of the study, blinding of treatment was not possible for participants or researchers.

Intervention

The PACE Steps to Success Programme is a multi-component intervention programme to integrate basic non-specialist palliative care in nursing homes. Using a train-the-trainer approach, an external trainer supports staff in the nursing homes to introduce a palliative care approach over the course of one year following a six-steps programme. The programme has three phases, implemented over a 12-month period i.e. two months preparation, six months implementation of six steps and four months consolidation with ongoing support where needed. The six steps are: 1) advance care planning with residents and families, 2) assessment, care planning, and review of resident needs and problems, 3) coordination of care via monthly multidisciplinary palliative care review meetings, 4) high-quality care with a focus on pain and depression, 5) care in last days of life and 6) care after death (see eTable 1 for details).[24]

Each country had PACE country trainers trained by experienced international trainers (JH and KF) during a one-week international workshop and supported via monthly one-hour online group-coaching sessions during the intervention period (by JH). In each nursing home, between one and six staff members were identified as PACE coordinators and trained and supported to develop the knowledge and skills to train all nursing home staff via workshops, support and education alongside the country trainers who visited or made contact every seven to 10 days. The materials were based on the Six Steps to Success for care homes developed in the UK from the Gold Standards Framework for Care Homes programme[22,23]. They were translated from

English into the relevant languages and cross-culturally adapted based on review meetings in several nursing homes per country[24].

Outcomes

Resident outcomes:

The primary resident outcome was comfort in the last week of life reported by staff using the End-of-Life in Dementia Scale Comfort Assessment while dying (EOLD-CAD).[26] The scale has four subscales: physical distress, dying symptoms, emotional distress, well-being. The minimal clinically important difference on the scale is 3 points[27]. Although the EOLD-CAD was originally developed and validated for people with dementia, it was recommended for use in mixed populations in nursing homes[28]. It has also shown to be responsive to change in a recent cluster RCT in acute geriatric hospital wards[29].

The secondary resident outcome was quality of care in the last month of life reported by staff using the Quality of Dying in Long Term Care (QOD-LTC). This scale comprises three subscales: personhood, preparatory tasks and closure[30].

We considered the use of staff to report primary and secondary resident outcome data as the best possible strategy in this population and setting: self-report of residents would not be feasible for all and possibly introduce selection bias, staff would have had most contact with residents compared with relatives, and response rate from staff would be higher than from relatives.

Other resident measures were:

- Comfort in the last week of life reported by relatives using the End-of-Life in Dementia Scale Comfort Assessment while dying (EOLD-CAD)[26]
- Relatives' perception of the quality of end-of-life care, measured using End-of-Life in Dementia – Satisfaction with Care (EOLD-SWC)[26]
- Family Perception of Physician-Family Communication reported by relatives (FPPFC)[31]

Staff outcomes:

The primary staff outcome was knowledge of palliative care, measured using the Knowledge Construct of the Palliative Care Survey. The scale comprises three subscales: end-of-life factors (knowledge of common end-of-life issues); knowledge of physical factors that can contribute to physical pain; knowledge of psychological factors that can contribute to physical pain[12,32]. There is strong empirical and psychometric support for the instrument and evidence of adequate validity and reliability for use in nursing homes[32]; however, the minimal clinically important difference is unknown.

Secondary staff outcomes:

- self-efficacy in communicating with residents and their families at the end of life (Self-Efficacy in End-of-Life Care Survey S-EOLC[33]),
- self-perceived educational needs regarding communication and cultural and ethical values (End-of-Life Professional Caregiver Survey EPCS[34]),
- opinions on palliative care (Rotterdam Move2PC[35]).

Before trial commencement, we had listed several primary resident and staff outcomes (see trial register as ISRCTN14741671 at www.isrctn.com). From this list, the PACE consortium selected the abovementioned outcomes as primary and secondary, thus after trial commencement but before the start of the analyses.

Data collection procedure and respondents

Each nursing home assigned one administrative contact person to the study who listed:

- all residents who had died over the previous four months, and two key respondents: (1) one staff member most involved in their care (preferably a nurse or care assistant), and (2) one closely involved relative (family or friend)
- all nurses and care assistants employed in the facility.

For deceased residents, baseline data were collected in all participating nursing homes (T0 at month 0) through after-death structured questionnaires to the key respondents (staff member and relative) and to the administrator/manager. These questionnaires surveyed:

- resident characteristics: age, gender, functional status using BANS-S[36] and presence of dementia; and
- primary, secondary and other resident outcomes.

Post-intervention (T1 at month 13 and T2 at month 17), the same data were collected on residents who had died during the previous four months.

For nurses and care assistants employed in the facility, baseline data were collected in all participating nursing homes (T0 at month 0) through structured questionnaires surveying:

- staff characteristics: age, gender, professional role (nurse or care assistant), whether formal palliative care training had been undertaken and years of experience working in direct care; and
- primary and secondary staff outcomes.

Post-intervention (T1 at month 13), the same data were collected on nurses and care assistants employed in the facility at that time.

Staff and relatives who were asked to complete questionnaires were not informed about the outcome measures or study hypotheses.

Statistical analyses

We estimated that a sample of 144 patients for each group (corresponding to 36 nursing homes with 4 deceased residents per nursing home) would achieve 90.6% power to detect a difference in mean EOLD-CAD score of 3 points[27], assuming a standard deviation of 5.61 points for each group, an intracluster correlation coefficient (ICC) of 0.3 and a significance level of 5%. This was increased to 288 patients per group (total sample size of 576) to allow for a 20% non-response of staff and a 50% non-response on relative questionnaires[24].

For resident outcomes, the unit of analysis was a resident death; for staff outcomes, the unit of analysis was the staff member.

We used linear mixed models (LMMs) to analyze continuous outcomes. These models accounted for the clustered study design i.e. residents or measurement points nested within staff, staff nested within nursing home, nursing homes nested within country. For continuous measurements where the respondents were staff, LMMs were fitted with staff, nursing home and country as random factors (only random intercepts), and with group (intervention versus usual care), time (post-intervention combining data collected between month nine and month 17 versus baseline), and their interaction group x time as fixed factors. For continuous measurements where the respondents were relatives, similar LMMs were fitted, but without a random intercept for staff.

Results are expressed as estimated means with corresponding 95% CIs. Comparisons are reported in terms of expected baseline-adjusted mean differences between groups post-intervention (group x time interaction) with 95% CIs. The presented ICC corresponds to the proportion of variance in the outcome at baseline that can be explained at the level of the nursing home and was calculated by fitting a null model with random intercepts for staff, nursing home and country on the baseline data.

LMM analyses were performed using SAS 9.4 software (© SAS Institute Inc., Cary, NC, USA). All hypothesis testing was two-sided. P-values and 95% confidence intervals were not adjusted for multiple testing. However, to address the problem of multiplicity with Bonferroni correction, p-values should be compared against a significance level of 1% for the primary resident-level analyses and 1.25% for the primary staff-level analyses. All analyses were on an intention-to-treat and complete-case basis, assuming data were missing at random.

Informed consent

All persons filling in questionnaires gave their prior informed consent in writing. In Poland and the Netherlands, an informed consent was not required because questionnaires were filled in anonymously.

Ethics

We obtained ethics approval from the relevant ethics committees in all countries[24] (see online only supplement).

Role of the funding source

The funder of the study had no role in study design, data collection, data analysis, data interpretation, or writing of the report. The lead author had full access to all the data in the study and had final responsibility for the decision to submit for publication.

Results

Trial recruitment started in each country after obtaining ethics approval (after May 2015) with the last data collection completed in the UK December 2017.

Of 160 clusters assessed for eligibility, 82 were excluded, and 78 were recruited and randomized to intervention or control after baseline data collection (Figure S1). Characteristics of participating nursing homes are described in eTable3.

Resident outcomes

Concerning deceased residents, we collected 551/610 questionnaires from staff at baseline (Response rate (RR) 90.3%) and 984/1178 post-intervention (RR 83.5%) in 37 intervention and 36 control homes. We collected 259/467 questionnaires from relatives at baseline (RR 55.5%) and 498/939 at post-intervention (RR 53.0%) (figure 1). Response rates per country are included in eTable 2.

Characteristics of deceased residents are presented in Table 1. Non-response analyses show no differences in deceased residents' characteristics between cases where the staff member returned a questionnaire and cases where the staff member did not return a questionnaire (eTable 5).

The primary resident outcome comfort in the last week of life (End-of-Life in Dementia Scale Comfort Assessment while Dying total score) reported by staff did not differ between intervention and control groups (baseline-adjusted mean difference -0.55, 95%CI -1.71;0.61; p=0.35, Table 2).

The secondary resident outcome quality of care in the last month of life (Quality of Dying in Long-Term Care total score) reported by staff differed significantly between intervention and control groups (baseline-adjusted mean difference 3.40, 95%CI 2.01;4.80; p<0.001, Table 2). We found a significant difference between intervention and control on the subscale 'Preparatory tasks' (baseline-adjusted mean difference 6.77, 95%CI 4.19;9.36; p<0.001, Table 2), but not on the other two subscales.

We found no significant differences between control and intervention groups for the measures reported by relatives i.e. resident's comfort in the last week of life (End-of-Life in Dementia Scale Comfort Assessment while Dying total score), relatives' perception of the quality of end-of-life care (End-of-Life in Dementia – Satisfaction with Care total score) and relatives' perception of physician-family communication (Family Perception of Physician-Family Communication; eTable 8).

Staff outcomes

We collected 2680/3638 questionnaires on staff at baseline (RR 73.7%) and 2437/3510 post-intervention (RR 69.4%) in 37 intervention and 38 control homes (figure 2). Characteristics of participating staff are presented in Table 3.

The primary staff outcome knowledge of palliative care (Palliative Care Survey) differed significantly between intervention and control groups for the subscale 'End-of-Life Factors' (baseline-adjusted mean difference 0.04, 95%CI 0.02;0.05; p<0.001, Table 4) but not for the other subscales or the total scale score (baseline-adjusted mean difference 0.02, 95%CI 0.001;0.03; p=0.03) (see eTable 9 for item differences).

Regarding secondary staff outcomes, we found that staff in the intervention group indicated fewer educational needs regarding cultural and ethical values (End-of-Life Professional Caregiver Survey, subscale cultural and ethical values) than in the control group (baseline-adjusted mean difference 0.11, 95%CI 0.05; 0.17; p<0.001, Table 4), but not regarding resident/family communication (End-of-Life Professional Caregiver Survey, subscale communication; baseline-adjusted mean difference 0.05, 95%CI -0.003;0.11; p=0.07). There was no significant difference in staff self-efficacy in communicating with residents and their families at the end of life (Self-Efficacy in End-of-Life Care Survey baseline-adjusted mean difference 0.09, 95%CI -0.04 0.21; p=0.16). Opinions on palliative care (Rotterdam Move2PC) differed (Online only eTable 5) on two items with staff in the intervention group being more likely to say 'palliative care includes care for the family' and 'residents should be clearly informed about imminent death' (p=0.03).

Discussion

This multi-facility cluster-RCT in seven European countries found that the PACE Steps to Success Programme did not improve the comfort in the last week of life of residents as reported by staff. We found a significant difference between intervention and control groups for staff knowledge of end-of-life care issues, but this difference was very small and hence not clinically important. We did not find any negative effects.

Our study is the first cluster-RCT testing the effectiveness of a one-year multicomponent palliative care programme on a very large scale in 78 nursing homes in seven different countries. A major strength of our trial is its pragmatic nature, focusing on implementation in actual practice in countries with different health care systems[10], varying nursing home populations[8] and end-of-life care 'cultures'[2], which increases external validity and generalizability of our findings. Additional strengths are the high-quality research design and the measurement of multiple resident and staff outcomes with good to high response rates for this type of research.

Our trial also has limitations. Firstly, staff filling in the questionnaires were not blinded. This might have influenced their responses, in particular for items such as evaluations of the quality of care, as staff may have wanted to report better quality after the intervention. However, given that the study did not find an improvement in staff-reported comfort in the last week of life in the intervention group, suggests that bias on the outcome measures due to an overly optimistic assessment is limited. Secondly, evaluations of quality of care in the last month of life and comfort were performed after death, which might have introduced recall bias. Nevertheless, in this population, after-death evaluations by staff have been judged appropriate for several reasons including that complete data are difficult to achieve in prospective studies with living patients due to high attrition rates and incorrect prognostication[5,37,38]. However, the fact that we identified deaths in the previous four months means that some staff may have reported on a death that occurred four months ago, while other staff reported on a more recent death. Prospective data collection, eg. asking staff to complete an assessment within two weeks of a resident death, would have been a stronger approach, although this would have substantially inflated the workload for staff.

Several reasons might explain why the PACE programme did not reach its intended effects. First, the programme might be too complex with too many components to be implemented within a one-year time frame. A systematic review of nursing home interventions concluded that studies targeting specific care tasks were more likely to produce positive outcomes than those requiring broader practice changes[39] such as the PACE programme. Hence, it might be better to focus on one component at a time.

Second, the implementation of the intervention might have been suboptimal in some nursing homes. This was also the case in another palliative care trial in US nursing homes[1], where only six of the 14 intervention facilities had implemented the intervention as foreseen. The nursing home is a complex context and previous research has outlined the many contextual barriers, such as high staff turnover and workload[39], influencing the ability to adopt new practices. Also, although we did adapt the intervention materials to make them feasible and culturally appropriate for use in the seven countries[24], our PACE intervention might have been too standardized to ensure optimal implementation in all settings, not allowing tailoring of intervention components to the local nursing home context. A thorough process evaluation is needed to test this hypothesis.

Third, the different intervention components and the primary outcome measure –comfort in the last week of life– did not match perfectly. The intervention included six different steps targeting the whole trajectory of residents, from admission to death; however, care in the last days of life was only one of these steps, implemented at the end (step 5 at month seven). Moreover, the intervention programme focused more on symptom assessment than on management of complex symptoms in the terminal phase, hence, the closer involvement of GPs or specialist palliative care services might be necessary to achieve better comfort at the end of life. Finally, the focus on symptom assessment rather than management could also have increased staff's ability to recognize symptoms, leading to improved reporting and masking the potential effect.

The finding that the quality of care in the last month of life did significantly improve after the PACE intervention needs further study. The change was most apparent in the subscale 'preparatory tasks'. Hence it could be hypothesized that the advance care planning step in the PACE programme brought about a conversational shift in nursing homes around the end of life. It was also the first step introduced as part of the PACE programme, thus implemented for the longest time in the nursing homes. Although this might explain the effect found, we need to be careful with this interpretation as this was a secondary outcome of the study.

The results of the PACE trial affirm the difficulty to improve the end of life of nursing home residents. However, nursing homes in future must be able to provide excellent palliative care to all residents as an integral part of their work. Moving forward, it might be necessary to (a) focus on one more delineated or targeted component at a time (e.g. one step in the programme), (b) allow more flexibility and tailoring to the local context during implementation, and (c) ensure a close fit between the intervention and outcome measures used in the evaluation.

In conclusion, we did not observe an improvement in comfort of residents in the last week of life after introducing the PACE Steps to Success Programme, and improvements in staff knowledge of palliative care were minimal. The observed differences in quality of care in the last month of life are promising but need further investigation.

Declarations

Contributors

All authors were involved in the design of the study and the figures, data interpretation, and writing of the article, and all approved the final version of the manuscript. LVDB, EH, LP, RM, BOP, RP, MOV, MTK, KF, SP, KZ, MK, GG, SP, CB and TS contributed to data collection. SDB, LVDB, EH and TS analyzed the outcome data.

Competing interests declaration

We declare no competing interests.

Funding

This work was supported by the European Union's Seventh Framework Programme (FP7/ 2007e2013) under grant agreement 603111 (PACE project Palliative Care for Older People). It has been co-funded by Polish Ministry of Science and Higher Education in the years 2014-2019 based on the decision no 3202/7PR/2014/2 (Nov. 25th 2014) and by the Swiss Academy of Medical Sciences in the years 2015-2017. LP is a Postdoctoral Fellow of the Research Foundation-Flanders. LP and TS are recipients of an AXA Research Fund Postdoctoral Grant.

Role of funder

The funders had no role in study design; conduct of the study; collection, management, analysis, and interpretation of the data; preparation, review, or approval of the manuscript; and decision to submit the manuscript for publication.

Acknowledgements

We thank the Biostatistics Unit of Ghent University (R Colman, MSc) for advising the statistical analyses and the Department of Epidemiology and Biostatistics of the UMC Amsterdam, Vrije Universiteit (Dr. MA Jonker, PhD) for performing the randomization. We thank all participating nursing homes and participants, all country trainers, and all PACE collaborators who are not in the author list (Eddy Adang, Paula Andreasen, Ilona Barańska, Harriet Finne-Soveri, Teija Hammar, Rauha Heikkilä, Danni Collingridge Moore, Violetta Kijowska, Suvi Leppäaho, Federica Mammarella, Martina Mercuri, Outi Kuitunen-Kaija, Agnieszka Pac, Emilie Morgan de Paula, Paola Rossi, Ivan Segat, Jenny T. van der Steen, Agata Stodolska, Marc Tanghe, and Anne B. Wichmann). We thank Jane Ruthven (MA) for language editing. Authors have no potential conflicts of interest to declare.

Access to data

LVdB and TS had full access to all the data in the study and take responsibility for the integrity of the data and the accuracy of the data analysis.

Data Sharing statement

The authors commit to making the relevant data available on reasonable request.

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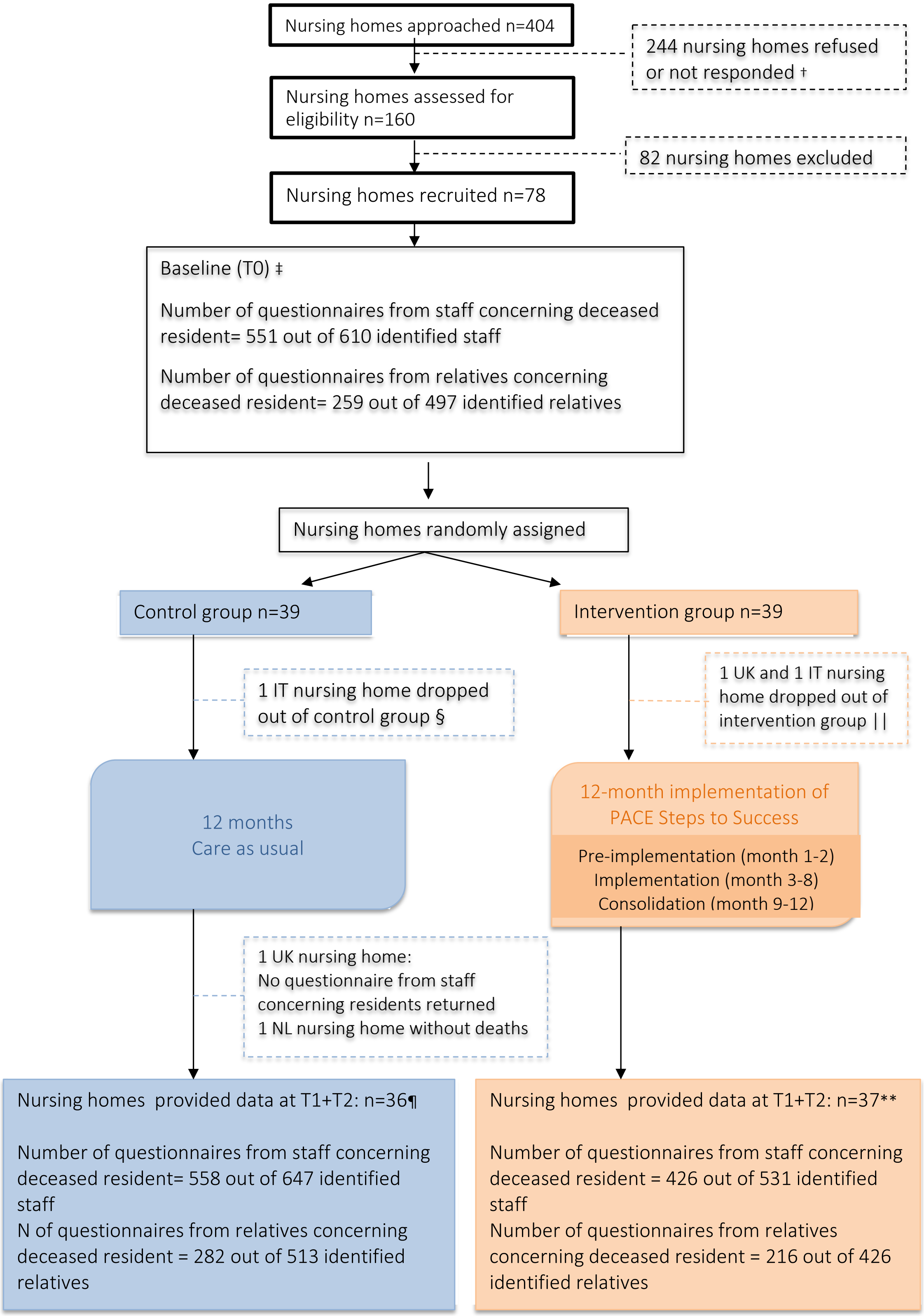
Figure 1: Flowchart of recruitment, randomization and data collection at resident level*



* The flowchart includes the number of clusters or nursing homes participating throughout the trial, in intervention and control group, and the number of deceased residents identified at baseline and post-intervention in both groups. T0=baseline measurement at month 0; T1=month 13; T2=month 17; Staff = nurse or care assistant most involved in care for that resident
† Reasons for refusing included insufficient time, no interest, understaffing, already involved in other studies, change in management.
‡ We identified 617 deceased residents across nursing homes. For 7 residents, no staff member could be identified; for 120 residents, no relative could be identified.
Reasons for drop-outs: § Reorganising of the nursing home; || intervention was taking too much time.
¶ We identified 649 deceased residents in the control group. For 2 residents, no staff member could be identified; for 136, no relative could be identified.
** We identified 542 deceased residents in the intervention group. For 11 residents, no staff member could be identified; for 116, no relative could be identified.

Table 1. Characteristics of deceased residents

	Baseline (T0)		Post-intervention (T1+T2)	
	Control (n=272)	Intervention (n=279)	Control (n=558)	Intervention (n=425)
Age at time of death, unadjusted mean (SD)*	85.22 (9.13)	85.68 (9.00)	85.58 (8.81)	85.91 (8.57)
Gender, female, unadjusted frequency	190/269 (70.6%)	160/264 (60.6%)	354/547 (64.7%)	265/414 (64.0%)
Functional status one month before death (BANS-S), unadjusted mean (SD) †	19.93 (4.31)	19.03 (4.90)	18.95 (4.93)	18.75 (5.14)
Resident had dementia, unadjusted frequency	188/262 (71.8%)	194/276 (70.3%)	399/556 (71.8%)	278/416 (66.8%)

Data are mean (SD) or n (%). The table presents characteristics of deceased residents for whom an assessment by nurses was made.
* Data missing at baseline for 11 cases in intervention and 4 cases in control group. Data missing at post-intervention for 11 cases in intervention and 18 cases in control group.
†Data missing at baseline for 14 cases in intervention and 9 cases in control group. Data missing at post-intervention for 19 cases in intervention and 10 cases in control group.

Table 2. Resident outcomes: cluster-adjusted mean scores and differences for the primary and secondary outcomes

	Baseline score		Post-intervention score*		Baseline-adjusted mean difference between groups post-intervention (95% CI)	P interaction†	ICC
	Control	Intervention	Control	Intervention			
	Mean (95% CI) Number of cases	Mean (95% CI) Number of cases	Mean (95% CI) Number of cases	Mean (95% CI) Number of cases			
Primary resident outcome							
Comfort in the last week of life (CAD-EOLD, range 14-42)‡	30.22 (28.92; 31.53) N = 251	30.64 (29.33; 31.95) N = 258	31.00 (29.77; 32.23) N = 526	30.86 (29.61; 32.12) N = 387	-0.55 (-1.71; 0.61)	0.35	0.08
Physical distress‡	29.32 (28.0524; 30.5803) N= 252	29.38 (28.12; 30.64) N= 260	29.59 (28.46; 30.71) N= 529	29.52 (28.35; 30.70) N= 387	-0.13 (-1.62; 1.37)	0.87	0.04
Dying symptoms‡	31.21 (29.80; 32.62) N= 255	32.02 (30.60; 33.44) N=258	32.24 (30.96; 33.53) N= 527	32.50 (31.17; 33.83) N=391	-0.55 (-2.11; 1.01)	0.49	0.05
Emotional distress‡	32.98 (31.72; 34.24) N=252	33.48 (32.22; 34.74) N=259	33.72 (32.61; 34.83) N=528	33.65 (32.49; 34.81) N=386	-0.57 (-2.13; 0.99)	0.47	0.03
Well-being‡	29.71 (26.87; 32.55) N= 252	29.16 (26.32; 32.01) N= 258	28.37 (25.61; 31.13) N= 524	29.27 (26.48; 32.06) N= 387	1.45 (-0.34; 3.23)	0.11	0.11
Secondary resident outcome							
Quality of care in the last month of life (QOD-LTC, range 11-15)‡	39.09 (36.71; 41.48) N = 264	37.89 (35.50; 40.29) N = 266	39.28 (36.96; 41.61) N = 541	41.49 (39.13; 43.85) N = 399	3.40 (2.01; 4.80)	<0.001	0.05
Personhood‡	47.20 (46.06; 48.34) N = 268	45.97 (44.83; -47.12) N = 271	47.51 (46.47; 48.55) N = 548	47.60 (46.52; -48.68) N = 411	1.33 (0.07; 2.58)	0.038	0.06
Closure‡	33.90 (31.19; 36.62) N = 264	33.82 (31.10; 36.55) N = 268	34.32 (31.73; 36.92) N = 543	36.64 (33.99; 39.28) N = 402	2.40 (0.26; 4.54)	0.028	0.03
Preparatory tasks‡	29.57 (23.67; 35.46) N = 258	29.27 (23.36; 35.18) N = 259	29.92 (24.10; 35.74) N = 538	36.40 (30.54; 42.26) N = 382	6.77 (4.19; 9.36)	<0.001	0.07

All estimated means, and 95% CIs, are cluster-adjusted; differences are cluster and baseline adjusted. ICC=unconditional intraclass correlation coefficient from baseline assessments.

*Post intervention measurements collected for residents at T1 (=month 13) and T2 (=month 17).

† Interaction effect of group (control and intervention) and timepoint (baseline and post-intervention) calculated with a mixed linear regression model. We calculated differences in change (post-intervention minus baseline) between the intervention and control groups (interaction group x time).

‡ Total scale scores are averages per subscale multiplied by total number of items. Cases with missing data on more than 50% of items per subscale were excluded from the calculation of the total scale scores.

Table 3. Characteristics of staff (staff outcomes)

	Baseline (T0)		Post-intervention (T1)	
	Control (n=1409)	Intervention (n=1270)	Control (n=1278)	Intervention (n=1159)
Age, unadjusted mean (SD)*	42.3 (12.1)	43.7 (11.6)	42.3 (12.1)	44.1 (11.7)
Gender (Female), unadjusted frequency	1224/1375 (89.0%)	1092/1253 (87.2%)	1094/1229 (89.0%)	990/1131 (87.5%)
Professional role, unadjustedfrequency				
Care assistant	565/1205 (46.9%)	509/1091 (46.7%)	546/1087 (50.2%)	470/977 (48.1%)
Nurse	640/1205 (53.1%)	582/1091 (53.3%)	541/1087 (49.8%)	507/977 (51.9%)
Undertaken formal training in palliative care (yes†), unadjusted frequency	797/1337 (59.6%)	643/1218 (52.8%)	732/1196 (61.2%)	718/1086 (66.1%)
Years of experience working in direct resident care, unadjusted mean (SD) ‡	14.7 (10.8)	15.1 (10.8)	14.9 (11.0)	14.9 (10.7)

Data are unadjusted mean (SD) or unadjusted frequency n/N (%)

* Data missing at baseline for 48 cases in intervention and 63 cases in control group. Data missing at post-intervention for 63 cases in intervention and 95 cases in control group.

† Yes, as part of education to become nurse or care assistant, or additional education after obtaining the degree.

‡ Data missing at baseline for 68 cases in intervention and 91 cases in control group. Data missing at post-intervention for 101 cases in intervention and 151 cases in control group.

Table 4. Staff outcomes: Cluster-adjusted mean scores and differences for the primary and secondary outcomes

	Baseline score (T0)		Post-intervention score*		Baseline-adjusted mean difference between groups post-intervention (95% CI)	P interaction†	ICC
	Control	Intervention	Control	Intervention			
	Mean (95% CI) Number of cases	Mean (95% CI) Number of cases	Mean (95% CI) Number of cases	Mean (95% CI) Number of cases			
Primary staff outcome							
Knowledge of palliative care (PCS, range 0-1)§	0.58 (0.52; 0.63) N = 1399	0.58 (0.52; 0.63) N = 1261	0.59 (0.54; 0.65) N = 1273	0.61 (0.56; 0.67) N = 1148	0.02 (0.001; 0.03)	**.03**	0.02
End-of-life factors	0.39 (0.31; 0.47) N = 1398	0.39 (0.31; 0.47) N = 1261	0.41 (0.33; 0.49) N = 1272	0.45 (0.37; 0.53) N = 1146	0.04 (0.02; 0.05)	**<0.001**	0.02
Physical	0.83 (0.79; 0.87) N = 1387	0.83 (0.79; 0.87) N = 1244	0.84 (0.80; 0.88) N = 1247	0.83 (0.80; 0.87) N = 1129	-0.01 (-0.03;0.01)	0.31	0.02
Psychological	0.69 (0.63; 0.76) N = 1378	0.70 (0.63; 0.76) N = 1241	0.71 (0.64; 0.77) N = 1244	0.72 (0.65; 0.78) N = 1124	0.01 (-0.02; 0.04)	0.51	0.01
Secondary staff outcomes							
Staff self-efficacy In communicating with residents at the end of life and their families with the subscale 'Communication' (S-EOLC, range 0-7)‡	4.83 (4.44; 5.23) N = 1270	4.72 (4.32; 5.11) N = 1155	4.81 (4.42; 5.21) N = 1156	4.79 (4.39; 5.18) N = 1039	0.09 (-0.04; 0.21)	0.16	0.0009
Staff educational needs regarding patient and family communication with the subscale 'Patient and family communication' (EPCS, range 1-5)‡	3.81 (3.63; 3.99) N =1310	3.77 (3.59; 3.96) N = 1161	3.82 (3.63; 4.00) N = 1167	3.83 (3.64; 4.01) N = 1049	0.05 (-0.003; 0.11)	0.07	0.01
Staff educational needs regarding cultural and ethical values with the subscale 'cultural and ethical values' (EPCS, range 1-5)‡	3.74 (3.52; 3.96) N = 1376	3.69 (3.47; 3.91) N = 1235	3.73 (3.51; 3.96) N = 1244	3.79 (3.56; 4.01) N = 1102	0.11 (0.05; 0.17)	**<0.001**	0.009

All means and 95% CIs are cluster-adjusted; differences are cluster and baseline adjusted. ICC=unconditional intraclass correlation coefficient from baseline assessments.
All staff members who filled in a questionnaire at baseline (T0) and/or at post-intervention (T1) are included in the analyses.
* Post intervention measurements collected for staff only at T1 (=month 13).
† Interaction effect of group (control and intervention) and timepoint (baseline and post-intervention) calculated with a mixed linear regression model. We calculated differences in change (post-intervention minus baseline) between the intervention and control groups (interaction group x time).
‡Total scores are averages per subscale/whole scale multiplied by total number of items. Cases with missing data on more than 25% of items per scale/subscale were excluded from the calculation of the total scores
§ Aggregated score of all items of the Knowledge construct of the Palliative Care Survey.

eTable 1: The six steps of the PACE Steps to Success Programme

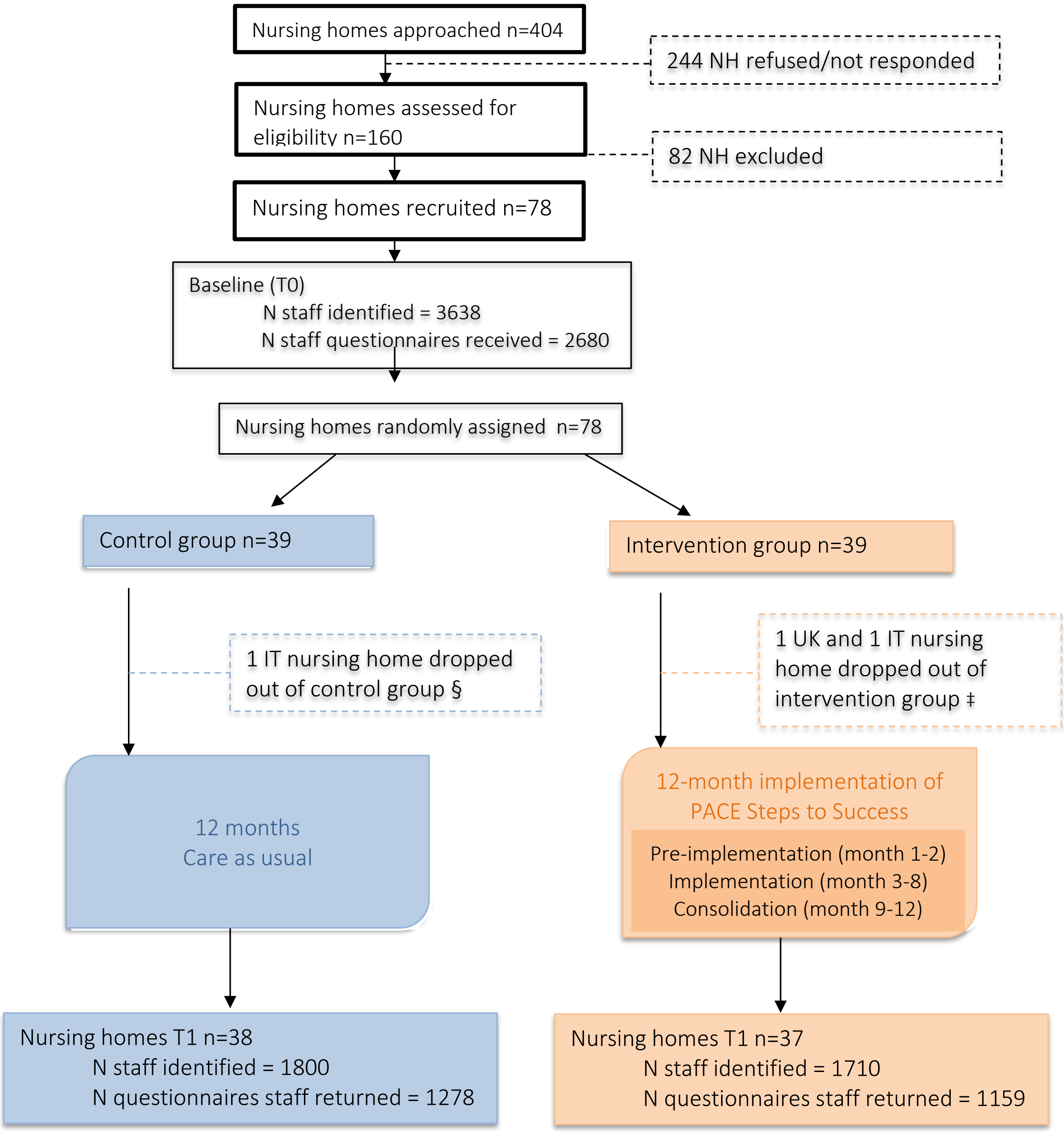
Step	Tool/material used	Description
1. Advance care planning with residents and family	‘Looking and Thinking Ahead’ document	Advance care planning (ACP) discussions with residents and/or families are conducted to elicit wishes and preferences around end-of-life care. This communication process usually takes place in the context of an anticipated deterioration in the individual’s condition in the future, with attendant loss of capacity to make decisions and/or ability to communicate wishes to others. ACP discussions may either be planned or ‘opportunistic’, meaning that it can be initiated when a resident brings up the subject voluntarily. As palliative care aims to improve the quality of the remaining life, these discussions should not be just about the very few days, but also about living well during the last years of life.
2. Assessment, care planning, and review of resident needs and problems	‘Mapping Changes in Condition’ chart	A ‘Mapping Changes in Condition chart’ is used monthly by nurses and care assistants to plot changes (deterioration and improvement) in a resident’s physical condition. Nurses and care assistants are ideally placed to identify the various clinical triggers that indicate that a frail older person may be entering the last phase of their life. The chart helps staff recognize changes over months. By completing this every month (and every week when a resident is in the last phase of his of her life) one can see a trajectory over time of how the resident has been.
3. Co-ordination of care	Palliative Care Register with monthly multidisciplinary palliative care review meetings	Using a Palliative Care Register, residents who are identified as expected to live less than six months are discussed in detail during monthly multidisciplinary review meetings. The register prompts staff about different aspects of care to be considered. A summary sheet is sent to physicians who were not able to attend the meeting.

4. Delivery of high-quality care with a focus on pain and depression	Pain Assessment and Management Tool including numerical pain scale or PAINAD in case of advanced dementia[2] ‘Geriatric Depression Scale’ (short version)[3] or ‘Cornell Depression Scale for people with dementia’[4]	Staff is educated about general principles of palliative care for frail older people including those with dementia, symptom control and complex communication skills. This step also involves the training of care staff to assess and manage the particular symptoms of pain and depression. Pain assessment is undertaken on all current residents in the facility and on admission of all new residents. Assessment is continued regularly if pain is not controlled and/or at six-monthly review. Assessment of depression is undertaken if a resident is considered depressed., or following admission when a resident settled into the nursing home if mood appears low.
5. Care in the last days of life	Integrated care plan for the last days of life using the Last Days of Life checklist	Use of an integrated care plan for the last days of life to empower staff to provide high quality care to the dying resident and their family. The checklist prompts and guides the care in the last days of life, ensuring that appropriate medication is available or unnecessary medication is discontinued in anticipation of symptoms during the dying process. The checklist also focuses on recognizing dying, communication with family, regular assessment of symptoms, hydration, and psychosocial and spiritual support.
6. Care after death	Monthly reflective de-briefings groups	Monthly reflective debriefing meetings to support staff following a death and to encourage experiential learning.

This tables summarizes the six steps of the PACE Steps to Success Programme. It is implemented with the help of an external country trainer over a 12-month period, in three phases. After a 2-month preparation phase, the six steps are implemented consecutively during month 3 to 8 (one step per month); in month 9 to 12, there is consolidation phase with ongoing support from the country trainer where needed. The PACE Steps to Success Programme is described in full elsewhere[1] eTable 2: Overview of outcomes measured

		Unit of analysis	Respondent	Measurement instruments
Resident-level outcomes				
Primary outcome	Comfort in the last week of life	Deceased resident	Staff	End-of-Life in Dementia Scales – Comfort Assessment while dying (EOLD-CAD)
Secondary outcome	Quality of care in the last month of life	Deceased resident	Staff	Quality of Dying in Long Term Care (QOD LTC)
Other measures	Comfort in the last week of life of the residents	Deceased resident	Relative	End-of-Life in Dementia Scales – Comfort Assessment while dying (EOLD-CAD)
	Quality of end-of-life care according to the relatives	Deceased resident	Relative	End-of-Life in Dementia Scales – Satisfaction with Care (EOLD-SWC)
	Quality of communication between relatives and physicians	Deceased resident	Relative	Family Perception of Physician-Family Communication (FPPFC)
Staff-level outcomes				
Primary outcome	Knowledge of palliative care	Staff	Staff	Palliative care survey (PCS) construct ‘Palliative care knowledge’
Secondary outcomes	Self-efficacy (confidence) in communicating with residents at the end of life and their families	Staff	Staff	Self-Efficacy in End-of-Life Care Survey (S-EOLC) subscale ‘Communication’
	Self-perceived educational needs regarding patient and family communication and cultural and ethical values	Staff	Staff	End-of-Life Professional Caregiver Survey (EPCS), subscales ‘Patient and family communication’ and ‘cultural and ethical values’
	Opinions on palliative care	Staff	Staff	Rotterdam Move2PC, 11 statements regarding opinions

eFigure 1. Flowchart of recruitment, randomization and data collection at staff level*



* The flowchart includes the number of clusters or nursing homes participating throughout the trial, in intervention and control group, and number of staff identified at baseline and post-intervention in both groups.
T0=baseline measurement at month 0; T1=month 13; Staff = nurse or care assistant
† Reasons for refusing included insufficient time, no interest, understaffing, already involved in other studies, change in management.
Reasons for drop-outs: ‡ Intervention was taking too much time; § Reorganising of the nursing home

eTable 3. Characteristics of the participating nursing homes

Characteristics	Control group (N= 39)	Intervention group (N=39)
Country		
Belgium	6	6
England	7	7
Finland	6	6
Italy	7	7
Poland	4	4
Switzerland	4	4
The Netherlands	6	6
Status of the nursing home		
Public non-profit	17	21
Private non-profit	9	8
Private for profit	12	9
Specialist palliative care team present in the facility (yes)	7	4
Specialist palliative care advice available to professionals delivering palliative care in the facility (yes)	27	18
Opioids available 24/7 for residents in need of palliative care (yes, for all/most/some residents)	34	33
Regular multidisciplinary meeting (with at least a physician and a nurse) to review treatment and care plans organized in the facility	32	29

eTable 4. Response Rates per country

	Staff questionnaire				Staff* concerning deceased resident questionnaire				Relative concerning deceased resident questionnaire			
	Control		Intervention		Control		Intervention		Control		Intervention	
	T0	T1	T0	T1	T0	T1 + T2	T0	T1+T2	T0	T1 + T2	T0	T1 + T2
BELGIUM	88.6%	67.1%	96.7%	72.6%	95.6%	77.5%	97.4%	93.5%	88.9%	73%	78.9%	69.2%
ENGLAND	29.9%	31.0%	57.5%	62.4%	70.4%	84.7%	100%	66.2%	35%	36.8%	38.5%	35.7%
FINLAND	87.1%	82.3%	87.8%	69.8%	94%	97%	89.2%	73.9%	53.5%	61.5%	35.5%	53%
ITALY	76.2%	69.6%	74.2%	74.4%	96.7%	88.4%	92.9%	88.8%	39.2%	32.3%	38.6%	30.9%
THE NETHERLANDS	56.1%	86.4%	47.3%	32.9%	87.5%	70.4%	78.9%	51.5%	65.6%	66.7%	55.6%	29%
POLAND	85.5%	76.8%	70.1%	98.6%	87.9%	72.5%	100%	98.4%	40%	26.5%	31.8%	42.3%
SWITZERLAND	83.7%	77.3%	93.8%	81.6%	100%	87%	100%	98%	73.1%	59.7%	68.2%	59.2%

RRs lower than 50% are in red.
T0=baseline measurement at month 0; T1=month 13; T2= month 17; *staff= nurse or care assistant most involved in the resident’s care.

eTable 5. P-values for differences between response and non-response for staff assessment

	Baseline (T0)		Post-intervention (T1+T2)	
	Response (n=272) Non-response (n=35)	Response (n=279) Non-response (n=31)	Response (n=558) Non-response (n=91)	Response (n=425) Non-response (n=114)
	Control	Intervention	Control	Intervention
Mean age at time of death†	*P= 0.906*	*P= 0.963*	*P=0.320*	*P=0.957*
Gender†	*P=0.638*	*P=0.811*	*P=0.927*	*P=0.539*
Mean length of stay in nursing home†	*P=0.368*	*P=0.585*	*P= 0.528*	*P=0.607*

*Pearson's Chi^2 test
† reported by the nursing home administrator

eTable 6. P-values for differences between response and non-response for relatives’ assessments

	Baseline (T0)		Post-intervention (T1+T2)	
	Response (n=130) **Non-response** **(n=177)**	**Response (n=128)** **Non-response** **(n=182)**	**Response (n=273)** **Non-response** **(n=376)**	**Response (n=221)** **Non-response** **(n=317)**
	Control	**Intervention**	**Control**	**Intervention**
Mean age at time of death†	*P= 0.728*	*P= 0.278*	*P=0.449*	*P=0.113*
Gender†	*P=0.829*	*P=0.259*	*P=0.777*	*P=0.473*
Mean length of stay in nursing home†	*P=0.380*	*P=0.285*	*P= 0.437*	*P=0.342*

*Pearson’s Chi^2 test
† reported by the nursing home administrator

eTable 7. Cluster-adjusted mean scores and differences for the individual items of the secondary outcome at resident level (QOD-LTC)

Subscale	Item	Baseline score		Post-intervention score*		**Baseline-adjusted mean difference between groups post-intervention (95% CI)**	P interaction†
		Control	Intervention	Control	Intervention		
		Estimated mean (95% CI) Number of staff	Estimated mean (95% CI) Number of staff	Estimated mean (95% CI) Number of staff	Estimated mean (95% CI) Number of staff		
Personhood	There was a nurse or aide with whom resident felt comfortable	4.03 (3.84; 4.23) N = 259	3.96 (3.76; 4.15) N = 270	4.03 (3.85; 4.21) N = 539	4.13 (3.95; 4.31) N = 413	0.17 (-0.04; 0.39)	0.11
	Resident received affectionate touch daily	4.34 (4.18; 4.51) N = 266	4.26 (4.09; 4.42) N = 271	4.34 (4.18; 4.49) N = 546	4.45 (4.29; 4.60) N = 409	0.19 (0.02; 0.37)	**0.0312**
	Resident's physician knew her/him as a whole person including life and personality	3.78 (3.47; 4.10) N = 267	3.56 (3.24; 3.87) N = 267	3.86 (3.56; 4.17) N = 543	3.81 (3.50; 4.12) N = 406	0.17 (-0.06; 0.40)	0.15
	Resident's dignity was maintained	4.50 (4.33; 4.67) N = 258	4.37 (4.20; 4.54) N = 256	4.59 (4.43; 4.75) N = 528	4.52 (4.36; 4.69) N = 375	0.06 (-0.09; 0.22)	0.43
	Resident's clothes and body were kept clean	4.75 (4.65; 4.86) N = 253	4.75 (4.65; 4.85) N = 256	4.77 (4.68; 4.86) N = 531	4.74 (4.64; 4.83) N = 371	-0.03 (-0.14; 0.09)	0.66
Closure	Resident appeared to be at peace	3.70 (3.48; 3.92) N = 264	3.71 (3.49; 3.94) N = 268	3.78 (3.58; 3.98) N = 540	3.92 (3.71 4.13) N = 398	0.12 (-0.11; 0.36)	0.29
	Resident indicated that she or he was prepared to die	2.51 (2.08; 2.94) N = 266	2.41 (1.98; 2.84) N = 269	2.58 (2.16; 2.99) N = 537	2.81 (2.39; 3.23) N = 409	0.33 (0.02; 0.64)	**0.0348**

	Resident maintained her or his sense of humour	3.02 (2.78; 3.26) N = 259	3.09 (2.85; 3.33) N = 258	3.006 (2.80; 3.21) N = 534	3.21 (2.99; 3.42) N = 389	0.13 (-0.17; 0.43)	0.40
Preparatory tasks	Resident had treatment preferences in writing	2.36 (1.80; 2.91) N = 264	2.50 (1.94; 3.06) N = 268	2.44 (1.90; 2.99) N = 544	3.11 (2.56; 3.67) N = 406	0.52 (0.21; 0.83)	**0.0010**
	Resident's funeral was planned	2.53 (1.93; 3.14) N = 261	2.48 (1.87; 3.09) N = 261	2.42 (1.82; 3.01) N = 539	3.11 (2.51; 3.72) N = 392	0.76 (0.46; 1.05)	**<.0001**
	Resident had named a decision-maker in the event that she or he was no longer able to make decisions	3.16 (2.54; 3.79) N = 257	2.95 (2.32; 3.57) N = 264	3.27 (2.66; 3.88) N = 536	3.69 (3.07; 4.31) N = 399	0.63 (0.30; 0.96)	**0.0002**

All means and 95% CIs are cluster adjusted; differences are cluster and baseline adjusted.

*Post-intervention measurements collected at T1=month 13 and T2=month 17.

† Interaction effect of group (control and intervention) and timepoint (baseline and post-intervention) calculated with a mixed linear regression model. We calculated differences in change (post-intervention minus baseline) between the intervention and control groups (interaction group x time).

eTable 8. Other measures at resident level: Cluster adjusted estimates of comfort in the last week of life, quality of end-of-life care and communication reported by relatives

	Baseline score		Post-intervention score*		**Baseline-adjusted mean difference between groups post-intervention (95% CI)**	**P interaction†**
	Control	**Intervention**	**Control**	**Intervention**		
	Estimated mean (95% CI) Number of staff	Estimated mean (95% CI) Number of staff	Estimated mean (95% CI) Number of staff	Estimated mean (95% CI) Number of staff		
Quality of Dying with End-of-Life in Dementia Scale 'Comfort Assessment while dying' (EOLD-CAD) reported by relatives *(range 14-42) (Higher scores indicate better quality of dying)*	29.84 (28.72; 30.96) N=113	28.68 (27.55; 29.81) N=112	30.15 (29.31; 30.98) N=242	29.90 (28.93; 30.88) N=197	0.91 (-1.03; 2.85)	0.36
Relatives' perception of the quality of end-of-life care with End-of-Life in Dementia – Satisfaction with Care (EOLD-SWC) *(range 10-40) (Higher scores indicate better quality of end-of-life care)*	33.05 (31.56; 34.54) N=123	31.27 (29.78; 32.77) N=121	32.33 (31.01; 33.64) N=256	32.27 (30.88; 33.66) N=215	1.72 (-0.15; 3.59)	0.07
Family Perception of Physician-Family Communication reported by relatives with FPPFC *(range 0-3) (Higher scores indicate better quality of communication)*	1.93 (1.65; 2.22) N=119	1.87 (1.59; 2.15) N=116	1.96 (1.69; 2.22) N=238	1.88 (1.61; 2.15) N=190	-0.02 (-0.29; 0.25)	0.90

All means and 95% CIs are cluster adjusted; differences are cluster and baseline adjusted.

*Post-intervention measurements collected at T1=month 13 and T2=month 17.

† Interaction effect of group (control and intervention) and timepoint (baseline and post-intervention) calculated with a mixed linear regression model. We calculated differences in change (post-intervention minus baseline) between the intervention and control groups (interaction group x time).

eTable 9. Cluster adjusted estimates of staff knowledge of palliative care: Individual items of the primary outcome at staff level (Palliative care Survey), subscale end-of-life factors

	Baseline score (T0)		Post-intervention score*		Odds ratio (95% CI for the group*time interaction)	P interaction†
	Control	Intervention	Control	Intervention		
	Estimated proportion (95% CI) Number of staff	Estimated proportion (95% CI) Number of staff	Estimated proportion (95% CI) Number of staff	Estimated proportion (95% CI) Number of staff		
Case Mrs. Davis*: In the past few days, Mrs. Davis has become unresponsive. How will you assess her need for pain medication? (Since she was in pain when she was conscious, I assume she's still in pain)	0.53 (0.49; 0,57) N = 1337	0.55 (0.51; 0.59) N = 1209	0.59 (0.55; 0.63) N = 1229	0.62 (0.58; 0.66) N = 1110	1.05 (0.80 – 1.37)	0.72
Case Mrs. Davis*: Mrs. Davis is nearing death and her respirations are shallow and rattling. Her husband says, "I don't want her to suffocate." Which should you do? (Reassure her husband that the rattling is normal and is not causing suffering)	0,39 (0,34; 0,44) N = 1311	0.40 (0,35; 0,45) N = 1166	0.47 (0.42; 0.52) N = 1198	0.55 (0.50; 0.60) N = 1956	1.36 (1.01 – 1.83)	**0.04**
Case Mrs. Davis*: We have to treat Mrs. Davis' weight loss (disagree)	0.35 (0.30; 0.39) N = 1366	0.39 (0.34; 0.43) N = 1234	0.35 (0.31; 0.40) N = 1243	0.48 (0.43; 0.53) N = 1119	1.43 (1.06 – 1.92)	**0.02**
Case Mrs. Davis*: If Mrs. Davis continues to lose weight, she will need a feeding tube (disagree)	0.94 (0.92; 0.96) N = 1363	0.92 (0.88; 0.95) N = 1228	0.96 (0.94; 0.97) N = 1235	0.99 (0.98; 0.99) N = 1113	4.64	**<0.001**
Addiction is a problem with pain medication (disagree)	0.44 (0.39; 0.48) N = 1365	0.43 (0.38; 0.48) N = 1226	0.43 (0.39; 0.48) N = 1236	0.51 (0.46; 0.56) N = 1112	1.41 (1.08 – 1.84)	**0.01**
Residents can sleep when they are in pain (agree)	0.20 (0.17; 0.23) N = 1366	0.19 (0.16; 0.23) N = 1234	0.23 (0.20; 0.27) N = 1236	0.23 (0.19; 0.26) N = 1112	1.02 (0.76 – 1.37)	0.89
Feeding tubes prevent aspiration (disagree)	0.37 (0.33; 0.41) N =1354	0.34 (0.30; 0.39) N = 1223	0.39 (0.35; 0.43) N = 1219	0.39 (0,35; 0,44) N = 1101	1.14 (0.86 – 1.57)	0.36
Feeding tubes prolong life (disagree)	0.20 (0.16; 0.23) N = 1355	0.22 (0.18; 0.26) N = 1219	0.20 (0.16; 0.23) N = 1218	0.24 (0.20; 0.28) N = 1103	1.12 (0.82 – 1.51)	0.48
A nurse answers a resident's call light at 1 a.m. and she requests PRN pain medication. When the nurse returns with the medication she is asleep. The nurse decides not to wake her and puts the medication back (disagree)	0.0004 (0.0002; 0,0007) N =1365	0.0005 (0.0003; 0,0009) N = 1219	0.0005 (0.0003; 0.0009) N = 1217	0,0007 (0.0004; 0.001) N = 1104	1.00 (0.09 – 11.75)	1.00

* Case Mrs. Davis: Mrs. Davis has been in your facility for 3 months. She has a variety of problems including very advanced heart disease, osteoporosis (a disease that weakens the bones), a right hip fracture from a fall, and Alzheimer's disease. On admission, she could not walk or transfer and required total assistance with feeding. She takes oxycodone 10 mg every 4-6 hours for pain associated with osteoporosis and her hip fracture (oxycodone is a type of strong opioid, a drug used to relieve pain). In the last month, you notice that she is eating less (she has lost 10 pounds) and coughs when drinking. She no longer recognizes her family.

All staff members who filled in a questionnaire at baseline (T0) and/or at post-intervention (T1) are included in the analyses. All means and 95% CIs are cluster adjusted; differences are cluster and baseline adjusted.
*Post intervention measurements collected only at T1=month 13.
† Interaction effect of group (control and intervention) and timepoint (baseline and post-intervention) calculated with a mixed linear regression model. We calculated differences in change (post-intervention minus baseline) between the intervention and control groups (interaction group x time).

eTable 10. Other secondary outcomes at staff level: Cluster adjusted estimates of staff opinions towards palliative care with the Rotterdam Move2PC

	Baseline score (T0)		Post-intervention score*		Odds ratio (95% CI for the group*time interaction)	P interaction†
	Control	Intervention	Control	Intervention		
	Estimated proportion (95% CI) Number of staff	Estimated proportion (95% CI) Number of staff	Estimated proportion (95% CI) Number of staff	Estimated proportion (95% CI) Number of staff		
The aim of palliative care is treatment of pain only (DISAGREE)	0.74 (0.7-0.78) N = 1409	0.82 (0.78-0.85) N = 1270	0.76 (0.72-0.8) N = 1279	0.82 (0.78-0.85) N = 1159	0.883 (0.641 - 1.215)	0.44
Palliative care starts in the last weeks of life (DISAGREE)	0.46 (0.42-0.5) N = 1409	0.57 (0.53-0.62) N = 1270	0.49 (0.44-0.53) N = 1279	0.58 (0.54-0.63) N = 1159	0.924 (0.704 - 1.211)	0.57
Palliative care and intensive life prolonging treatment can be combined (AGREE)	0.33 (0.3-0.37) N = 1409	0.31 (0.27-0.35) N = 1270	0.27 (0.24-0.31) N = 1279	0.3 (0.26-0.34) N = 1159	1.274 (0.962 - 1.686)	0.09
Palliative care includes spiritual care (AGREE)	0.77 (0.74-0.8) N = 1409	0.79 (0.76-0.82) N = 1270	0.76 (0.73-0.79) N = 1279	0.81 (0.78-0.84) N = 1159	1.25 (0.929 - 1.682)	0.14
Palliative care includes care for resident’s family/relatives (AGREE)	0.9 (0.86-0.93) N = 1409	0.91 (0.87-0.93) N = 1270	0.87 (0.83-0.91) N = 1279	0.92 (0.88-0.94) N = 1159	1.496 (1.046 - 2.139)	**0.03**
The acute care hospital is an appropriate place to die (DISAGREE)	0.6 (0.55-0.64) N = 1409	0.62 (0.58-0.66) N = 1270	0.58 (0.54-0.62) N = 1279	0.6 (0.56-0.65) N = 1159	0.976 (0.752 - 1.267)	0.86
To arrange any kind of hospice or terminal care deprives residents of all hope (DISAGREE)	0.6 (0.56-0.64) N = 1409	0.58 (0.54-0.62) N = 1270	0.6 (0.56-0.64) N = 1279	0.61 (0.57-0.65) N = 1159	1.125 (0.863 - 1.466)	0.39
Visits of a relative should be permitted all day (AGREE)	0.85 (0.81-0.89) N = 1409	0.85 (0.8-0.88) N = 1270	0.85 (0.81-0.89) N = 1279	0.86 (0.82-0.89) N = 1159	1.162 (0.836 - 1.616)	0.37
Residents should be clearly informed about imminent death (AGREE)	0.39 (0.35-0.44) N = 1409	0.4 (0.36-0.45) N = 1270	0.37 (0.32-0.41) N = 1279	0.45 (0.4-0.5) N = 1159	1.342 (1.038 - 1.735)	**0.03**
A resident having a prognosis of only a few days to live should not be transported to home or hospice (AGREE)	0.05 (0.03-0.08) N = 1409	0.06 (0.04-0.09) N = 1270	0.05 (0.03-0.08) N = 1279	0.07 (0.04-0.1) N = 1159	1.124 (0.759 - 1.664)	0.56
Usually life prolonging treatment in the hospital is continued too long (AGREE)	0.11 (0.08-0.16) N = 1409	0.13 (0.09-0.18) N = 1270	0.1 (0.07-0.14) N = 1279	0.15 (0.11-0.2) N = 1159	1.291 (0.911 - 1.831)	0.15

All staff members who filled in a questionnaire at baseline (T0) and/or at post-intervention (T1) are included in the analyses. All means and 95% CIs are cluster adjusted; differences are cluster and baseline adjusted. ICC=unconditional intraclass correlation coefficient from baseline assessments.

*Post intervention measurements collected only at T1=month 13.

† Interaction effect of group (control and intervention) and timepoint (baseline and post-intervention) calculated with a mixed linear regression model. We calculated differences in change (post-intervention minus baseline) between the intervention and control groups (interaction group x time).

CHAPTER 7

LACK OF EFFECT OF A MULTICOMPONENT PALLIATIVE CARE PROGRAMME FOR NURSING HOME RESIDENTS ON HOSPITAL USE IN THE LAST MONTH OF LIFE AND ON PLACE OF DEATH:

A SECONDARY ANALYSIS OF A MULTI–COUNTRY CLUSTER RANDOMIZED CONTROL TRIAL

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Honinx E, Smets T, et al. Lack of Effect of a Multicomponent Palliative Care Program for Nursing Home Residents on Hospital Use in the Last Month of Life and on Place of Death: A Secondary Analysis of a Multicountry Cluster Randomized Control Trial. Journal of the American Medical Directors Association. Published online 2020. doi:10.1016/j.jamda.2020.05.003

Abstract

Objectives

'PACE Steps to Success' is a one-year train-the-trainer programme aiming to integrate non-specialist palliative care into nursing homes via staff education and organizational support. In this study we aimed to explore whether this programme resulted in changes in residents' hospital use and place of death.

Design

Secondary analysis of the PACE cluster randomized controlled trial (ISRCTN14741671). Data were collected on deaths over the previous four months via questionnaires at baseline and post-intervention.

Setting and Participants

Questionnaires were completed by nurse/care-assistant most involved from 78 nursing homes in seven EU countries.

Measures

We measured number of emergency room visits, hospital admissions, length of hospital stay and place of death. Baseline and post-intervention scores between intervention and control groups were compared and we conducted exploratory mixed-model analyses. We collected 551/610 questionnaires at baseline and 984/1178 post-intervention in 37 intervention and 36 control homes.

Results

We found no statistical significant effects of the programme on emergency room visits (OR=1.38, p=0.32), hospital admissions (OR=0.98, p=0.93), length of hospital stay (geometric mean difference=.85, p=0.44) or place of death (OR=1.08, p=0.80).

Conclusions and Implications

We found no effect of the PACE programme on either hospital use in the last month of life or place of death. Although this may be related to implementation problems in some homes, the programme might also require a more specific focus on managing acute end-of-life situations and a closer involvement of general practitioners or specialist palliative care services to influence hospital use or place of death.

Keywords: Palliative care, nursing homes, hospital use, RCT, end-of-life care

Introduction

The PACE Steps to Success programme is a one-year palliative care programme for nursing homes[1-2] which aims to implement a general non-specialist palliative care approach in six steps over a 12-month period using a train-the-trainer approach. It aims to train staff to deliver high-quality end-of-life care in the nursing home, starting from advance care planning until the delivery of high-quality care in the last days of life and after death.

To evaluate its effectiveness we conducted a cluster randomized controlled trial in seven EU countries[3]. While we did not find an effect on the primary outcome, resident comfort in last week of life measured by staff, the programme was promising regarding the secondary outcome, the resident quality of care in the last month of life using the QoD-LTC scale (baseline-adjusted mean difference on a scale of 11 to 55, 3.40; 95%CI, 2.01-4.80;$P < .001$)[3,4]. The change was most apparent in the subscale 'preparatory tasks' (baseline-adjusted mean difference, 6.77; 95% CI, 4.19-9.36;$P < .001$), containing items such as 'resident had treatment preferences in writing', 'resident's funeral was planned' and 'resident had named a decision-maker in the event that she or he was no longer able to make decisions'[3]. From the process evaluation of the trial[5] we learned that implementation was highly variable across nursing homes and countries, but the training for 'advance care planning' (first step of the programme), appeared to have reached most staff.

Based on this knowledge, we aimed to explore further whether the PACE programme had an effect on place of death and hospital use at the end of life in a secondary analysis. While avoiding hospitalizations in not a delineated step in the PACE training programme, the topic is addressed as part of the intervention, and particularly in the first step where advance care planning is discussed including preferences for place of care and death, and in the fifth step focusing on organizing care in the last days of life in the nursing home. Place of death is also an important quality indicator of end-of-life care and although sometimes needed, hospitalization of older patients with complex care needs comes with a number of drawbacks and should thus be avoided as much as possible[6-7-8-9]. We hypothesized that the improvement in quality of care in the last month of life and staff training regarding advance care planning and care in the last days of life could have impacted hospital use and place of death.

The research questions of this secondary analysis are:

(1) does the ‘PACE Steps to Success’ programme have an effect on hospital use in the last month of life of nursing home residents in terms of numbers of emergency room visits, hospital admissions and length of stay following admission

(2) does the programme have an effect on the place of death of nursing home residents?

Methods

Study design

To compare the PACE Steps to Success Programme with usual care, a clustered randomized controlled trial (2015-2017) was conducted in 78 nursing homes in Belgium, England, Finland, Italy, the Netherlands, Poland and Switzerland [2]. We randomized at the level of the nursing home instead of at the individual level because the programme involved the training of nurses and care assistants in each nursing home. The trial was registered on July 30th, 2015 at www.isrctn.com – ISRCTN14741671 (FP7-HEALTH-2013-INNOVATION-1 603111). Central randomization was blinded and stratified by country and median number of beds in a 1:1 ratio; in each country, all participating nursing homes were categorized into two groups based on the median number of beds. Then, half were assigned to the control group (usual care) and half to the intervention group (PACE programme). Blinding of treatment allocation was not possible for participants or researchers collecting data because of the nature of the study.

More details about the study design and protocol have been published[3,2].

PACE Steps to Success Programme

The six steps of the PACE programme (Table 1) include (1) advance care planning with residents and family via discussions about current and future care, (2) care planning, assessment, and review of needs and problems via change-mapping charts, (3) coordination of care via monthly multidisciplinary review meetings, (4) high-quality care delivery focusing on pain and depression via assessment and management charts, (5) care in the last days of life using a checklist, and (6) after-death care via reflective debriefing sessions for staff[10].

Participating nursing homes

Nursing homes in a predetermined region in each country were asked for participation via phone or e-mail. We assessed whether they were eligible based on specific inclusion and exclusion criteria. Nursing homes were included if they (1) provided nursing care and personal assistance with activities of daily living by staff on-site, and medical care by a general practitioner (GP) off-site; (2) had a minimum of 30 beds and 15 deaths in the past year; and (3) the manager/director signed a written consent to participate (before randomization) and allowed up to six staff members to spend half a day per week as PACE coordinators. They were excluded if they (1) already contributed to the programme's pilot study; or (2) were already using palliative care guidelines or instruments or were certified users of the Gold Standards Framework[11] or InterRAI-PC[12]. If a nursing home was excluded, did not reply or declined to participate, another was randomly chosen from the list until there were enough in each country.

Data collection

Each nursing home assigned one administrative contact person who identified all residents dying over the previous four months, and one staff member most involved in their care (nurse or care assistant). Baseline data (T0 at month 0) on the deceased residents were collected through after-death structured questionnaires. Post-intervention, at month 13 (T1) and month 17 (T2), analogous after-dead questionnaires were collected on residents dying during the previous four months. In those questionnaires, the nurse most involved in care and the home administrator provided data on the resident characteristics (age, gender, functional and cognitive status during last month of life, and presence of dementia at the time of death) and on hospital use outcomes. Resident records were used by staff if needed.

Outcomes and measurements

Questionnaires were forward-backward translated according to EORTC guidelines where official translations did not exist[13]. In the current paper, we focus on the variables related to hospital use in the last month of life and place of death, i.e. visits to the emergency room (ER), hospital admissions, the length of hospital stay if admitted, admission to the intensive care unit (ICU), total nights spent in the ICU, place of death and, if death occurred in hospital, the reason for the last admission. The presence of dementia was based on the estimation of either the nursing staff or the general practitioner. Functional and cognitive status during last month of life was calculated using the Bedford Alzheimer Nursing Severity Scale (BANS-S). Scores on BANS-S range from 7 to 28 and higher scores indicate greater severity.

Statistical analysis

These secondary analyses in the current study were post hoc, i.e. not planned prior to the start of the trial. A non-response analysis regarding the main demographic characteristics of the residents (age, gender, length of stay) was performed to examine missingness in the data. Exploratory descriptive analyses of the hospital use data and place of death were conducted by comparing baseline scores between control and intervention groups in SPSS24 without adjusting for clustering. In R (RStudio Version 1.2.1335)[14], generalized linear mixed models with three random intercepts were fitted to account for clustering within staff member, nursing home, and country. Because of concerns for overfitting, we only considered those outcomes (ER visits, hospital admissions, length of hospital stay, death in hospital) with at least 30 respondents for the mixed model analysis. For the binary outcomes, a binomial distribution with logit link was specified. For length of hospital stay, a linear distribution with identity link was specified and the natural logarithm of length of hospital stay was used as outcome. Then, the adjusted estimated geometric mean difference in length of stay was calculated. Geometric mean multiplies values, whereas arithmetic mean uses their sum, and then splits them up by taking the root. Results were transformed back to the original scale by taking the exponential. Geometric mean is better in managing outliers than median or arithmetic mean. The fixed part of all models contained group (intervention versus control), time (T1+T2 versus T0) and their two-way interaction. All hypothesis testing was two-sided with significance level of 0.05.

Ethical aspects

Consent to participate was obtained from the nursing home management before the randomization was performed. Written informed consent was obtained from all participating staff except for Poland and the Netherlands, where a separate informed consent is not needed for anonymous questionnaires. Ethics approval for the study was obtained from the relevant committees in all countries[2].

Results

We collected 551/610 (response rate: 90%) questionnaires from staff at baseline and 984/1178 (response rate: 84%) post-intervention in 37 intervention and 36 control homes (Figure 1A in

Appendix). Response rates per country are given in Table 2. For the demographic characteristics, 604/613 (response rate: 99%) questionnaires were collected from nursing home administrators at baseline and 1146/1179 (response rate: 97%) at post-intervention.

Non-response analysis

A non-response analysis found no statistically significant differences regarding demographic characteristics of the residents (age, gender, length of stay; Table 1A in Appendix).

Resident characteristics at baseline

None of the resident characteristics differed significantly at baseline between the control group and the intervention group (Table 3). The mean age of residents at the time of death was comparable (85 in control group – 86 in intervention group). In both groups, most of the deceased residents were female (70.6% control – 60.6% intervention) and more than 70% had dementia at time of death (71.8% control – 70.3% intervention). The mean cognitive and functional status during last month of life was similar in both groups (19.9 in control group – 19.0 in intervention group).

Hospital use in the last month of life

ER visits in the last month of life decreased in the control group (16.6% baseline – 13.3% post intervention) and increased in the intervention group (15.9% baseline – 18.7% post-intervention), but with an increase in one-time visits (73.8% baseline – 83.3% post-intervention) and a drop in multiple visits (26.2% baseline – 16.7% post-intervention) in the intervention group. The number of hospital admissions for more than 24 hours in the last month did not change in the control group (24.9% baseline and 24.6% post-intervention), with a majority being admitted once (77.8% baseline – 83.5% post-intervention). The number of admissions increased with 3% in the intervention group (23.9% baseline – 27% post-intervention). Most admissions were once-only (85.7% baseline – 80% post-intervention). The mean length of stay in the hospital remained seven days on average in the control group and shortened from ten days (baseline) to seven days (post-intervention) in the intervention group. Of those who were hospitalized, the number of residents admitted to the ICU in the last month of life increased with 5% (8% baseline – 12.5% post-intervention). The number of admitted residents in the intervention group however dropped strongly (21.2% baseline – 11.1% post-intervention). Because of low numbers of cases the significance of this difference could not be tested. In both groups, the mean length of stay in the ICU remained nearly stable (four days baseline – five days post-intervention).

The mixed models showed no statistically significant effects of the PACE programme on one of the three hospital use variables (Table 4): ER visits (p=0.32), hospital admissions (p=0.93), length of hospital stay (p=0.44). In our sample, the geometric mean difference in length of stay before versus after implementation of the programme was 15% lower in the control group than in the intervention group. This means that the decline in length of stay post-intervention was 15% larger in the intervention group. However, this estimated difference varies extensively and was not statistically significant in the multilevel analyses (95% confidence interval ranges from 47% lower to 31% higher difference in control group; p=0.44).

Place of death

The number of residents that died in-hospital decreased in the control group (17.5% baseline – 13.6% post-intervention) and almost remained the same in the intervention group (16.7% baseline – 17.8% intervention). For residents who died in hospital, the reason for the last hospital admission was most often 'sudden onset or exacerbation of symptoms' or 'due to a life-threatening situation' (control group: 81.8% baseline – 71.2% post-intervention; intervention group: 70.7% baseline – 68.8 post-intervention). Other reasons were for a specific treatment (control group: 13.3% baseline – 20.5% post-intervention; intervention group: 12.2% baseline – 9.4% post-intervention) or a specific diagnostic evaluation to make further decisions (control group: 4.5% baseline – 12.3% post-intervention; intervention group: 12.2% baseline – 14.1% post-intervention). In the mixed model analyses, no statistically significant effects of the PACE programme on place of death were found (Table 4; p=0.80).

Discussion

We found no statistically significant effect of the PACE Steps to Success programme on emergency room visits, hospital admissions, length of hospital stay in the last month of life, or place of death. We did observe a shorter mean length of stay post-intervention; however, this was not statistically significant.

To the authors' knowledge, this is the first study to explore the effectiveness of a nursing home-based multicomponent palliative care programme on hospital use in the last month of life on such a large scale. The strengths of this study include the high-quality research design, the high response rates at all times of measurement, and the fact that non-response analysis shows minimal indication of bias.

Contrary to our hypothesis, this secondary analysis did not find a statistically significant effect of the PACE programme on nursing home residents' hospital use in the last month of life or on their place of death. Several reasons might explain this. Overall, programmes aiming to implement a general non-specialist palliative care approach such as this one might not be sufficient to improve specific outcomes like hospitalizations at the end of life or place of death. An earlier review investigating the effectiveness of staff interventions to improve resident outcomes in nursing homes highlighted that studies targeting specific care tasks were more likely to produce positive outcomes than those requiring global practice changes[15]. While the PACE training programme did include several components[2] such as 'care in the last days of life' (step 5) or 'advance care planning' aiming to prepare for future care (step 1) that were found to be related to end-of-life hospitalizations in earlier research, these might not have been focused or targeted enough on preventing unnecessary hospitalizations themselves[16,17,18]. Additionally, several other important elements might have been missed as there were no specific steps explicitly targeting hospitalizations at the end of life.

More specifically, the PACE training programme did not include specific clinical or pharmacological guidelines on treatment of dying symptoms (for staff or GPs), nor did it focus on when to involve GPs and specialist palliative care services. Yet, we did find that for residents who ultimately died in hospital, staff indicated a sudden onset or exacerbation of symptoms or a life-threatening situation as the main reason for the hospital admission. As nursing home staff and GPs play an important role in end-of-life decision-making in nursing homes (we only included nursing homes with an offsite GP), they might not have been sufficiently qualified to address such end-of-life situations or even available. For complex cases, the involvement of specialist palliative care services might also be essential, and the PACE programme was not focused on including these. A previous trial in US nursing homes[19] also suggested that reducing end-of-life hospitalizations is more achievable when there are permanent palliative care teams, well-integrated advanced practice nurses who offer clinical support to other staff, and good teamwork, communication and organizational readiness.

Although family was highlighted as an important stakeholder in the PACE programme (particularly in step 1 and 5), they might be not targeted well or systematically enough in the PACE programme to reach effect on end-of-life hospitalizations. A recent qualitative study conducted in US nursing homes compared those with high and low hospitalization rates[20]. Staff at high-hospitalizing facilities were more likely to leave complex choices about hospitalization to families while those at low-hospitalizing facilities were more convinced that certain residents should not be hospitalized and felt responsible for helping residents and families come to the same conclusion (following an 'enhanced autonomy model'). Other research also showed that as acute medical problems emerge in nursing homes, the family often requests hospitalization, whether or not in consultation with nursing home staff[21,22]. This decision is mainly made out of fear of imminent death, in case of an acute medical condition the acute hospital setting is seen as a safe place by the family[13,21,22]. Hence, involving family early on, as part of the advance care planning process, and educating staff as well as family on the benefits and burdens of hospitalizations at the end of life will be important elements to consider in future interventions.

As well as reasons related to the PACE intervention itself, implementation problems might also partly explain the lack of effects found in this secondary analysis. The process evaluation showed that the implementation of the programme was feasible in all types of nursing homes, but also very challenging, and highly variable between countries and nursing homes[5]. The implementation rating consisted of two components: fidelity (score between 0 and 8 for the number, order and timing of delivered steps) and the staff's appreciation of the programme and the trainers' competences (score between 0 and 8). The fidelity scores for all homes were computed via country trainers' diary notes and were high in most countries, ranging between 5 and 8. The appreciation score, which was measured with staff evaluation questionnaires, ranged between 3.2 and 7.8. Combining both scores resulted in 64.9% of the homes with a medium implementation rating, 29.7% of homes with a high implementation rating and 5.4% with a low implementation rating. Finally, the nursing home is a very complex context and sustainably changing practice can therefore be very difficult. Characteristics of the intervention itself, as well as of the individuals involved and the contextual factors shaping the nursing home are all important categories influencing the implementation, regardless of its specific target or focus. More details on the implementation of the programme are published in the process evaluation[5].

Limitations

Our research also has limitations. Firstly, due to the retrospective nature of the study, recall bias is possible, even though staff could always use the resident's file when filling in the questionnaire. Secondly, mixed model analyses were not possible for the admission to and total nights in the ICU because the minimum level of respondents (n=30) was not reached for these variables. Thirdly, we did not ask for clinical details of all hospitalizations but only the main reason for the last hospitalization of those who died in hospital, nor did we question relatives on hospitalization in the last month. Finally, the exploratory analyses in this study were secondary post hoc analyses so caution is required when interpreting the findings. The study was originally not powered to detect differences in hospitalization rates.

Conclusions and Implications

This secondary analysis found that the PACE Steps to Success Programme did not affect hospital use in the last month of life or place of death. Reasons for this might be the complexity of the implementation of palliative care in nursing homes as well as the specific components of the intervention itself. Future research could investigate whether a targeted multicomponent intervention specifically aimed at reducing unnecessary end-of-life hospitalisations, which takes into account the whole nursing home context, focuses on residents and family, and includes staff education as well as involvement of GPs and specialist palliative care services to improve end-of-life symptom management, could lead to more success.

Conflicts of interest

The authors declare that they have no competing interests.

References Chapter 7

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Table 1: The six steps of the PACE Steps to Success Programme

Step	Tool/material used	Description
7. Advance care planning (discussions)	'Looking and Thinking Ahead' document	Advance care planning (ACP) discussions with residents and families are organized to acquire wishes and preferences around end-of-life care.
8. Care planning, assessment and review	'Mapping Changes in Condition' chart	A 'Mapping Changes in Condition chart' is used monthly by nurses and care assistants to plot changes (deterioration and improvement) in a resident's physical condition.
9. Coordination of care	Palliative Care Register with monthly multidisciplinary palliative care review meetings	Using a Palliative Care Register, residents who are expected to live less than six months are discussed in detail during monthly multidisciplinary review meetings. A summary sheet is sent to physicians who were not able to attend the meeting.
10. High-quality care delivery	Pain Assessment and Management Tool including numerical pain scale or PAINAD in case of advanced dementia[2] 'Geriatric Depression Scale' (short version)[3] or 'Cornell Depression Scale for people with dementia'[4]	Staff learn about symptom control and complex communication skills, with a focus on pain and depression.
11. Care in the last days of life	Integrated care plan for the last days of life using the Last Days of Life checklist	The checklist stimulates and guides the care in the last days of life, with a focus on recognizing dying, communication with family, regular assessment of symptoms, anticipatory medication prescription, hydration, and psychosocial and spiritual support.
12. After-death care	Monthly reflective de-briefings groups	Reflective meetings following a death are held to support staff and encourage experiential learning.

This table summarizes the PACE Steps to Success Programme. It is described in full elsewhere[1]

Table 2. Response Rates per country

	Staff* concerning deceased resident questionnaire			
	Control		Intervention	
	T0	**T1 + T2**	**T0**	**T1+T2**
Belgium	95.6% (N=43/45)	77.5% (N=86/111)	97.4% (N=37/38)	93.5% (N=100/107)
England	70.4% (N=57/81)	84.7% (N=72/85)	100% (N=51/51)	66.2% (N=43/65)
Finland	94% (N=47/50)	97% (N=102/105)	89.2% (N=48/65)	73.9% (N=99/134)
Italy	96.7% (N=59/61)	88.4% (N=130/147)	92.9% (N=52/56)	88.8% (N=71/80)
The Netherlands	87.5% (N=28/32)	70.4% (N=50/71)	78.9% (N=15/19)	51.5% (N=17/33)
Poland	87.9% (N=29/33)	72.5% (N=37/51)	100% (N=31/31)	98.4% (N=62/63)
Switzerland	100% (N=26/26)	87% (N=67/77)	100% (N= 22/22)	98% (N=48/49)

T0=baseline measurement at month 0; T1=month 13; T2= month 17; *staff= nurse or care assistant most involved in the resident's care.

Table 3. Resident and hospital use characteristics of deceased residents for whom an assessment by staff was made

	Baseline		Post-intervention (T1 + T2)	
	Control	Intervention	Control	Intervention
	(N = 272)	(N = 279)	(N = 558)	(N = 425)
Resident characteristics				
Age at death, cluster-unadjusted mean (SD)*	85.22 (9.13)	85.68 (9.00)	85.58 (8.81)	85.91 (8.57)
Gender (female), cluster-unadjusted frequency (count/n (%))	190/269 (70.6%)	160/264 (60.6%)	354/547 (64.7%)	265/414 (64%)
Functional status during last month of life (BANS-S), cluster-unadjusted mean (SD) †	19.93 (4.31) ‡§	19.03 (4.90) ‡	18.95 (4.93) §	18.75 (5.14)
Dementia at time of death, cluster-unadjusted frequency (count/n (%))	188/262 (71.8%)	194/276 (70.3%)	399/556 (71.8%)	278/416 (66.8%)
Hospital use in the last month of life	Count (% or *M*)	Count (% or *M*)	Count (% or *M*)	Count (% or *M*)
Did the resident visit the emergency room in the last month of life (for less than 24 hours)? (yes)	43/259 (16.6%)	42/264 (15.9%)	71/533 (13.3%)	72/385 (18.7%)
How often did the resident visit the emergency room in the last month of life (for less than 24 hours)?				
Once	36/43 (83.7%)	31/42 (73.8%)	51/71 (71.8%)	60/72 (83.3%)
Twice or more	7/43 (16.3%)	11/42 (26.2%)	20/71 (28.2%)	12/72 (16.7%)
Was the resident admitted to the hospital in the last month of life for more than 24 hours? (yes)	63/253 (24.9%)	63/264 (23.9%)	127/517 (24.6%)	100/371 (27%)
How often was the resident admitted to the hospital in the last month of life for more than 24 hours?				
Once	49/63 (77.8%)	54/63 (85.7%)	106/127 (83.5%)	80/100 (80%)
Twice or more	14/63 (22.2%)	9/63 (14.3%)	21/127 (16.5%)	20/100 (20%)
If admitted to hospital in last month of life, average length of stay in hospital in days, cluster-unadjusted mean^	7.29 (4.88) N = 48	9.56 (8.56) N = 52	7.31 (7.36) N = 95	7.08 (5.75) N = 71
Was the resident admitted to an ICU in the last month of life? (yes)	4/49 (8.2%)	11/52 (21.2%)	12/96 (12.5%)	8/72 (11.1%)
If admitted to an ICU in the last month of life, average length of stay in the ICU in days? cluster-unadjusted mean``	4.25 (3.86) N = 4	4.91 (5.49) N = 11	4.08 (2.97) N = 12	4.63 (4.84) N = 8
Resident died in hospital	46/263 (17.5%)	45/269 (16.7%)	75/551 (13.6%)	72/405 (17.8%)
If the resident died in hospital, what were the medical reasons for the last admission to the hospital?				
A specific diagnosis was required to take further decisions	2/44 (4.5%)	5/41 (12.2%)	9/73 (12.3%)	9/64 (14.1%)
For specific treatment	6/44 (13.3%)	5/41 (12.2%)	15/73 (20.5%)	6/64 (9.4%)
Sudden onset or exacerbation of symptoms or a life-threatening situation	36/44 (81.8%)	29/41 (70.7%)	52/73 (71.2%)	44/64 (68.8%)

Data are mean (SD) or n/N (%)

*Missing data at baseline for 11 cases in intervention and 4 cases in control group. Data missing at post-intervention for 11 cases in intervention and 18 cases in control group.

†Missing data at baseline for 14 cases in intervention and 9 cases in control group. Data missing at post-intervention for 19 cases in intervention and 10 cases in control group.

^Missing data at baseline for 26 cases in intervention and 34 cases in control group. Data missing at post-intervention for 82 cases in intervention and 73 cases in control group.

``Missing data at baseline for 26 cases in intervention and 33 cases in control group. Data missing at post-intervention for 72 cases in intervention and 96 cases in control group.

‡ P value (adjusted) for the difference in functional status between control and intervention group at baseline: p=0.008; Functional status, mean (adjusted): 19.77 in control and 18.45 in intervention group.

§ P value (adjusted) for the difference in functional status between control groups at baseline and post-intervention: p=0.008; Functional status, mean (adjusted): 19.77 in control at baseline and 18.87 in control group post-intervention.

°Other includes: LTCF/hospice/Pall care unit/other

Abbreviations: SD (Standard Deviation), BANS-S (Bedford Alzheimer Nursing Severity Scale), ICU (Intensive Care Unit)

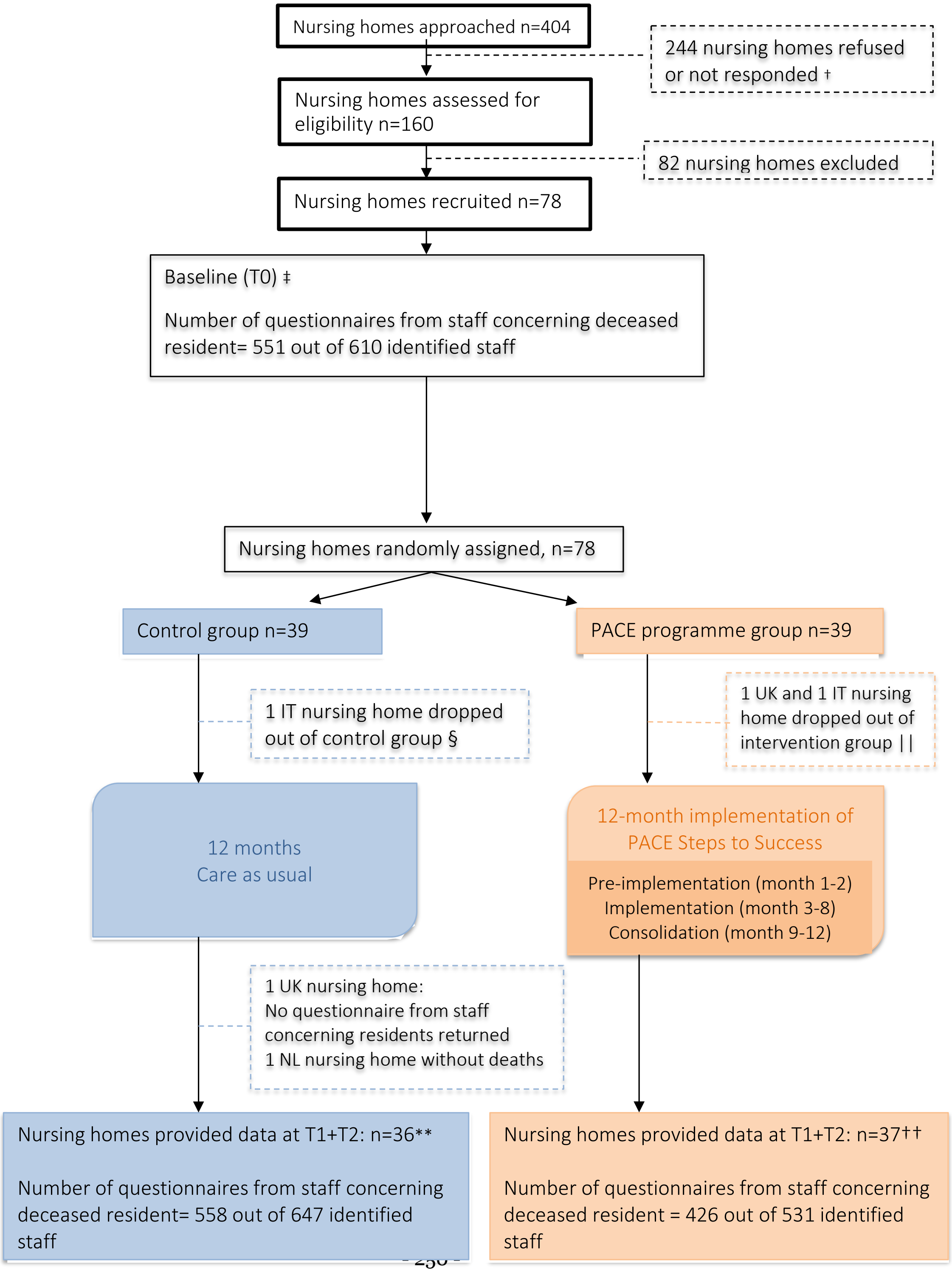
Table 4. Cluster-adjusted estimates of hospital use in the last month of life and place of death of residents of long-term care facilities, assessed by nurses.

	Baseline score (T0)		Post-intervention score (T1+T2)		OR (95% CI)	P interaction
	Control (n=272)	Intervention (n = 279)	Control (n = 558)	Intervention (n = 425)		
	Probability (95% CI) Number of cases	Probability (95% CI) Number of cases	Probability (95% CI) Number of cases	Probability (95% CI) Number of cases		
Did the resident visit the emergency room in the last month of life? (yes)	0.14 (0.10 – 0.21) N=43	0.13 (0.09 -0.20) N=42	0.11 (0.08 – 0.16) N=71	0.14 (0.10 – 0.20) N=72	1.38 (0.73 – 2.62)	0.32
Was the resident admitted to a hospital in the last month of life? (yes)	0.24 (0.16 – 0.34) N=63	0.24 (0.16 – 0.34) N=62	0.25 (0.18 – 0.34) N=127	0.24 (0.17 – 0.34) N=99	0.98 (0.57 – 1.66)	0.93
Resident died in the hospital	0.14 (0.08 – 0.23) N=46	0.16 (0.10 – 0.25) N=45	0.12 (0.07 – 0.18) N=75	0.14 (0.09 – 0.22) N=72	1.08 (0.58 – 2.02)	0.80
	Expected count (95% CI) Number of cases	Expected count (95% CI) Number of cases	Expected count (95% CI) Number of cases	Expected count (95% CI) Number of cases	**Adjusted estimated geometric mean* difference (95% CI)**	**P interaction**
If admitted to hospital in last month of life, average length of stay in hospital	6 (4 – 8) N=49	7 (5 – 9) N=48	5 (4– 6) N=91	5 (4 – 7) N=73	0.85 (0.53 – 1.31)	0.44

CI = Confidence interval; OR = Odds Ratio

Appendix Chapter 7

Figure 1: Flowchart of recruitment, randomization and data collection at resident level*



* The flowchart includes the number of clusters or nursing homes participating throughout the trial, in intervention and control group, and the number of deceased residents identified at baseline and post-intervention in both groups. T0=baseline measurement at month 0; T1=month 13; T2=month 17; Staff = nurse or care assistant most involved in care for that resident
† Reasons for refusing included insufficient time, no interest, understaffing, already involved in other studies, change in management.
‡ We identified 617 deceased residents across nursing homes. For 7 residents, no staff member could be identified; for 120 residents.
Reasons for dropouts: § Reorganizing of the nursing home; || intervention was taking too much time.
¶ We identified 649 deceased residents in the control group. For 2 residents, no staff member could be identified; for 136.
** We identified 542 deceased residents in the intervention group. For 11 residents, no staff member could be identified; for 116.
IT = Italy, UK = United Kingdom, NL = the Netherlands

Table 1A. P-values for differences between response and non-response for nurses' assessments*.

	Baseline (T0)		Post-intervention (T1+T2)	
	Response (n=272) Non-response (n=35)	Response (n=279) Non-response (n=31)	Response (n=558) Non-response (n=91)	Response (n=425) Non-response (n=114)
	Control	Intervention	Control	Intervention
Mean age at time of death†	P= 0.906	P= 0.963	P=0.320	P=0.957
Gender†	P=0.638	P=0.811	P=0.927	P=0.539
Mean length of stay in nursing home†	P=0.368	P=0.585	P= 0.528	P=0.607

*Difference between cases where questionnaires were and were not returned
† reported by the nursing home administrator
Results of Pearson's Chi2 test

GENERAL DISCUSSION AND CONCLUSIONS

INTRODUCTION

The main objectives of this dissertation were to describe facility-, resident-, and staff characteristics of palliative care in nursing homes in Europe and to compare those characteristics between countries; to study the prevalence of potentially inappropriate treatments and end-of-life hospitalizations of nursing home residents and to explore the differences in prevalence between six European countries; and to evaluate the effect of the PACE palliative care programme for nursing homes in Europe on resident and staff outcomes and on hospital use. The main results of the studies undertaken to meet these objectives will be discussed in subsequent paragraphs of this part. First, the main findings will be summarized; next, the methodological considerations will be addressed; then, a general discussion of the most important findings will be provided; and several implications for practice, policy and research will be suggested.

1 SUMMARY OF THE MAIN FINDINGS

In the following paragraph, the main results of the previous chapters are summarized in three separate themes: palliative care in nursing homes in Europe (PART I of this dissertation); potentially inappropriate treatments and hospitalizations at the end of life (PART II of this dissertation); and evaluation of a palliative care programme in nursing homes in Europe (PART III of this dissertation).

1.1. PALLIATIVE CARE IN NURSING HOMES IN EUROPE

Based on the PACE study I (2015), we found that nursing home residents currently die at a very old age, on average around 85 years, except in Poland where the mean age at time of death is 81 (Chapter 1). The percentage of residents that die within the nursing home is 80% in Poland, 82% in England and Belgium, 85% in Finland, 87% in Italy and 89% in the Netherlands. A large proportion of the residents (47% – 74%) have multiple comorbidities at the end of life and at least 60% has dementia at time of death, often at a very severe or advanced stage. Clinical complications during the last month of life are frequent and consist mainly of eating or drinking problems (51.9% in England; 66.4% in Finland and Poland). The average length of stay in the nursing home is relatively short in all countries and varies between 6 months in Poland and Italy and 2 years in Belgium. The highest percentages of residents with poor cognitive and functional status one month before death are found in Poland and Italy, where residents also have the shortest length of stay.

Across countries, we found a large heterogeneity in the extent to which nursing home nurses and care assistants agree with the basic principles of palliative care – measured with the Rotterdam Move2PC questionnaire[1] – but with room for improvement in all countries (Chapter 2). Staff in England more often agreed with these principles, whereas staff in Italy and Poland less often agreed than in the other countries. The level to which staff agreed with these principles was significantly associated with country, age, professional role, and formal training. Older staff had a higher score of agreement than younger staff, as had nurses compared to care assistants and staff who had undertaken palliative care training compared to those who had not.

Finally, we identified several areas of improvement for the organization of palliative care in nursing homes in six European countries, using the IMPACT structural indicators for quality of palliative care (Chapter 3). Dedicated palliative care functions, specialist palliative care teams, and an assigned contact person who maintained regular contact with the resident and relatives were often not structurally embedded in the organization of nursing home care in most countries, in particular in Finland and Poland. There was little structural availability of specialist advice for professionals delivering palliative care in Finland, Italy and Poland. The availability of opioids was low in nursing homes in Poland. Almost all structural indicators for quality of palliative care differed significantly between countries.

1.2. POTENTIALLY INAPPROPRIATE TREATMENTS AND HOSPITALISATIONS AT THE END OF LIFE

We found that artificial ventilation, resuscitation, blood transfusions, chemotherapy or radiotherapy, dialysis and surgery were rarely used in the last week of life of nursing home residents in most of the studied countries (Chapter 4). However, the prevalence of most treatments differed in a statistically significantly way between countries. Poland had the highest percentage of residents receiving at least one potentially inappropriate treatment in the last week of life. Artificial nutrition and/or hydration were common treatments in Poland

and Italy, in particular the administration of artificial fluids, even in residents with advanced dementia. Antibiotics were frequently administered in all countries, albeit with the highest rates in Poland and Italy, and antidiabetics were most often administered in Poland. Furthermore, our results show that between 12% (Italy) and 26% (Belgium) of the residents were hospitalized in the last month of life – with 16% in the Netherlands, 22% in Finland, 23% in England and 25% in Poland – with most of those residents being hospitalized only once (Chapter 5). Hospitalizations were less likely if residents had a written advance directive with regard to 'do not transfer to hospital' and if their nurse spoke with a relative about preferences with regard to medical treatments and the course of care. The availability of the physician in the last week of life also decreased likelihood of hospitalization. The percentage of residents dying in-hospital was 6% in the Netherlands, 9% in England and Finland, 13% in Italy, 18% in Belgium and 19% in Poland. If the resident eventually died in the hospital, the reason for the last hospital admission was mostly a sudden onset or exacerbation of symptoms or a life-threatening situation. The physician and nurse were usually the ones who requested the last admission, in the Netherlands this was also often at the resident's request. If the physician expected the resident's death, residents were less likely to die in the hospital. A poorer functional status was associated with a reduced likelihood of both hospitalization and in-hospital death.

1.3. EVALUATION OF A PALLIATIVE CARE PROGRAMME IN NURSING HOMES IN EUROPE

We compared the effect of the PACE programme – a one-year multicomponent intervention to integrate basic non-specialist palliative care in nursing homes – with usual nursing home care via a multifacility cluster-randomized clinical PACE trial in Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland. We analyzed the programme effect on resident outcomes as reported by staff, including comfort in the last week of life (primary resident outcome; measured with the EOLD-CAD[2]), and quality of care in the last month of life (secondary resident outcome; measured with the QOD-LTC[3]). In addition, we examined if the programme affected staff outcomes, including knowledge of palliative care (primary staff

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[2] End-of-Life in Dementia Scale Comfort Assessment While Dying

[3] Quality of Dying in Long Term Care

outcome; measured with the Palliative Care Survey), staff self-efficacy, educational needs, and opinions on palliative care (secondary staff outcomes; measured with the S-EOLC[4], the EPCS[5] and the Rotterdam Move2PC, respectively). The multifacility cluster-RCT found that the PACE Steps to Success Programme did not improve the comfort in the last week of life of residents as reported by staff. Results indicated a significant difference between intervention and control groups for staff knowledge of palliative care issues, but this difference was very small and probably not clinically important. Further, the secondary resident outcome quality of care in the last month of life reported by staff differed significantly between intervention and control groups. We detected a significant difference between intervention and control responses on the QOD-LTC subscale *preparatory tasks*. We therefore argued that step one – the advance care planning step of the programme – resulted in a conversational change regarding end-of-life decisions in nursing homes. Consequently, we hypothesized that the improvement in quality of care in the last month of life that we found, could have impacted hospital use and place of death. We therefore conducted a secondary analysis to investigate whether the PACE programme had an effect on hospital use in the last month of life of nursing home residents in terms of numbers of emergency department visits, hospital admissions, and length of stay following admission, and whether the program has an effect on the place of death of nursing home residents. Results indicated no statistically significant effect of the PACE program on emergency department visits, hospital admissions, length of hospital stay in the last month of life, or place of death. We did observe a shorter mean length of stay post-intervention; however, this was not statistically significant.

2 METHODOLOGICAL CONSIDERATIONS

To answer the research questions of this dissertation, several methods and different study designs were used. **Chapters 1** to **5** were based on the PACE cross-sectional study of deceased nursing home residents in six European countries. In **Chapter 6**, a cluster-randomized clinical trial was conducted of the PACE Steps to Success Programme in 78 nursing homes in seven European countries. The last chapter, **Chapter 7**, present results of a secondary analysis of the

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[4] Self-Efficacy in End-of-Life Care Survey

[5] End-of-Life Professional Caregiver Survey

data from the PACE cluster-randomized clinical trial. In the following paragraphs, key methodological considerations, strengths and limitations are discussed for 1) the cross-sectional study design; and 2) the cluster-randomized clinical trial.

2.1. CROSS–SECTIONAL STUDY

In **Chapters 1** to **5**, we used a cross-sectional study of deceased residents in nursing homes conducted in 2015 in six European countries: Belgium (Flanders), England, Finland, Italy, the Netherlands and Poland. In each country, participating nursing homes reported every death that occurred among the residents over the preceding three-month period. For each identified deceased resident, structured questionnaires were sent to the key respondents. For this PhD, we used questionnaires from: the nursing home administrator, the nursing staff member most involved in care (preferably a nurse) and the treating physician (a general practitioner, elderly care physician or physician employed in the nursing home). For each participating nursing home, the administrator was also asked to fill out a questionnaire on nursing home characteristics.

This cross-sectional study resulted in the first large-scale international database that described and evaluated the facility-, resident-, and staff characteristics of palliative care in nursing homes in Europe, based on representative samples of nursing homes in six European countries. To our knowledge, the extent of this data collection that integrated structural, system-level data with staff and resident outcomes is so far unprecedented. For this study, six European countries – Belgium, Finland, Italy, the Netherlands, Poland, and the United Kingdom – were selected to represent a diversity of countries regarding different criteria. These countries cover the Northern, Eastern, Southern and Western geographic regions of Europe, have different economic histories, with varying health care systems and nursing home types at diverse stages of palliative care development[2,3]. This methodology might inform other countries on how to conduct comparable representative research in nursing homes. Moreover, by studying deceased residents, we also gained insight into the dying process in addition to information on the care process, which resulted in a broad overview of dying in nursing homes in Europe. The extensiveness of the data, which also included measurements of outcomes (e.g. hospitalizations) as well as care processes (e.g. potentially inappropriate treatments), staff agreement with palliative care principles, and care home structures/characteristics (e.g. nursing home type, organizational structures), enabled the analysis of associations between these different measures and formulation of hypotheses about the most suitable palliative care practices for nursing homes.

Furthermore, we paid close attention to the quality assurance of the data collection across all countries. In fact, the data collection procedures were described in detail in a quality assurance manual to guarantee high-quality processes. All researchers involved in PACE were trained extensively by the project coordinator to ensure data collection proceeded as instructed. Also, strict forward/backward procedures for translations of the questionnaires were used, following the EORTC guidelines[4]. After finalizing the translations, each country tested the questionnaires in three nursing homes per country. Also, three physicians were contacted to test the questionnaires for physicians. The questionnaires were tested face-to-face, with an emphasis on comprehensiveness and duration. Decisions about the final version of the questionnaires were based on this feasibility test.

Finally, the use of structured questionnaires offers the advantage that data can be pseudonymized. The paper questionnaires sent to the participants were provided with a participant code and an attached document that guaranteed full anonymity and confidentiality. After completion, the questionnaires were returned directly to the researchers in a sealed envelope. To protect residents' personal data, the lists of residents selected for research and the questionnaires were pseudonymized for each nursing home. The pseudonymization key was maintained by the nursing home manager. The involved researchers were not informed of the deceased residents' identity, nor of the identity of staff member that filled in the questionnaire.

The main limitation of the study concerns the cross-sectional study design itself. Although it allows describing and comparing characteristics and outcomes between countries, cross-sectional data cannot identify cause-effect relations; based on these data one can only hypothesize about what steps need to be taken towards better nursing home outcomes.

Another limitation is the use of proxy respondents and the retrospective character. Research indicates that the opinions of patients and those of their proxies are not always consistent[5]. In addition, the key respondents had to evaluate several aspects of the provided care from three months ago, which means that a recall bias cannot be excluded. However, in case of doubt, staff were able to consult the residents' files. The multi-perspective aspect of the study (input from nursing home administrators, nurses or care assistants and physicians) also contributed to the reliability of the data.

Furthermore, finding a representative sample of nursing homes for each country was difficult given that for some countries no publicly available national (or regional) lists of nursing homes existed (Italy) or extra initiatives were needed to increase participation (England). Furthermore, the fact that a few nursing homes were very far apart and were new to the field of research, made data collection quite time consuming.

The use of structured questionnaires also comes with a few disadvantages. To begin with, since respondents are not directly addressed or questioned, the risk of non-response is high[6,7]. Up to two reminders were sent to non-responders (after three and six weeks). Thus, it took some time before a sufficient number of questionnaires was returned. Nevertheless, for some countries (England) and respondent groups (physicians), the response rate remained very low, possibly due to a lack of time or motivation. Some specific questions also turned out to be poorly answered (Chapter 4) or interpreted in different ways, especially if the translations did not exactly match (Chapter 2). After all, it is not possible to ask for clarity when filling in the questionnaire.

2.2. CLUSTER–RANDOMIZED CLINICAL TRIAL TO STUDY EFFECTIVENESS

The field of nursing home research falls short in high-quality palliative care trials[8,9]. In fact, our cluster-randomized clinical trial – which was designed to study the effectiveness of the palliative care intervention for nursing homes 'PACE Steps to Success' in Belgium (Flanders), England, Finland, Italy, the Netherlands, Poland and Switzerland – offers a strong design and analytical character and presents a resident-centered outcome measure as the primary outcome. As in the cross-sectional study, the large-scale international database based on samples of nursing homes from seven European countries – with different health and nursing home care systems – is unique.

Another strong feature of the study lies within the evaluation of the programme's impact in everyday practice of nursing homes. In addition, the intervention tools and materials are tailored to each specific cultural context and provided in six languages (Dutch, English, Finnish, French, Italian, and Polish). This pragmatic character of the study improves the generalizability of our results and enables their application outside the context of our study. An additional strength of the study was the assessment of various outcomes, both on staff and resident level, with good-to-high response rates considering the type of research.

The trial also holds some limitations. First, we were unable to evaluate the effectiveness of the PACE programme for each individual country separately since the trial was powered across all countries. Second, the questionnaires that were filled in post-intervention corresponded to residents who died between month 9 and month 17 of the intervention. Since the PACE programme ran until month 12, some of the residents already died before the programme was completed or a couple months after the finalization of the programme. This may have hindered the process of grasping the true impact of the programme. Third, blinding of treatment allocation was not possible for researchers or participants, owing to the nature of the study. In fact, participating staff and researchers were aware of which nursing homes were in the intervention group, which could have influenced the responses or may have resulted in social desirability, confirmation or detection bias. Finally, it remains debatable whether the Palliative Care Survey that we used to measure the primary staff outcome 'staff knowledge' is sensitive enough to detect change in knowledge within a year time[10]. This may be one possible explanation of why staff knowledge after the intervention improved only slightly and not to a clinically relevant degree.

This study emphasizes the difficulty of eliciting changes in resident-centered outcomes in palliative research, in particular in the complex nursing home environment. Ceiling effects (nursing homes scoring relatively high at the beginning of the intervention might show smaller improvements after the intervention than low scoring nursing homes), a lack of appropriate measurement tools, and proxy and recall bias all contribute to the challenge that is assessing resident-centered outcomes in palliative care research. Moreover, considering nursing homes and their high staff turnover, hard-to-reach relatives and the absence of incentives for participating in research, conducting research in nursing homes remains complicated.

3 DISCUSSIONS OF THE MAIN FINDINGS

In subsequent paragraphs some reflections on the main results are provided, structured according to the three main themes and objectives that have been handled in this dissertation.

3.1. COMPLEXITY OF PALLIATIVE CARE IN NURSING HOMES IN EUROPE: POPULATION, STAFF AND ORGANIZATION

Is the nursing home evolving into "a place to die"?

Nursing home residents from Belgium, England, Finland, Italy, the Netherlands and Poland die at a high age (85 years) with multiple comorbidities, poor functional and cognitive status, advanced dementia and clinical complications (Chapter 1). Their length of stay in the nursing home is relatively short[11]: only six months in Poland and Italy, where also the highest levels of cognitive and functional impairment and high levels of advanced dementia at the time of death were found. Policy in certain countries aims to keep people at home as long as possible until home care has become impossible due to high levels of disability[12]. In fact, countries like Italy and Poland have a stronger tradition of informal care, provided by relatives[13,14]. On top of that, Polish and Italian nursing homes have lower number of available beds compared to the other countries which can lead to long waiting lists for nursing home accommodation[15]. These findings confirm that nursing homes are more and more becoming places where people go to live at the very end of their lives when they are highly dependent and have complex health problems, making palliative care the most appropriate care approach to improve quality of life and dying for this population across the entire illness trajectory.

The appropriateness of palliative care lies within its focus on ageing, frailty, complex health problems, dementia and comorbidities, while seeking to improve quality of life and maintain the dignity and autonomy of individuals and their families, preparing them for a good death. There are however difficulties in how to implement an adequate palliative care approach suitable for all residents – related to the difference in trajectory between diseases and the challenge in providing a home for long-stay residents while at the same time providing palliative care for short-stay residents – which has a large impact on the way palliative care is developed, provided and received[16,17]. An environment where physicians and nursing staff have a sense of common goal and confidence in each other's abilities – a multi-professional workforce – and where they provide continuity of care over time, while being supported by health care organizations is therefore recommended.

Given that more and more older people will require nursing home care in the future, time has come to actively promote palliative care as the preferred approach to care in nursing homes. Because the nursing home population is changing towards a more ill and unstable one, there is more to uniting than dividing palliative, geriatric and hospice care. If healthy ageing in the final months of life is directed at the dualism of living the best possible life, while simultaneously adjusting to progressive deterioration; then this is the moment to concentrate on the integration of palliative care services in nursing homes[18].

For some time, the health care system is pressured to come up with alternatives for current institutional care, predicting a significant shift in nursing homes structure, responsibility and function[19]. In fact, if – as predicted – the number of nursing home residents will indeed rise, so will the need for nursing home beds. For that reason, nursing homes should be supported to extend their functioning, so they are able to meet the needs of their residents. Nursing homes might require an evolution from isolated single focus healthcare settings to comprehensive geriatric and palliative care centers with a broad structure supported by a network of diverse health care teams[20].

Perhaps then the question is not "*Is the nursing home evolving into a place to die*" but rather, "*What can we do to create a place where all residents live and die well*".

Are nursing homes and their staff adapted to undergo this evolution ?

Currently, the integration of palliative care into nursing home care is very limited in some European countries[21]. Also, the complexity and intensity of care that is required for residents with a poor health status make the delivery of high-quality palliative care more challenging for nursing home staff. Caring for residents at the end of life entails a high burden of care for the nurses and care assistants working in this setting, and places extremely high demands on their knowledge, confidence and skills in providing palliative care[22,23]. The quality of care – which is a major concern in nursing homes[24] – is highly contingent on both staff and nursing home organization[25]. Substantial diversity exists regarding palliative care in nursing homes, further implying that nursing homes may have different access to physician care or are staffed in various ways[19]. However, nursing homes and countries also face many of the same challenges: a lack of (well-educated) staff, time and financial resources in combination with high rates of staff turnover, competing priorities of staff and scarce training opportunities. During the COVID-19 crisis these challenges have become painfully obvious. In addition, the crisis once again highlighted the difference in wages between nurses in nursing homes and their colleagues in hospitals[26]. Further, according to a previous PACE study on staff knowledge, palliative care knowledge of nurses and care assistants in nursing homes appeared inadequate in various European countries[27]. It is clear that nursing home resources did not follow the change in population. After all, to be able to provide palliative care to nursing home residents, staff require a certain level of equipment and understanding of the basic principles of palliative care.

We found that nurses and care assistants in European nursing homes differ considerably in the extent to which they agree with the basic principles of palliative care (*palliative care is applicable early in the course of a life-limiting illness; it can be combined with life-prolonging treatments; it is holistic in nature including physical, emotional, spiritual, and social aspects of care; and it also includes care for those close to the patient)*[1,28]. Staff in England most often agreed with these palliative care principles, whereas the extent to which nursing home staff in Poland and Italy agreed with the principles was lower than in the other countries (Chapter 2). The link can be made with the low level of palliative care knowledge in Poland and Italy, which often goes hand in hand with less favorable attitudes towards palliative care[27,29]. The European Association of Palliative Care (EAPC) Taskforce on Long-term Care Facilities stated that in countries like Poland and Italy, fewer initiatives to develop palliative care in nursing homes and less engagement with palliative care initiatives or care provision by and within nursing homes existed than in the other countries[21,30]. This could suggest that the extent to which nursing home staff agree with the basic palliative care principles might be affected by national policy, investment and development regarding palliative care and the palliative care initiatives and services within a nursing home. Nevertheless, there is room for improvement in all six countries. We discovered that a quarter of the nursing home staff still perceived palliative care as "terminal care" that starts in the last week of life. Most nursing home staff seem to disagree or are not familiar with the essence of what palliative care entails, a finding that also came up in earlier studies[31–35]. A lack of understanding of the meaning of palliative care may have negative implications for the quality of care for residents with serious conditions, receiving inadequate symptom treatment and psychosocial support throughout their illness trajectory.

Differences in the palliative care understanding of staff not only occur between countries and nursing homes, but also within a nursing home. Nurses agreed more often with the principles of palliative care than did care assistants, and staff who had undertaken training in palliative care palliative care more often agreed with the principles of palliative care than those who had not. Hence, education and training seem to be important factors to increase understanding of palliative care[27]. Previous research has also shown that a lack of training can lead to negative attitudes towards palliative care, which in turn can influence other care outcomes, whereas following training had a positive effect on staff opinions[36–38]. Also, cultural diversity might play a role in the differences of opinion between nurses and care assistants. In some areas, care assistants are more strongly represented by people from a minority group or with an immigrant background[39–41]. Cultural background has a strong impact on end-of-life decision-making and certain cultural values may be inconsistent with the values of traditional Western-based medicine[42]. This was not studied in PACE but might be relevant to explore further in future research.

To even out the differences in staff knowledge between countries and nursing homes, it is important to first ensure the presence of certain basic organizational structures in each nursing home. However, we found that the organization of palliative care had several areas for concern (Chapter 3). A common point for improvement was the limited structural availability and access to specialist palliative care support (i.e. specialist palliative care team and specialist palliative advice) in all countries. The provision of specialist palliative care was defined by the EAPC as one of the three levels of palliative care provision, next to (1) a palliative care approach provided by care staff and (2) general palliative care provided by primary care professionals[43]. Although all staff in nursing homes should be able to provide general palliative care to residents, research suggests that a general palliative care approach is not always sufficient to meet all needs of certain nursing home residents; these residents may benefit from specialist palliative care, especially when care needs become complex[44–46].

Other areas for concern regarding palliative care organization were country-specific. Dedicated palliative care functions, specialist palliative care teams, and a dedicated contact person who maintained regular contact with the resident and relatives were often not structurally embedded in the organization of nursing home care, in particular in Finland and Poland. There was little structural availability of specialist advice for professionals delivering palliative care in Finland, Italy and Poland and the availability of opioids was very low in nursing homes in Poland. As other research has already shown that the use and prescription of opioids is lower in nursing homes in Poland compared with other European countries, this last finding was not surprising[47–50]. It was suggested that the low opioid availability in nursing homes in Poland probably reflects the low opioid use in Poland in general[51,52]. Opioids are crucial in the treatments of pain at the end of life and are considered essential in the provision of adequate palliative care[46,52,53]. Possible side-effects, analgesic tolerance, the belief that opioids would hasten death and fear of opioid addiction, can hinder the access to opioids[54,55].

Poland, Finland and Italy appear to have more areas for improvement of palliative care organization than Belgium, England and the Netherlands. Diversity in organization of palliative care may be associated to different levels of its development[56]. Our results are indeed in line with the findings from the report of the EAPC Taskforce on Long-term Care Facilities to which we referred earlier; in Poland, and especially in Italy and Finland, fewer initiatives for palliative care development in nursing homes exist and those nursing homes are less engaged in palliative care initiatives than in Belgium, England and the Netherlands[21,30]. These findings confirm that basic palliative care requirements seem better embedded in Belgium, England and the Netherlands than in the other three countries.

We can conclude that staff qualification and the organization of palliative care in nursing homes remains a challenge in many countries. Within the field of palliative care, today's focus remains mainly on hospitals, hospices and home care[57,58]. Even regarding medical care and resident wellbeing, the nursing home setting is still underinvested[59]. Better palliative care information and education for staff and policy investment regarding basic organizational structures are a first step in preparing nursing homes and their staff for the necessary evolution towards a more comprehensive palliative care approach in nursing homes.

3.2. INAPPROPRIATE TREATMENTS AND HOSPITALISATIONS AT THE END OF LIFE

A general focus on treatment in nursing homes

It is evident that the older population is a vulnerable one for whom providing appropriate care at the end of life is crucial, albeit challenging [60–66]. The difficulty of predicting death in older people complicates the decision on whether a treatment is still appropriate. Certain treatments, medications and transfers are potentially inappropriate when administered to older people at the end of life. Although sometimes needed, they come with a number of drawbacks, in particular to those with dementia and to those living in nursing homes, and should therefore be carefully considered or avoided if possible when there is no strong clinical indication for them[67–74].

We found that many potentially inappropriate treatments such as artificial ventilation, resuscitation, blood transfusions, chemotherapy or radiotherapy, dialysis and surgery – were rarely used in the last week of life of nursing home residents (Chapter 4). Earlier research has shown that in the last week of life, many nursing home residents have a preference for non-aggressive treatments[75]. End-of-life decisions are preference-sensitive and treatment preferences seem to be more important determinants of end-of-life care than initially thought[76,77]. However, antibiotics were frequently administered in all six countries; between 10% and 40% of the residents received antibiotics in the last week of life. Earlier research on the use of antibiotics in nursing homes revealed a similar prevalence at the end of life[78–83]. Since predicting when residents will die is challenging, it is difficult to estimate whether an antimicrobial treatment will have a positive effect on their symptoms[84]. This complicates the decision on whether or not to administer it, particularly in residents with cognitive impairments, who are unable to express symptoms[85,86]. The percentage of residents receiving at least one potentially inappropriate treatment in the last week of life was highest in Poland. In contrast with the other countries, the use of antibiotics and artificial nutrition and/or hydration was common in Poland and Italy – in particular the administration of artificial fluids – even so in residents with advanced dementia.

Besides treatments that are administered in the nursing home, transfers out of the nursing home into hospitals are potentially inappropriate at the end of life. End-of-life hospitalizations have been associated with low survival rates, a suboptimal level of quality and satisfaction with care and a rapid functional decline[67–74]. These hospitalizations often result in hospital deaths. Yet, when residents are asked where they preferred to die, other research has shown that almost all chose to die out-of-hospital in the comfort of their own home[87–93]. We found that up to a quarter of the residents was hospitalized in the last month of life and between 6% and 19% of the residents died in-hospital (Chapter 5). Residents were more likely to be hospitalized in the last month of life if they had a better health status, i.e. better functional and cognitive status and no very severe or advanced dementia. If the physician did not expect a resident's death, the likelihood of in-hospital death increased, indicating that staff were more inclined to transfer residents to a hospital if they assumed he or she was not dying. Across all countries, the main reason for the last admission to the hospital for residents who eventually died in-hospital was 'a sudden onset or exacerbation of symptoms' or 'a life-threatening situation'. Also, although the physicians indicated they usually expected the resident's death, they were the ones – together with the nurses – who usually requested the last hospital admission. This implies that most final admissions were a reaction from staff to an urgent medical situation.

Both hospitalization and in-hospital deaths were more likely if the nurse and a relative did not have a conversation about preferences on medical treatments and the course of care. Also, hospitalizations were more likely if no written advance directive with regard to ‘do not transfer to hospital’ was drawn up. Advance directives are a crucial guide for staff and relatives in case residents lose the ability to make decisions about care and treatments themselves, which is common in residents with (advanced) dementia[94]. Yet, our study concluded that very few of the residents had an advance directive, in some countries this was even non-existent, despite the high rates of residents with dementia. Remarkably, not having an advance directive was not associated with dying in-hospital. These findings imply that although staff involvement and understanding of the residents’ preferences have a strong influence on in-hospital death of nursing home residents, having an advance directive appears not to be the most important factor contributing to in-hospital deaths. Also, even if the resident prefers not to be transferred to the hospital, nursing home staff need to feel equipped to provide the care that is required, making hospitalizations sometimes needed with the purpose of guaranteeing quality of care. This indicates that in acute situations, very complex decision-making takes place during which resident preferences have to be weighed against what is possible in terms of care in the nursing home.

Need for a less cure–oriented, less hospital–centric policy?

Globally, death has become more institutionalized over the years; when people are dying, they are often isolated from society, while their situation is little discussed[95,96]. A societal taboo on the subject of death, dying and palliative care plays an important role here. This results in a population that is not used to the whole aspect of death, with nursing home staff being less prepared for acute end-of-life symptoms, but also relatives being more anxious about death and willing to do what it takes to avoid it, which ultimately generates more hospital deaths[97]. Moreover, there is the increasing awareness among certain older people with a chronic illness that, in order to achieve a good death, they require professional help in a safe and medical environment[98]. Although they initially wished to die out-of-hospital[99], their preferred place of death might change in favor of the hospital when death is nearing, because of certain concerns regarding receiving appropriate care and being dependent on their relatives[100]. If that is the case, it is a matter of verifying whether these hospitalizations are indeed inappropriate and need to be avoided[101]. Finally, it is questionable whether all end-of-life hospitalizations even can be reduced given some are unavoidable or mandatory[102]. Avoidance in itself should not become a care goal. The ultimate aim remains to provide optimal palliative care tailored to the needs of the residents and their relatives.

Previous systematic reviews on hospitalizations of nursing home residents in the last month of life showed that for some countries – such as the United States – hospitalization rates were as high as 35% and even went up to 50% for German nursing homes. Higher rates were attributed to financial incentives that nursing homes in those countries receive for hospitalized residents and a more cure-oriented culture for terminally ill compared to the countries we studied[103–108]. Based on our study results we also hypothesized that legislation, care policy and care culture might play a major role in appropriateness of end-of-life care for nursing home residents. In particular, in Poland and Italy, advance care planning is not as highly incorporated in the care culture compared to the other countries[109]. Due to a cultural taboo that still prevails about death and dying, nursing home staff often feel incompetent to start an end-of-life conversation[63,110,111]. In fact, Polish and Italian nurses also seemed to have poor knowledge of the basic physical aspects of palliative care, in particular regarding appropriate indications for the use of feeding tubes[65]. In addition, Polish and Italian physicians had more difficulties in recognizing whether the resident was in the terminal phase[112]. Treatment decisions at the end of life remain therefore often undiscussed, which could lead to ethical problems or relatives making these decisions on their own and pressuring staff to administer all possible treatments[109,113]. A clear difference in care policy was also visible between types of nursing homes. Across all countries, albeit in particular in Poland, residents in type 2 nursing homes (24/7 care from on-site nurses or care assistants in combination with care from off-site physicians) were more often hospitalized and more often died in-hospital than residents in type 1 homes (with care from on-site physicians). Another PACE study on physician visits in the last months and week of life revealed that Polish residents from type 2 nursing homes received less physician visits then Polish residents from type 1 nursing homes[112]. In Poland, health care policy in both types differs because a type 1 nursing home is considered a medical institution, while a type 2 nursing home is considered a residential home.

Furthermore, we found that residents from Belgium were more often hospitalized compared to the other countries. Studies have shown that Belgian family physicians are usually expected to coordinate the care at the end of life of their patients, which would make them essential in avoiding hospitalizations in the last month of life[114]. However, many relatives request hospitalization without consulting the physician[115,116]. In the Netherlands, we found low hospitalization rates and a remarkably low percentage of residents dying in-hospital. Also, the last hospitalization of Dutch residents was more often requested by the resident than in the other countries. These findings were confirmed by earlier studies that compared hospitalization in the Netherlands with other countries[117–119]. In the Netherlands, nursing home care is managed by the elderly care physician in the nursing home instead, following a health care model that is less hospital-centric[68,120]. Moreover, the Dutch residents more often had a palliative care goal on the day of death than other residents. Additional research indicated that quality of life often outweighed prolongation of life and was considered an important aspect in end-of-life decision-making in the Netherlands, where discontinuing life-prolonging medical treatments was an accepted practice[121]. One last study counted several contact moments between physicians, nursing staff and relatives during which place of death and other care goals were discussed[122,123]. In combination with these studies, our findings suggest that in the Netherlands, close attention is paid to end-of-life discussions and ensuring nursing home residents can die where they reside.

3.3. TOWARDS A COMPREHENSIVE PALLIATIVE CARE APPROACH IN NURSING HOMES ?

Very few initiatives focus on the actual implementation of palliative care, and available evidence on those initiatives is tenuous[124]. Therefore, the PACE consortium developed the PACE 'Steps to Success Programme', a multicomponent six-steps programme that aimed to integrate basic non-specialist palliative care in nursing homes in seven countries: Belgium, England, Finland, Italy, the Netherlands, Poland and Switzerland. To evaluate the effectiveness of the programme, a cluster randomized clinical trial (RCT) was conducted with two primary outcomes; one on resident level – comfort in the last week of life as indicated by staff – and one on staff level – knowledge of palliative care (Chapter 6). The RCT revealed that the PACE programme did not improve comfort in the last week of life. A significant increase of staff knowledge after the intervention was found, albeit we interpreted this as a non-clinically important increase with a small effect size. The secondary resident outcome - quality of care in the last month of life – did improve significantly. However, since it is a secondary outcome, it requires more in-depth study. The improvement in quality of care was most visible in the Quality Of Dying in Long-Term Care subscale '*preparatory tasks*'. We therefore hypothesized that step one – the advance care planning step of the programme – resulted in a conversational change regarding end-of-life decisions in nursing homes. Being the first step of the programme, it was implemented the longest in the nursing homes. Also, although the process evaluation of the trial indicated that the implementation of the six steps was highly variable between countries and nursing homes, the advance care planning training seemed to have reached more staff than the other steps did[125].

To explore whether the improved care planning that resulted from the PACE programme also had an effect on hospitalizations in the last month of life and on place of death, we conducted a secondary analysis (Chapter 7). Even though avoiding hospital transfers was not a distinct step of the programme, the issue was addressed as part of the intervention in step one – where preferences for treatment and place of death were discussed – and step five, which focused on the organization of care during the final days of life in the nursing home. Literature search showed that despite the negative consequences for older people, hospitalizations of nursing home residents in the last month of life were frequent. Additionally, place of death is regarded as a quality indicator for palliative care[126]. Therefore, we considered hospitalizations and place of death to be relevant outcomes of a palliative care intervention like the PACE programme. We hypothesized that the increase in quality of care in the last month of life we found in the main study and the staff training from step one and five could have affected place of death and hospitalizations in the last month of life in terms of emergency department visits, hospital admissions, and length of hospital stay following admission. Contrary to our hypothesis, the secondary analysis did not find a statistically significant effect of the PACE programme on any of the three hospital-related outcomes or place of death. We did observe a shorter mean length of stay (three nights) post-intervention; however, this was not statistically significant.

A PACE study that assessed the cost-effectivenes of the PACE Steps to Success programme did find substantial medical cost savings after the intervention, mainly due to lower hospitalization-related costs – a decrease of approximately 1000€ – resulting from the difference in length of stay in the hospital[127]. The cost savings were most apparent in the geriatric, general and ICU ward. Although the length of stay and the cost savings on these wards did not change significantly, the combination of both changes did lead to significant cost savings. The study concluded that the PACE programme resulted in residents returning to the nursing home earlier, indicating that the programme might have prevented extended hospitalizations and that its integration into nursing home care could be cost-effective. There was still room for improvement regarding the number of hospitalizations.

For the absence of the expected effects of the PACE programme we give multiple possible explanations.

To start with, the various components of the programme could have been mismatched with the primary resident outcome —comfort in the last week of life. The six steps targeted the whole trajectory a resident followed, from admission to death. Only one of these steps (step five) focused on care in the last days of life and was solely implemented at the end of the programme, at month seven. In addition, the programme was more oriented towards symptom assessment than towards actual treatment of the end-of-life symptoms. Involving physicians or specialist palliative care services might be necessary to improve comfort at the end of life. This orientation towards symptom assessment could also have increased staff's ability to identify symptoms, resulting in enhanced reporting of the symptoms after the programme. This might have masked a potential intervention effect. In regard to the staff level primary outcome – staff knowledge – we used the Palliative Care Survey as a measurement tool, which might have been not sensitive enough to identify change in knowledge within a year[10]. We also only used part of the survey, focusing on end-of-life specifically and not all aspects of palliative care knowledge. This could explain why staff knowledge after the programme improved, yet not to a clinically relevant degree. Success of an intervention therefore depends on its components functioning as a whole[128]. Since they work both independently and interdependently, reaching a significant cause-and-effect relationship is challenging.

When a trial fails, one must not only question the effectiveness of the programme itself, but also the implementation and the setting – who conducted it, who received it, how was it introduced and delivered, was the setting supportive, enabling and prepared. Especially in health care interventions, lack of effect could rather be due to the system than the intervention per se[128]. The PACE programme could have been too complex, including too many components that were implemented during only one year. As was confirmed by a systematic review of nursing home interventions, programmes that targeted specific care elements were more likely to be successful than those targeting multiple outcomes simultaneously[129]. Thus, the implementation of the PACE programme may have been substandard in certain nursing homes[125,130]. Even though we culturally adapted the intervention and allowed modifications of some intervention materials to make them practical and fitting to each context, the programme could have been too standard to guarantee best execution in all nursing homes, preventing adequate adaptation of the components to the local nursing home context. As part of the process evaluation of the programme – which was not part of this PhD – we calculated the implementation rate, which consisted of a fidelity component – a score from 0 to 8 for the number, order, and timing of the delivered steps; i.e. the extent to which the six steps were delivered as intended – and an appreciation component – a score between 0 and 8 to describe staff's appreciation of the programme and the trainers[125]. The fidelity scores were high in most countries, ranging from 5 to 8, whereas the appreciation score ranged from 3.2 to 7.8. Combining the two scores resulted in a low implementation rate for 5.4% of the nursing homes, a medium implementation rate for 64.9% of the nursing homes and a high implementation rate for 29.7% of the nursing homes. The process evaluation showed that organizational problems may have resulted in a lower programme fidelity [112]. Absent or unreachable PACE coordinators, difficulty in planning the multidisciplinary review meetings due to a high number of staff involved (step three), and cancellation of meetings because of illness amongst staff, complicated implementation in some facilitaties. Moreover, characteristics of the PACE trainers such as experience in palliative care, in teaching and using a hands-on approach influenced the motivation of participating staff to engage in the programme. The training programme itself – the duration and number of training sessions as well as the time between sessions – also determined staff appreciation. Finally, certain country-specific challenges in implementation were identified. In Poland, a task-oriented attitude made it harder to follow the more holistic approach from the PACE programme. Whereas in Italy, palliative care was often linked to euthanasia. In both countries, cultural taboos about death hindered implementation. In England, training attendance was low due to long working hours or compensation days of staff. Swiss and Finnish nursing homes sometimes felt that the programme did not fit their staff needs or knowledge and expected a more technical programme. In Belgium and the Netherlands, constant reorganizations created uncertainty and instability within staff teams. In some Belgian nursing homes palliative care specialist nurses felt pushed aside, causing a difficult cooperation with the PACE coordinators. In the Netherlands, cooperation was complicated due to the large number of involved physicians. With the help of the process evaluation, we were able to collect evidence on important contextual barriers and facilitators that should be considered when implementing a complex intervention like the PACE programme.

With regard to the secondary analysis, even though the PACE programme did contain various care elements such as advance care planning and care in the last days of life, these may not have been sufficiently aimed at actually preventing hospitalizations in the last month of life[131–133]. In particular, the programme had an insufficient focus on when to involve physicians or specialist palliative care services and lacked comprehensive clinical or pharmacologic guidelines on the actual treatment of dying symptoms. For residents with complex care needs, involving specialist palliative care services is often needed. Just as in the first PACE study (Chapter 4), PACE study II specified that for residents who eventually died in-hospital, staff mentioned 'a sudden onset or exacerbation of symptoms' or 'a life-threatening situation' as the main reason for the hospital admission. This suggests that nursing home staff or physicians might have felt insufficiently capable to address such end-of-life situations and believed that a hospitalization was the better option. A paper that reported the results of a clinical trial from the United States stated that organizational readiness, in combination with effective communication and teamwork, supported by permanent palliative care teams and well-integrated advanced practice nurses, makes reducing hospitalizations more feasible[130]. Further, although family members were included as important stakeholders throughout the programme (in particular in step one and five) they may not have been targeted well or systematically enough. A recent qualitative study comparing American nursing homes with low and high hospitalization rates found that staff from low-hospitalizing nursing homes more often believed that certain residents should not be hospitalized and felt compelled to help residents and their relatives reach the same conclusion, whereas staff from high-hospitalizing nursing homes were more inclined to leave these decisions up to relatives[134]. Also, when acute medical conditions occur in a nursing home, relatives have a tendency to request for hospitalization with or without consultation of nursing home staff[135,136]. This request is often made out of fear for impending death, where the hospital setting is considered a safe place during a medical emergency[135–137].

The results of the PACE trial highlight the challenge of impacting resident outcomes in palliative care research, in particular in the complex setting of a nursing home. During the implementation of a complex nursing home intervention, the nursing home context must be taken into account. Elements such as nursing home management, staff skills and readiness, (care) culture, current ways of working and communicating strongly impact how nursing homes adopt innovative programmes, regardless of their specific target or focus[14,129].

A systematic review and meta-analysis of randomized clinical trials of patients with noncancer illness – which included the PACE trail – compared the effect of palliative care with usual care on important end-of-life outcomes[138]. The study found that palliative care was significantly related to less acute health care use and slightly lower symptom burden, albeit without finding a significant difference in quality of life. However, they stated that the variety among palliative care interventions can reduce their applicability in different nursing homes with variation in care practice and palliative care definitions and access. In addition, it remains a question mark which palliative care model is the most favourable and what time and place are optimal for its implementation.

4 IMPLICATIONS FOR PRACTICE, POLICY AND FUTURE RESEARCH

1 IMPLICATIONS FOR PRACTICE

A first important recommendation for all nursing homes in Europe is to bring about a cultural shift regarding palliative care: it is important recognize and promote palliative care as an adequate and necessary care approach and ensure that access to appropriate palliative care is not compromised. Therefore, we recommend nursing homes to integrate palliative care models earlier in the disease trajectory with seamless transitions to specialized care if appropriate, especially given the complexity of the setting and its population (often highly dependent) and short nursing home stays. This might help to guarantee cost-efficient and timely access to qualitative care for all nursing home residents during the entire disease process.

To integrate palliative care into nursing home care, different care components need attention. First, nursing homes are encouraged to pay more attention to advance care planning as this may help residents to express their care goals and preferences. Our findings have shown that a stronger staff and family involvement and understanding of the residents' preferences relates to less hospitalizations at the end of life. Second, we indicate the need for managing acute changes in symptoms before they worsen and would otherwise require hospital stays or burdensome treatments. To reduce the likelihood of hospitalizations and other potentially inappropriate procedures at the end of life, we recommend nursing homes to (1) enable end-of-life discussions between nursing home staff, residents and their relatives and (2) pay closer attention to the last days of life, for example through a treatment plan for when end-of-life symptoms occur. Staff often feel insufficiently qualified to address end-of-life situations, which is reinforced by the absence of physicians in nursing homes. It is important here to ensure a consistent communication between nursing staff, physicians and palliative care specialists, so nursing staff feel supported enough. Furthermore, repeated courses for all staff on the meaning of palliative care, on physical and psychological aspects of palliative care, on how to start end-of-life conversations, how to recognize the terminal phase of dying residents and physician training in how to treat specific end-of-life symptoms are important areas of improvement and can facilitate the implementation of the abovementioned recommendations.

Palliative care initiatives such as the PACE Steps to Success Programme and terminal care interventions that support nursing home staff on how to provide excellent care in the terminal phase can help addressing these different care components and can raise awareness on palliative care in nursing home staff. Since nursing homes differ in their palliative care approach, in their level of palliative care integration and in their availability of specialist palliative care services, such initiatives need to allow sufficient flexibility and tailoring to the local cultural and nursing home context during implementation. Further, it is essential that initiatives are specific and targeted enough and properly involve all important stakeholders in the nursing home: residents, staff, physicians, specialist palliative care services and relatives.

To make the implementation of a palliative care initiatives in nursing homes more feasible, we emphasize three steps of implementation[139]. First of all, certain conditions must be ensured before an intervention can be introduced. Organizational readiness – i.e. adequate capacity and stability of staff and management, a good fit between current care values and the ones being introduced, and support for the intervention from staff and management – is required prior starting. Second, palliative care and advance care practice must be embedded in the routine, day-to-day practice, for which the PACE Steps to Success or other materials can be used. Each country has its own health care system and will therefore have to find its own ways to improve palliative care. Third, the change must be sustainable. If the intervention is not incorporated into day-to-day practice, improvements may disappear over time after implementation, especially considering high staff turnover in nursing homes. As a health care provider or nursing home director it will be important to continue education and find ways to embed palliative care as a culture in the nursing home, in a sustainable way. This will require continuous training. Cooperation with other partners is also very important. In practice there are some good examples of nursing homes that are doing very well already, but there are other nursing homes where more investment in palliative culture is needed. This also became clear during the COVID-19 crisis.

2 IMPLICATIONS FOR POLICY

Within the field of palliative care, policies mainly focus on hospitals, hospices and home care. Even regarding medical care and resident wellbeing, the nursing home setting is still underinvested[59]. The results of this dissertation can be used by policy and other decision-makers to develop public health policies and interventions to improve the development of adequate palliative care in nursing homes and allow the exchange of good practices across national borders and across (types of) nursing homes.

A report from the EAPC Taskforce on Long-Term Care Facilities on the development of palliative care in nursing homes in Europe pointed out that in countries like Poland and Italy, fewer initiatives to develop palliative care in nursing homes existed and less engagement with the few existing palliative care initiatives by and within nursing homes was found[21,30]. We associated this lack of palliative care development and engagement with country differences in terms of staff attitudes, organizational structures, administration of inappropriate treatments and end-of-life hospitalization in nursing homes. Across all countries, we highlighted the need for a health care policy that ensures equal access to palliative care for all healthcare settings, for all residents, with detailed information on minimal equipment that should be available in nursing homes and the financial resources needed to provide it. Understanding how to meet the increasingly complex needs of nursing home residents efficiently, determining and providing the appropriate numbers and type of staff (i.e. skill mix), investing in dedicated functions for palliative care and the availability of adequate general and specialist palliative care for all nursing home residents in need of this kind of support, either via internal or external services, all appeared issues that need to be addressed to ensure equal access to palliative care in nursing homes.

Since so many residents develop advanced dementia at the time of death, we also recommend that policies addressing this sector highlight the need for the integration of high-quality palliative care together with high-quality dementia care, enabling nursing homes to become centers of excellence in dementia palliative care. Given the short length of stay, almost all residents of these nursing homes can be considered to be at the end of life, making palliative care the most appropriate care approach for this population. Policies supporting these nursing homes to integrate a palliative care approach may bring substantial benefit to the sector. It will be important for policy-makers to develop – in collaboration with the palliative and nursing home sector – a plan for effective scale-up of palliative care in nursing homes.

Throughout this dissertation, the need for staff education and training was repeatedly mentioned. Currently, effective palliative care training is not always included in curricula for nurses and care assistants[140]. Some training and online courses exist; however, these are often limited[141,142]. Certain training elements – a hands-on approach, innovative training strategies, managerial support, and the use of role modeling – are shown to be the most effective[143–145]. More and better education and training is thus needed to promote the better understanding of palliative care and to encourage its timely use for nursing home residents. Especially considering the various complex health problems of nursing home residents (dementia, comorbidities, clinical complications and poor cognitive and functional status) education should be a high priority of policy makers and educational bodies. Our findings have shown that knowledge on basic palliative care falls short, particularly among care assistants, despite the fact that they are responsible for direct patient care[140]. Therefore, it is most important to include them in trainings. The same applies to newly graduated and recently employed staff.

Potentially inappropriate end-of-life procedures where there is more room for improvement (e.g. hospitalizations, artificial nutrition and hydration treatments, antibiotics), require particular attention, especially in light of the current policy on artificial nutrition and hydration treatments in Italy and Poland. Substantial country differences in treatments in the last week of life call for the development of international guidelines to assist nursing home staff and physicians in treatment decision-making – while taking into account cultural differences – and in recognizing the terminal phase. Particularly for Poland, our findings may be an incentive to make opioids available 24/7 for all nursing home residents when they need them. To do this, the report of the Access To Opioid Medication in Europe (ATOME) group suggested that legal barriers that hinder the use of opioids in Poland need to be addressed, and that the misconception of opioids as being a life-shortening drug need to be corrected through adequate information and training for health care providers [146,147].

Finally, quality measures and nursing home regulations should incorporate parameters regarding the end-of-life and palliative care of nursing home residents. It is important that policy makers think about how quality measures for nursing homes can be used for palliative care. For example, the Minimum Data Set – which is a standardized screening tool used in the United States to monitoring quality of care of nursing home residents – measures their physical, psychological and psycho-social parameters to provide an overview of the resident's functional status[148–150]. Some palliative care measures are already included (e.g. pain) however, crucial items are missing, e.g. preferences for care and treatments at the end of life. Indications of quality of end-of-life care – as reported by relatives – should be mandatory, and palliative care involvement, end-of-life hospitalizations and other referrals should be included as important measures.

3 IMPLICATIONS FOR FUTURE RESEARCH

More and more people are dying in nursing homes and our studies showed the need as well as the difficulty of changing practice in this complex setting. We therefore must continue to invest in thorough and accurate research that supports nursing home residents to live their final months and years with comfort and dignity.

This dissertation illustrated that treatments in the last month of life of nursing home residents greatly differ between countries. Although for some treatments (e.g. regarding nutrition) international recommendations have been established, there are country-specific approaches depending on legislation, health care policy and organization, or culture. Furthermore, it is plausible that a difference in prescribing habits between countries is responsible for difference in treatments. However, this was not examined as part of this dissertation and should be included in future research. Also, for many other treatments, international guidelines do not yet exist. In particular, there is a lack of guidelines on antimicrobial stewardship in palliative care and perspectives on the indications for antibiotics strongly differ. This could possibly be the cause of the high use of antibiotics in the last week of life of nursing home residents. More research is thus needed to guide the use of antibiotics at the end of life of nursing home residents.

Despite the challenges of conducting palliative care research in the complex environment of nursing homes, it is essential that we carry on trying to improve resident-centered palliative care and end-of-life outcomes in this setting. Therefore, we must persist in developing and assessing different palliative care interventions in nursing homes. In future interventions, we could investigate whether a more targeted intervention specifically aimed at improving outcomes in the last week of life i.e. improving comfort while dying while preventing unnecessary end-of-life hospitalizations, could have a better outcome than the PACE trial. Such interventions would however also need to focus on the whole nursing home context, including all staff, family, staff as well as GPs and specialist palliative care services to improve end-of-life symptom management for residents.

In terms of evaluation methods, randomized clinical trials (RCT) are invaluable in this research area as they are necessary to provide high-quality causal evidence. However, it is important to recognize the added value of other complementary evaluation designs – such as those used in process evaluations – if we consider the implementation of interventions as a process rather than a one-time implementation. An RCT in a complex setting requires an embedded in-depth evaluation of the implementation of the intervention. In addition, future studies should examine the longer-term effects and sustainability of palliative care interventions in nursing homes. Observational representative studies that monitor care processes and outcomes over the longer term, combining quantitative with qualitative data, will provide important information on how nursing homes are evolving.

The evaluation of the PACE programme showed that the programme did not have a significant effect on the primary outcomes comfort in the last week of life and staff knowledge, nor on hospitalizations and place of death. Future trials should therefore consider how to ensure a closer fit between the intervention and outcome measures. This might be realized by not only thinking forward in terms of identifying the outcomes (i.e. what will be hope to achieve) but also thinking backward – a process calles backward outcome mapping – to consider whether the outcome of interest is solely influenced by the intervention or whether other intervention components are needed to achieve the outcome.

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SUMMARY

1 BACKGROUND

AGEING AND ILLNESS IN THE OLDER POPULATION

Along with population growth, international migration and urbanization, population ageing is one of the four megatrends of the world's population today. Up until recently, people aged 65 or over were outnumbered by children under the age of five. Currently, this ratio is reversing, while fertility rates are dropping. This will put us in the unique position of living in a world with more older than younger people, a world in which human life span that will continue to increase. The group of people aged 85 years and over, referred to as the oldest-old, will show the greatest percentual increase. The shift in life expectancy also comes with a change in leading causes of illness and death, as part of an epidemiologic transition. Even though a longer lifespan can also entail a longer activity and contribution to society and economy – provided this is supported by the environment (cfr. active ageing) – chronic and degenerative diseases, characterized by a longer and dynamic illness trajectory, will become prevalent. Therefore, long-term care provided in nursing homes and other residential settings will play an important role in the care for older people. One important challenge the population of today faces is the provision of high-quality palliative care for all those who need it, regardless of age, setting or disease.

PALLIATIVE CARE FOR NURSING HOME RESIDENTS

Palliative care is defined by the World Health Organization as "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual". In the past, palliative care was mainly provided to cancer patients in a hospice setting. However, due to the typical long trajectory of illnesses in older people these days, many of them may benefit from palliative care at any point during their illness, and not only in the terminal phase. Since nursing homes are an increasingly significant care environment for older people, these homes are in the unique position to deliver general palliative care. However, palliative care policies often fall short when it comes to the nursing home setting.

Currently, almost 40% of people of 65 years and over come to die in a nursing home (particularly in developed countries), and this percentage is expected to grow over the following years. For decades, nursing home deaths were considered a negative result from inadequate palliative care, something that needed to be avoided. In recent years, however, numbers show that more and more residents are already in their final stage of life when they enter a nursing home, with deterioration and death being unavoidable. People who enter the nursing home are often at an advanced age, with multiple chronic diseases and with a poor functional status. Care must therefore be adapted to the characteristics and complex care needs of nursing home residents. This would mean that staff are more and more required to answer the needs of a group considered to be 'at the end of life' i.e. last years or months of life.

From previous studies we have learned that the quality of palliative care and the quality of dying in European nursing homes are not optimal and that nursing staff knowledge concerning basic palliative care issues is substandard. However, some important knowledge gaps regarding palliative care in nursing homes still remain. First, from an epidemiological viewpoint, there is a lack of high-quality and representative socio-demographic and clinical data on the population of dying residents in nursing homes. Also, the extent to which nurses and care assistants from European nursing homes have developed basic palliative care attitudes is quite unknown, but nevertheless important to inform educational initiatives for this sector. Related to this, there are currently no data available to policy makers on the extent to which important organizational structures for the delivery of quality palliative care are present in different EU countries. Such knowledge, particularly when comparing different countries, would be relevant for national policymakers as well as nursing home directors or umbrella organizations as this would provide opportunities to learn from each other and improve where needed, for example in light of decisions regarding adequate resources and staffing.

POTENTIALLY INAPPROPRIATE TREATMENTS IN NURSING HOMES

Care today is often still centered around the disease of the residents, leading to a prolonged curative treatment during the disease trajectory, and is less focused on palliative care. The challenge in predicting when an older person will die, complicates the decision on the appropriateness of a treatment and whether or not to administer such treatment. Certain treatments are considered potentially inappropriate when provided at the end of life to older people with comorbidities and should thus be considered cautiously. Examples of these treatments are artificial nutrition and hydration treatments, antimicrobial treatments, certain medications such as statins, critical care treatments such as resuscitation or surgery, and treatments like chemotherapy. In order to offer more patient-centered palliative care, it is crucial to first learn about the prevalence of those treatments in nursing homes in different countries. End-of-life hospitalizations, together with the high number of residents that die in-hospital, is another area of concern within the challenging journey towards high-quality palliative care for nursing home residents. Hospital transfers at the end of life are considered to be of limited clinical benefit to residents, are often in violation with the resident's care preferences and comfort, and come with high costs and negative risks. The influx of older people with complex care needs into the hospital demands for adequate palliative care in this setting. Place of death is viewed as a quality indicator for palliative care, which includes avoiding unwanted in-hospital deaths and taking into consideration a resident's wish to die at home. Still, the majority of studies on hospitalizations at the end of life of nursing homes residents primarily focused on place of death, while leaving unexplored other hospitalization-related outcomes. We lack representative and international comparative data on potentially inappropriate treatments, hospitalizations and place of death. Studying cross-national variation in these end-of-life events can generate representative data and provide useful information for the development of palliative care policies and targeted interventions to meet the needs of nursing home residents, their relatives, and society as a whole.

A EUROPEAN PERSPECTIVE ON PALLIATIVE CARE IN NURSING HOMES

Policies on palliative care and health care differ strongly between countries, creating considerable differences in the quality of palliative care in nursing homes. Aside from the differences in national policies, culture and beliefs also may be included as barriers to adequate palliative care. European representative and comparative studies on palliative care practice in nursing homes are thus crucial. That is, international data enables policymakers to gain insight into the main issues of the nursing home population. Contrasting data between countries could facilitate a better understanding of national and international challenges and assist decisionmakers in creating hypotheses on palliative care organization. Earlier studies have mapped the different European palliative care policies, services and initiatives. They showed that palliative care development and implementation were limited in many European countries, that palliative care is initiated too late and that even though European countries varied in terms of quality of end-of-life care and quality of dying, all show room for improvement, even the countries with higher levels of palliative care development in nursing homes. These studies identified the variety in palliative care provision, integration and quality in nursing homes across European countries and the difficulties these countries still need to overcome. There is a clear need to improve palliative care in this setting.

INITIATIVES TO IMPROVE PALLIATIVE CARE IN NURSING HOMES

Evidence-based initiatives to improve palliative care in nursing homes in Europe are limited and most of them are aimed at one care aspect. Research however showed that achieving actual change appears to require a comprehensive, whole-setting approach, while targeting specific aspects that are underdeveloped. Only a few large-scale interventions have been implemented. Review studies of these interventions concluded they were insufficient to improve palliative care. These interventions can however be useful in pointing out the weaknesses of evidence on successful palliative care interventions for nursing homes. Besides the lack of effective interventions, high-quality studies evaluating the existing interventions are scarce, often due to methodological weaknesses or flaws in the interventions themselves. Clearly there is a need for research on initiatives to improve palliative care in nursing homes across Europe. In this regard, the PACE 'Steps to Success Programme' was developed. The programme aimed to enhance high-quality palliative care for all nursing home residents in Europe, by promoting organizational change and assisting staff in developing their roles as a palliative caregiver. The intervention ran for 12 months in the participating nursing homes, while being evaluated in a randomized clinical trial (RCT) that studied the impact of the programme. The RCT compared the effect of the programme with usual nursing home care in terms of resident and relative outcomes, staff knowledge and attitudes, quality of palliative care, quality of dying and cost-effectiveness.

2 RESEARCH AIMS

PART I aims to describe facility-, resident-, and staff characteristics of palliative care in nursing homes in Belgium, England, Finland, Italy, the Netherlands, and Poland and to compare those characteristics between the six countries. **PART II** aims to study the prevalence of potentially inappropriate treatments and hospitalizations at the end of life of nursing home residents in Belgium, England, Finland, Italy, the Netherlands and Poland, and to explore the differences in prevalence between the six countries. **PART III** aims to evaluate the effect of a palliative care programme in nursing homes in Belgium, England, Finland, Italy, the Netherlands, Poland and Switzerland on resident and staff outcomes and on hospitalizations.

3 METHODOLOGY

PACE is a European funded project (European Union's Seventh Framework Programme, 2014-2019) which compares palliative care for elderly people in care or nursing homes in European countries and aims to advise policymakers on optimal palliative care practices.
Two studies were used for this dissertation: PACE study I and PACE study II.

PACE study I is a cross-sectional study that aims to describe and compare nursing homes in six European countries – Belgium, the United Kingdom, Finland, Italy, the Netherlands and Poland – in terms of resident outcomes, quality, costs and structures of palliative care and staff knowledge and attitudes toward palliative care, and analyzes the relationship among these structures, processes, and outcomes. PACE study II includes a multifacility cluster-randomized clinical trial (2015-2017) in Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland, to compare the PACE 'Steps to Success Programme' with usual care. The PACE 'Steps to Success Programme' is a multicomponent intervention program to integrate basic non-specialist palliative care in nursing homes. Using a train-the-trainer approach, an external trainer supports staff in the nursing homes to introduce a palliative care approach over the course of one year following a six-step program. In both studies, participating nursing homes in each country reported every death that occurred among the residents in the preceding months. For each identified deceased resident, structured questionnaires were sent to the key respondents: the nursing home administrator, the nursing staff member most involved in care (preferably a nurse) and the treating physician (a general practitioner, elderly care physician or physician employed in the nursing home). For each participating nursing home, the administrator was also asked to fill out a questionnaire on nursing home characteristics.

4 SUMMARY OF THE MAIN FINDINGS

PALLIATIVE CARE IN NURSING HOMES IN EUROPE

We found that nursing home residents currently die at a very old age, on average around 85 years, except in Poland where the mean age at time of death is 81 (Chapter 1). The percentage of residents that die in the nursing home is 80% in Poland, 82% in England and Belgium, 85% in Finland, 87% in Italy and 89% in the Netherlands. A large proportion of the residents (47% – 74%) have multiple comorbidities at the end of life and at least 60% suffer from dementia at time of death, often at a very severe or advanced stage. Clinical complications during the last month of life are frequent and consist mainly of eating or drinking problems (51.9% in England; 66.4% in Finland and Poland). The average length of stay in the nursing home is relatively short in all countries and varies between six months in Poland and Italy and two years in Belgium. The highest percentages of residents with poor cognitive and functional status one month before death are found in Poland and Italy, where residents also have the shortest length of stay. Across countries, we found a large heterogeneity in the extent to which nursing home nurses and care assistants agree with the basic principles of palliative care – measured with the Rotterdam Move2PC questionnaire – but with room for improvement in all countries (Chapter 2). Staff in England more often agreed with the principles, whereas staff in Italy and Poland less often agreed with the principles than in the other countries. The level to which staff agreed with the principles was significantly associated with country, age, professional role, and formal training. Older staff had a higher score of agreement than younger staff, as had nurses compared with care assistants and staff who had undertaken palliative care training compared with those who had not. Finally, we identified several areas of improvement for the organization of palliative care in nursing homes in six European countries, using the IMPACT structural indicators for quality of palliative care (Chapter 3). Dedicated palliative care functions, specialist palliative care teams, and a dedicated contact person who maintained regular contact with the resident and relatives were often not structurally embedded in the organization of nursing home care in most countries, in particular in Finland and Poland. There was little structural availability of specialist advice for professionals delivering palliative care in Finland, Italy and Poland. The availability of opioids was low in nursing homes in Poland. Almost all structural indicators for quality of palliative care differed significantly between countries.

POTENTIALLY INAPPROPRIATE TREATMENTS AND HOSPITALISATIONS AT THE END OF LIFE

We found that artificial ventilation, resuscitation, blood transfusions, chemotherapy or radiotherapy, dialysis and surgery were rarely used in the last week of life of nursing home residents in most of the studied countries (Chapter 4). However, the prevalence of most treatments differed statistically significantly between countries. Poland had the highest percentage of residents receiving at least one potentially inappropriate treatment in the last week of life. Artificial nutrition and/or hydration were common treatments in Poland and Italy, in particular the administration of artificial fluids, even in residents with advanced dementia. Antibiotics were frequently administered in all countries, albeit with the highest rates in Poland and Italy, and antidiabetics were most often administered in Poland. Furthermore, our results show that between 12% (Italy) and 26% (Belgium) of the residents were hospitalized in the last month of life – with 16% in the Netherlands, 22% in Finland, 23% in England and 25% in Poland – with most of those residents being hospitalized only once (Chapter 5). Hospitalizations were less likely if residents had a written advance directive with regard to ‘do not transfer to hospital’ and if their nurse spoke with a relative about preferences with regard to medical treatments and the course of care. The availability of the physician in the last week of life also decreased likelihood of hospitalization. The percentage of residents dying in-hospital was 6% in the Netherlands, 9% in England and Finland, 13% in Italy, 18% in Belgium and 19% in Poland. If the resident eventually died in the hospital, the reason for the last hospital admission was mostly a sudden onset or exacerbation of symptoms or a life-threatening situation. The physician and nurse were usually the ones who requested the last admission, in the Netherlands this was also often at the resident’s request. If the physician expected the resident’s death, residents were less likely to die in the hospital. A poorer functional status was associated with a reduced likelihood of both hospitalization and in-hospital death.

EVALUATION OF A PALLIATIVE CARE PROGRAMME IN NURSING HOMES IN EUROPE

We compared the effect of the PACE programme – a one-year multicomponent intervention to integrate basic non-specialist palliative care in nursing homes – with usual nursing home care via a multifacility cluster-randomized clinical PACE trial in Belgium, England, Finland, Italy, the Netherlands, Poland, and Switzerland. We analyzed the programme effect on resident outcomes as reported by staff, including comfort in the last week of life (primary resident outcome; measured with the EOLD-CAD[6]), and quality of care in the last month of life (secondary resident outcome; measured with the QOD-LTC[7]). In addition, we examined if the programme affected staff outcomes, including knowledge of palliative care (primary staff outcome; measured with the Palliative Care Survey), staff self-efficacy, educational needs, and opinions on palliative care (secondary staff outcomes; measured with the S-EOLC[8], the EPCS[9] and the Rotterdam Move2PC, respectively). The multifacility cluster-RCT found that the PACE 'Steps to Success Programme' did not improve the comfort in the last week of life of residents as reported by staff. Results indicated a significant difference between intervention and control groups for staff knowledge of palliative care issues, but this difference was very small and not probably clinically important. Further, the secondary resident outcome quality of care in the last month of life reported by staff differed significantly between intervention and control groups. We detected a significant difference between intervention and control responses on the QOD-LTC subscale *preparatory tasks*. We therefore argued that step one – the advance care planning step of the programme – resulted in a conversational change regarding end-of-life decisions in nursing homes. Consequently, we hypothesized that the improvement in quality of care in the last month of life that we found, could have impacted hospital use and place of death. We therefore conducted a secondary analysis to investigate whether the PACE programme had an effect on hospital use in the last month of life of nursing home residents in terms of numbers of emergency department visits, hospital admissions, and length of stay following admission, and whether the program has an effect on the place of death of nursing

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[6] End-of-Life in Dementia Scale Comfort Assessment While Dying

[7] Quality of Dying in Long Term Care

[8] Self-Efficacy in End-of-Life Care Survey

[9] End-of-Life Professional Caregiver Survey

home residents. Results indicated no statistically significant effect of the PACE program on emergency department visits, hospital admissions, length of hospital stay in the last month of life, or place of death. We did observe a shorter mean length of stay post-intervention; however, this was not statistically significant.

5 DISCUSSIONS OF THE MAIN FINDINGS

COMPLEXITY OF PALLIATIVE CARE IN NURSING HOMES IN EUROPE: POPULATION, STAFF AND ORGANIZATION

Is the nursing home evolving into "a place to die"?

Our findings confirm that nursing homes are more and more becoming places where people go to live at the very end of their lives when they are highly dependent and have complex health problems, making palliative care the most appropriate care approach to improve quality of life and dying for this population across the entire illness trajectory. There are however difficulties in how to implement an adequate palliative care approach suitable for all residents. The challenge in providing a home for long-stay residents while at the same time providing palliative care for short-stay residents, has a large impact on the way palliative care is developed, provided and received.

Given that more and more older people will require nursing home care in the future, time has come to actively promote palliative care as the preferred approach to care and to concentrate on the integration of palliative care services in nursing homes. Because the nursing home population is changing towards a more ill and unstable one, there is more to uniting than dividing palliative, geriatric and hospice care. For some time, the health care system is pressured to come up with alternatives for current institutional care, predicting a significant shift in nursing homes structure, responsibility and function. In fact, if – as predicted – the number of nursing home residents will indeed rise, so will the need for nursing home beds. For that reason, nursing homes should be supported to extend their functioning, so they are able to meet the needs of their residents. Nursing homes require an evolution from isolated single focus healthcare settings to comprehensive geriatric centers with a broad structure supported by a network of diverse health care teams. We must thus ask ourselves "*What can we do to stop nursing homes from evolving into just a place to die*".

Are nursing homes and their staff adapted to undergo this evolution ?

Currently, the integration of palliative care into nursing home care is very limited in some European countries. The quality of care – which is a major concern in nursing homes – is highly contingent on both staff and nursing home organization. Substantial diversity exists regarding end-of-life care in nursing homes, further implying that nursing homes may have different access to physician care or are staffed in various ways. However, nursing homes and countries also face many of the same challenges: a lack of (well-educated) staff, time and financial resources in combination with high rates of staff turnover, competing priorities of staff and scarce training opportunities. Further, according to a previous PACE study on staff knowledge, palliative care knowledge of nurses and care assistants in nursing homes appeared inadequate in various European countries. It is clear that nursing home resources did not follow the change in population. After all, to be able to provide palliative care to nursing home residents, staff require a certain level of equipment and understanding of the basic principles of palliative care. We found that nurses and care assistants in European nursing homes differ considerably in the extent to which they agree with the basic principles of palliative care. Nevertheless, there is room for improvement in all six countries; a quarter of the nursing home staff still perceived palliative care as "terminal care" that starts in the last week of life, which means that most nursing home staff disagree or are not familiar with the essence of what palliative care entails. A lack of understanding of the meaning of palliative care may have negative implications for the quality of care for residents with serious conditions. We concluded that education and training are important factors playing a role in the different palliative care approaches.

To even out the differences in staff knowledge between countries and nursing homes, it is important to first assure the presence of certain basic organizational structures in each nursing home. However, we found that the organization of palliative care had several areas for concern; mainly regarding limited availability and access to specialist palliative care support in all countries and the low availability of opioids in Poland. Poland, Finland and Italy appeared to have more areas for improvement of palliative care organization than Belgium, England and the Netherlands, where basic palliative care requirements were better guaranteed. We concluded that staff qualification and the organization of palliative care in nursing homes remains an international challenge. Within the field of palliative care, today's focus remains mainly on hospitals, hospices and home care. Even regarding medical care and resident wellbeing, the nursing home setting is still underinvested. Better palliative care information and education for staff and policy investment regarding basic organizational structures are a first step in preparing nursing homes and their staff for the necessary evolution towards a more comprehensive palliative care approach in nursing homes.

INAPPROPRIATE TREATMENTS AND HOSPITALISATIONS AT THE END OF LIFE

A general focus on treatment in nursing homes

The difficulty of predicting death in older people complicates the decision on whether a treatment is still appropriate. Certain treatments, medications and transfers are potentially inappropriate when administered to older people at the end of life. Although sometimes needed, they come with a number of drawbacks, in particular to those with dementia and to those living in nursing homes, and should therefore be carefully considered or avoided if possible when there is no strong clinical indication for them.

We found that many potentially inappropriate treatments – artificial ventilation, resuscitation, blood transfusions, chemotherapy or radiotherapy, dialysis and surgery – were rarely used in the last week of life of nursing home residents. However, antibiotics were frequently administered in all six countries (10% – 40%). The percentage of residents receiving at least one potentially inappropriate treatment in the last week of life was highest in Poland. The use of antibiotics and artificial nutrition and/or hydration was common in Poland and Italy – in particular the administration of artificial fluids – even so in residents with advanced dementia. Besides treatments that are administered in the nursing home, transfers out of the nursing home into hospitals are potentially inappropriate at the end of life. We found that up to a quarter of the residents was hospitalized in the last month of life and between 6% and 19% of the residents died in-hospital. Residents were more likely to be hospitalized in the last month of life if they had a better health status and staff were more inclined to transfer residents to a hospital if they assumed he or she was not dying. Physicians and nurses were the ones who usually requested the last hospital admission and indicated that the main reason for the last admission to the hospital for residents who eventually died in-hospital was ‘a sudden onset or exacerbation of symptoms’ or ‘a life-threatening situation’. Both hospitalization and in-hospital deaths were more likely if the conversation about care preferences between the nurse and a relative did not take place. Also, hospitalizations were more likely if no written advance directive with regard to ‘do not transfer to hospital’ was drawn up. Remarkably, not having an advance directive was not associated with in-hospital deaths. These findings imply that although staff involvement and understanding of the residents’ preferences have a strong influence on in-hospital death of nursing home residents, having an advance directive appears not to be the most important factor contributing to in-hospital deaths. Also, even if the resident prefers not to be transferred to the hospital, nursing home staff need to feel equipped to provide the care that is required, making hospitalizations sometimes needed with the purpose of guaranteeing quality of care. This indicates that in acute situations, very complex decision-making takes place during which resident preferences have to be weighed against what is possible in terms of care in the nursing home.

Need for a less cure–oriented, less hospital–centric policy?

Our study demonstrated that legislation, care policy and care culture play a major role in appropriateness of end-of-life care for nursing home residents. In particular, in Poland and Italy, advance care planning is not as highly incorporated in the care culture compared to the other countries, which we associated with a cultural taboo about death that still prevails in those countries, nursing home staff often feeling incompetent to start an end-of-life conversation and more difficulties in recognizing the terminal phase. Treatment decisions at the end of life remain therefore often undiscussed, which could lead relatives making these decisions on their own and pressuring staff to administer all possible treatments.

In Belgium – the land with the highest hospitalization rate – family physicians are usually expected to coordinate the care at the end of life of their patients, which would make them essential in avoiding hospitalizations in the last month of life. However, many relatives request hospitalization without consulting the physician. In the Netherlands – the land with the lowest hospitalization rates and in-hospital deaths – nursing home care is managed by the elderly care physician in the nursing home instead, following a health care model that is less hospital-centric. Furthermore, in the Netherlands – where discontinuing life-prolonging medical treatments is an accepted practice and quality of life is considered an important aspect in end-of-life decisions – residents more often have a palliative care goal on the day of death. In combination with these studies, our findings suggest that in the Netherlands, close attention is paid to end-of-life discussions and ensuring nursing home residents can die where they reside.

TOWARDS A COMPREHENSIVE PALLIATIVE CARE APPROACH IN NURSING HOMES ?

To evaluate the effectiveness of the PACE ‘Steps to Success Programme’ – a multicomponent six-steps programme that aimed to integrate basic non-specialist palliative care in nursing homes in seven countries: Belgium, England, Finland, Italy, the Netherlands, Poland and Switzerland – a cluster randomized clinical trial (RCT) was conducted. The RCT revealed that the PACE programme did not improve comfort in the last week of life. The secondary resident outcome - quality of care in the last month of life – did improve significantly. The improvement in quality of care was most visible in the QOD-LTC subscale ‘*preparatory tasks*’, which led us to hypothesize that the advance care planning step of the programme (step one) resulted in a conversational change regarding end-of-life decisions in nursing homes. To explore whether the improved care planning that resulted from the PACE programme also had an effect on hospitalizations in the last month of life and on place of death, we conducted a secondary analysis. Even though avoiding hospital transfers was not a distinct step of the programme, the issue was addressed as part of the intervention in step one – where preferences for treatment and place of death were discussed – and step five, which focused on the organization of care during the final days of life in the nursing home. We hypothesized that the increase in quality of care in the last month of life we found in the main study and the staff training from step one and five could have affected place of death and hospitalizations in the last month of life in terms of emergency department visits, hospital admissions, and length of hospital stay following admission. Contrary to our hypothesis, the secondary analysis did not find a statistically significant effect of the PACE programme on any of the three hospital-related outcomes or place of death.

A PACE study that assessed the cost-effectiveness of the PACE Steps to Success programme did find substantial medical cost savings after the intervention, mainly due to lower hospitalization-related costs – a decrease of approximately 1000€ – resulting from the difference in length of stay in the hospital. The study concluded that the PACE programme resulted in residents returning to the nursing home earlier, indicating that the programme might have prevented extended hospitalizations and that its integration into nursing home care could be cost-effective. There was still room for improvement regarding the number of hospitalizations.

For the absence of the expected effects of the PACE programme we give multiple possible explanations.

To start with, the various components of the programme could have been mismatched with the primary resident outcome —comfort in the last week of life. The six steps targeted the whole trajectory a resident followed, from admission to death. Only one of these steps (step five) focused on care in the last days of life and was only implemented at the end of the programme, at month seven. In addition, the programme was more oriented towards symptom assessment than towards actual treatment of the end-of-life symptoms. Involving physicians or specialist palliative care services might be necessary to improve comfort at the end of life.

When a trial fails, one must not only question the effectiveness of the programme itself, but also the implementation, the setting – who conducted it, who received it, how was it introduced and delivered. Especially in health care interventions, lack of effect could rather be due to the system than the intervention per se. The PACE programme could have been too complex, including to many components that were implemented during only one year, making the implementation substandard in certain nursing homes. Even though we culturally adapted the intervention and allowed modifications of some intervention materials to make them practical and fitting to each context, the programme could have been too standard to guarantee best execution in all nursing homes, preventing adequate adaptation of the components to the local nursing home context. The process evaluation (not part of this PhD) indicated a low implementation rate for 5.4% of the nursing homes, a medium implementation rate for 64.9% of the nursing homes and a high implementation rate for 29.7% of the nursing homes. They suggested that characteristics of the PACE coordinators and trainers or country-specific challenges – working hours, constant reorganizations, large staff numbers, staff expectations and attitudes and cultural taboos – may have resulted in a lower programme fidelity.

With regard to the secondary analysis, even though the PACE programme did contain various care elements these may not have been sufficiently aimed at actually preventing hospitalizations in the last month of life. In particular, the programme had an insufficient focus on when to involve physicians or specialist palliative care services and lacked clinical or pharmacologic guidelines on the actual treatment of dying symptoms. For residents with complex care needs, involving specialist palliative care services is however often needed. Further, although family members were included as important stakeholders throughout the programme (in particular in step one and five) they may have been not targeted well or systematically enough. When acute medical conditions occur in a nursing home, relatives have a tendency to request for hospitalization with or without consultation of nursing home staff, often out of fear for impending death.

The results of the PACE trial highlight once again the challenge of affecting resident outcomes in palliative research, in particular in the complex setting that is a nursing home. During the implementation of a complex nursing home intervention, the nursing home context must be factored in. In fact, it strongly impacts how nursing homes adopt innovative programmes, regardless of their specific target or focus. It remains a question mark which palliative care model is the most favorable and what time and place are optimal for its implementation.

6 IMPLICATIONS FOR PRACTICE, POLICY AND FUTURE RESEARCH

IMPLICATIONS FOR PRACTICE

A first important recommendation for all nursing homes in Europe is to bring about a cultural shift regarding palliative care: it is important recognize and promote palliative care as an adequate and necessary care approach. Therefore, we recommend nursing homes to integrate palliative care models earlier in the disease trajectory with seamless transitions to specialized care if appropriate. This might help to guarantee cost-efficient and timely access to high-quality care for all nursing home residents during the entire disease process. To integrate palliative care into nursing home care, different care components need attention. First, nursing homes are encouraged to pay more attention to advance care planning as this may help residents to express their care goals and preferences. Second, we indicate the need for managing acute changes in symptoms before they worsen and would otherwise require hospital stays or burdensome treatments. We recommend nursing homes to (1) enable end-of-life discussions between nursing home staff, residents and their relatives and (2) pay closer attention to the last days of life, for example through a treatment plan for when end-of-life symptoms occur. Third, repeated courses for all staff on palliative care are important areas of improvement and can facilitate the implementation of the abovementioned recommendations. Palliative care initiatives such as the PACE 'Steps to Success Programme' can help addressing these different care components and can raise awareness on palliative care in nursing home staff. Such initiatives need to allow sufficient flexibility and tailoring to the local cultural and nursing home context during implementation, they need to be specific and targeted enough and properly involve all important stakeholders in the nursing home: residents, staff, physicians, specialist palliative care services and relatives. To make the implementation of palliative care initiatives in nursing homes more feasible, we emphasize three steps of implementation. First of all, certain conditions, e.g. organizational readiness, must be ensured before an intervention can be introduced. Second, palliative care and advance care practice must be embedded in the routine, day-to-day practice, for which the PACE Steps or other materials can be used. Third, if the intervention is not incorporated into day-to-day practice, improvements may disappear over time after implementation. As a health care provider or nursing home director it will be important to continue education and find ways to embed palliative care as a culture in the nursing home, in a sustainable way.

IMPLICATIONS FOR POLICY

The results of this dissertation can be used by policy and other decision-makers to develop public health policies and interventions to improve the development of adequate palliative care in nursing homes and allow the exchange of good practices across national borders and across (types of) nursing homes. We highlight the need for a health care policy that ensures equal access to palliative care for all healthcare settings, for all residents, with detailed information on minimal equipment that should be available in nursing homes and the financial resources needed to provide it. We also recommend that policies addressing this sector highlight the need for the integration of high-quality palliative care together with high-quality dementia care, enabling nursing homes to become centers of excellence in dementia palliative care. Policies supporting these nursing homes to integrate a palliative care approach may bring substantial benefit to the sector. It will be important for policymakers to develop – in collaboration with the palliative and nursing home sector – a plan for effective scale-up of palliative care in nursing homes. Further, more and better education and training is needed to promote the better understanding of palliative care and to encourage its timely use for nursing home residents. Especially considering the various complex health problems of nursing home residents, education should be a high public health priority. Potentially inappropriate end-of-life procedures require particular attention, especially in light of the current policy in some countries. Substantial country differences call for the development of international guidelines to assist nursing home staff and physicians in treatment decision-making, while taking into account cultural differences, and in recognizing the terminal phase. Finally, quality measures and nursing home regulations should incorporate parameters regarding the end-of-life and palliative care of nursing home residents.

IMPLICATIONS FOR FUTURE RESEARCH

We must continue to invest in thorough and accurate research that supports nursing home residents to live their final months and years with comfort and dignity. This dissertation illustrated that treatments in the last month of life of nursing home residents greatly differ between countries. For many treatments, international guidelines do not yet exist. More research is thus needed to guide the administration of treatments at the end of life of nursing home residents. Furthermore, despite the challenges of conducting palliative care research in the complex environment of nursing homes, it is essential that we carry on trying to improve resident-centered palliative care and end-of-life outcomes in this setting. Therefore, we must persist in assessing different palliative care interventions in nursing homes. In future interventions, we could investigate whether a more targeted intervention specifically aimed at improving outcomes in the last week of life i.e. improving comfort while dying while preventing unnecessary end-of-life hospitalizations, could have a better outcome than the PACE trial. Such interventions would however also need to focus on the whole nursing home context. In terms of evaluation methods, randomized clinical trials (RCT) are invaluable in this research area as they are necessary to provide high-quality causal evidence. However, it is important to recognize the added value of other complementary evaluation designs. Future studies should examine the longer-term effects and sustainability of palliative care interventions in nursing homes. Observational representative studies that monitor care processes and outcomes over the longer term, combining quantitative with qualitative data, will provide important information on how nursing homes are evolving. Finally, future trials should consider how to ensure a closer fit between the intervention and outcome measures. This might be realized by not only thinking forward in terms of identifying the outcomes (i.e. what will be hope to achieve) but also thinking backward – a process called backward outcome mapping – to consider whether the outcome of interest is solely influenced by the intervention or whether other intervention components are needed to achieve the outcome.

NEDERLANDSE SAMENVATTING

1 SITUERING

VERGRIJZING EN ZIEKTE BIJ DE OUDERE BEVOLKING

Samen met bevolkingsgroei, internationale migratie en verstedelijking is vergrijzing een van de vier megatrends van de huidige wereldbevolking. Tot voor kort was de bevolkingsgroep van 65 jaar en ouder kleiner dan de groep van kinderen onder de vijf jaar. Momenteel keert deze verhouding om, en dat terwijl de vruchtbaarheidscijfers dalen. Dit zal ons in de unieke positie brengen dat we in een wereld leven met meer oudere dan jongere mensen, een wereld waarin de levensduur van de mensheid zal blijven toenemen. De groep van 85 jaar en ouder, aangeduid als *de oudsten*, zal de grootste percentuele toename vertonen. De verschuiving in de levensverwachting gaat gepaard met een verandering in de belangrijkste oorzaken van ziekte en dood, als gevolg van een epidemiologische overgang. Hoewel een langere levensduur ook kan leiden tot meer activiteit en een langere bijdrage aan de samenleving en de economie - mits ondersteuning van de omgeving (cfr. Active ageing) - zullen chronische en degeneratieve ziekten, die gekenmerkt worden door een slepend en dynamisch ziektetraject, de kop opsteken. Daarom zal langdurige zorg in woonzorgcentra en andere woonomgevingen een belangrijke rol spelen in de zorg voor ouderen. Een belangrijke uitdaging voor de huidige bevolking is het bieden van hoogwaardige palliatieve zorg voor iedereen die deze nodig heeft, ongeacht leeftijd, setting of ziekte.

PALLIATIEVE ZORG VOOR BEWONERS VAN WOONZORGCENTRA

Palliatieve zorg wordt door de Wereldgezondheidsorganisatie gedefinieerd als "een aanpak die de kwaliteit van leven van patiënten en hun families die geconfronteerd worden met een levensbedreigende ziekte verbetert, door het voorkomen en verlichten van lijden door middel van vroegtijdige opsporing en een correcte beoordeling en behandeling van pijn en andere problemen, fysiek, psychosociaal en spiritueel". In het verleden werd palliatieve zorg vooral verleend aan kankerpatiënten in een hospicesetting. Echter, door het lange ziektetraject bij ouderen vandaag, kunnen velen van hen op elk moment van hun ziekte baat hebben bij palliatieve zorg, en niet alleen in de terminale fase. Omdat woonzorgcentra steeds belangrijkere zorgomgevingen voor ouderen worden, bevinden deze centra zich in de unieke positie om algemene palliatieve zorg te leveren. Het palliatieve zorgbeleid schiet echter vaak tekort als het gaat om deze setting.

Op dit moment komt bijna 40% van de mensen van 65 jaar en ouder in een woonzorgcentrum te overlijden (vooral in ontwikkelde landen), en dit percentage zal naar verwachting in de komende jaren toenemen. Decennialang werden sterfgevallen in woonzorgcentra beschouwd als een negatief gevolg van onvoldoende palliatieve zorg, iets wat vermeden moest worden. De laatste jaren tonen cijfers echter dat steeds meer bewoners zich al in de laatste levensfase bevinden als ze een woonzorgcentrum binnenkomen, waarbij achteruitgang en sterfte onvermijdelijk zijn. Zij hebben vaak een gevorderde leeftijd, met meerdere chronische ziekten en met een zwakke functionele status. De zorg moet daarom worden aangepast aan de kenmerken en complexe zorgbehoeften van de rusthuisbewoners. Dit zou betekenen dat er steeds meer personeel nodig is om te voldoen aan de behoeften van een groep die wordt beschouwd als 'aan het eind van het leven', met name de laatste jaren of maanden van het leven.

Eerdere studies toonden aan dat de kwaliteit van palliatieve zorg en de kwaliteit van het sterven in Europese woonzorgcentra niet optimaal is en dat de basiskennis van het verplegend personeel met betrekking tot palliatieve zorgkwesties gebrekkig is. Er zijn echter nog steeds enkele onbeantwoorde vragen over palliatieve zorg in woonzorgcentra. Ten eerste is er vanuit epidemiologisch standpunt een gebrek aan hoogwaardige, representatieve, sociaal-demografische en klinische gegevens over stervende rusthuisbewoners. Ook is de houding van verpleegkundigen en zorgassistenten uit Europese woonzorgcentra ten opzichte van palliatieve zorg vrij onbekend, maar desondanks belangrijk om educatieve initiatieven in deze sector te informeren. Voorts zijn er momenteel geen gegevens beschikbaar voor beleidsmakers over de mate waarin belangrijke organisatorische structuren voor het leveren van kwaliteitsvolle, hoogwaardige palliatieve zorg aanwezig zijn in verschillende EU-landen. Dergelijke kennis zou, met name door het vergelijken van verschillende landen, relevant zijn voor zowel nationale beleidsmakers als voor de directie van woonzorgcentra of overkoepelende organisaties, aangezien dit mogelijkheden biedt om van elkaar te leren en te verbeteren waar nodig, bijvoorbeeld op vlak van beslissingen over voldoende middelen en personeel.

POTENTIEEL ONGEWENSTE BEHANDELINGEN IN WOONZORGCENTRA

De zorg is vandaag de dag nog vaak gericht op de ziekte zelf, wat leidt tot een langdurige curatieve behandeling tijdens het ziektetraject, en is minder gericht op de bewoner zelf noch op palliatieve zorg. De uitdaging om te voorspellen wanneer een oudere persoon zal sterven, bemoeilijkt de beslissing over de geschiktheid van een behandeling en het al dan niet toedienen van die behandeling. Bepaalde behandelingen worden als potentieel ongewenst beschouwd wanneer ze aan het einde van het leven worden gegeven aan oudere mensen met co-morbiditeit en moeten dus voorzichtig worden overwogen. Voorbeelden van deze behandelingen zijn: kunstmatige voeding- en vochtbehandelingen, antimicrobiële behandelingen, bepaalde medicijnen zoals statines, kritische zorgbehandelingen zoals reanimatie of chirurgie, en behandelingen zoals chemotherapie. Om meer patiëntgerichte palliatieve zorg te kunnen bieden, is het cruciaal om eerst de prevalentie van die behandelingen in woonzorgcentra in verschillende landen te onderzoeken. Een ander struikelpunt op de weg naar hoogwaardige palliatieve zorg voor rusthuisbewoners zijn de ziekenhuisopnames aan het levenseinde en het grote aantal bewoners dat in het ziekenhuis overlijdt. Ziekenhuisopnames aan het levenseinde worden beschouwd als mogelijk nadelig voor bewoners, zijn vaak in strijd met de zorgvoorkeuren en het comfort van de bewoner, en brengen hoge kosten en negatieve risico's met zich mee. De instroom van ouderen met complexe zorgbehoeften in het ziekenhuis vraagt om adequate palliatieve zorg in deze setting. De plaats van overlijden wordt gezien als een kwaliteitsindicator voor palliatieve zorg, waarmee onder andere ongewenste sterfgevallen in het ziekenhuis kunnen worden voorkomen en rekening wordt gehouden met de wens van de bewoner om thuis te sterven. Het merendeel van de onderzoeken naar ziekenhuisopnames aan het levenseinde van rusthuisbewoners is dan ook in de eerste plaats gericht op de plaats van overlijden, terwijl andere factoren in verband met ziekenhuisopnames weinig worden onderzocht. We komen tekort aan representatieve en internationaal vergelijkende gegevens over potentieel ongewenste behandelingen, ziekenhuisopnames en de plaats van overlijden. Het bestuderen van de internationale variatie in deze behandelingen aan het levenseinde kan leiden tot representatieve gegevens en nuttige informatie voor de ontwikkeling van een palliatief zorgbeleid en interventies gericht op de behoeften van rusthuisbewoners, hun familieleden en de gehele maatschappij.

EEN EUROPESE KIJK OP PALLIATIEVE ZORG IN WOONZORGCENTRA

Het beleid rond palliatieve zorg en gezondheidszorg verschilt sterk van land tot land, waardoor er grote verschillen zijn in de kwaliteit van de palliatieve zorg in woonzorgcentra. Naast verschillen in nationaal beleid, kunnen ook cultuur en geloofsovertuigingen worden beschouwd als drempels voor de toediening van adequate palliatieve zorg. Europese representatieve en vergelijkende studies over de palliatieve zorgpraktijk in woonzorgcentra zijn dan ook van cruciaal belang. Internationale gegevens kunnen beleidsmakers immers in staat stellen om inzicht te krijgen in de belangrijkste vraagstukken van de rusthuispopulatie. Deze gegevens werpen licht op nationale en internationale uitdagingen en kunnen beleidsmakers helpen bij het creëren van hypothesen over de organisatie van de palliatieve zorg. Eerdere studies hebben de verschillende Europese beleidslijnen, diensten en initiatieven op het gebied van palliatieve zorg in kaart gebracht. Ze toonden aan dat de ontwikkeling en implementatie van palliatieve zorg in veel Europese landen beperkt was, dat palliatieve zorg te laat wordt geïnitieerd en dat, hoewel de kwaliteit van de zorg aan het levenseinde en de kwaliteit van het sterven in de Europese landen verschilde, overal ruimte is voor verbetering, zelfs in landen met een sterkere ontwikkeling van palliatieve zorg in woonzorgcentra. Deze studies hebben de verscheidenheid in de palliatieve zorg, de integratie en de kwaliteit van de woonzorgcentra in de Europese landen in kaart gebracht alsook de moeilijkheden die deze landen nog moeten overwinnen. Er is een duidelijke behoefte aan verbetering van de palliatieve zorg in deze setting.

INITIATIEVEN OM PALLIATIEVE ZORG IN WOONZORGCENTRA TE VERBETEREN

Wetenschappelijk onderbouwde initiatieven om palliatieve zorg in woonzorgcentra in Europa te verbeteren zijn beperkt en meestal gericht op één zorgaspect, bijvoorbeeld wilsverklaringen. Uit onderzoek is echter gebleken dat een daadwerkelijke verandering van de zorg een alomvattende aanpak vereist, gericht op specifieke werkpunten. Er zijn slechts enkele grootschalige interventies uitgevoerd. Uit evaluatiestudies van deze interventies is gebleken dat ze niet volstaan om de palliatieve zorg te verbeteren. Deze interventies kunnen echter nuttig zijn om de tekortkomingen in de ontwikkeling van succesvolle palliatieve zorginterventies voor woonzorgcentra bloot te leggen. Naast het gebrek aan effectieve interventies zijn kwaliteitsvolle studies die de bestaande interventies evalueren schaars, vaak als gevolg van methodologische zwaktes of mankementen in de interventies zelf. Het is duidelijk dat er behoefte is aan onderzoek naar initiatieven om de palliatieve zorg in Europese woonzorgcentra te verbeteren. Met het oog hierop, is het PACE ‘Steps to Success Programme' ontwikkeld. Het programma is gericht op het verbeteren van hoogwaardige palliatieve zorg voor alle rusthuisbewoners in Europa, door het bevorderen van organisatorische veranderingen en het ondersteunen van het personeel bij het ontwikkelen van hun rol als palliatieve zorgverlener. De interventie duurde 12 maanden in de deelnemende woonzorgcentra en werd geëvalueerd in een gerandomiseerd klinisch onderzoek (RCT) dat de impact van het programma bestudeerde. De RCT vergeleek het effect van het programma met de normale zorg aan de hand van uitkomsten op niveau van bewoners en familie, kennis en houding van het personeel, kwaliteit van de palliatieve zorg, kwaliteit van het sterven en kosteneffectiviteit.

2 ONDERZOEKSDOELEN

DEEL I beschrijft de kenmerken van de palliatieve zorg in woonzorgcentra in België, Engeland, Finland, Italië, Nederland en Polen en vergelijkt deze kenmerken tussen de zes landen. **DEEL II** bestudeert de prevalentie van potentieel ongewenste behandelingen en ziekenhuisopnames aan het levenseinde van rusthuisbewoners in België, Engeland, Finland, Italië, Nederland en Polen en onderzoekt de verschillen in prevalentie tussen de zes landen. **DEEL III** evalueert het effect van een palliatief zorgprogramma voor woonzorgcentra in België, Engeland, Finland, Italië, Nederland, Polen en Zwitserland aan de hand van uitkomsten op niveau van bewoners en personeel en aan de hand van ziekenhuisopnames.

3 METHODOLOGIE

PACE is een Europees gefinancierd project (Seventh Framework Programme van de Europese Unie, 2014-2019) dat palliatieve zorg voor ouderen in woonzorgcentra in Europese landen vergelijkt en tot doel heeft beleidsmakers te adviseren over optimale palliatieve zorgpraktijken.

Voor dit proefschrift wordt gebruikt gemaakt van twee studies: PACE study I en PACE study II.

PACE study I is een cross-sectionele studie die woonzorgcentra in zes Europese landen – België, het Verenigd Koninkrijk, Finland, Italië, Nederland en Polen – beschrijft en vergelijkt op vlak van bewonersuitkomsten, kwaliteit, kosten en structuren van de palliatieve zorg en de kennis en houding van het personeel ten opzichte van palliatieve zorg, en die de relatie tussen deze structuren, processen en uitkomsten analyseert. PACE study II omvat een cluster-gerandomiseerde klinische trial (2015-2017) in verschillende woonzorgcentra in België, Engeland, Finland, Italië, Nederland, Polen en Zwitserland om het PACE 'Steps to Success Programme' te vergelijken met normale zorg. Het PACE 'Steps to Success Programme' is een multi-component interventieprogramma om niet-gespecialiseerde, basis palliatieve zorg in woonzorgcentra te integreren. Met behulp van een train-de-trainer aanpak ondersteunt een externe trainer het personeel in de woonzorgcentra bij het introduceren van een palliatieve zorgaanpak gedurende een jaar aan de hand van een zes-stappenprogramma. In beide onderzoeken rapporteren de deelnemende woonzorgcentra in elk land elk sterfgeval dat zich in de voorafgaande maanden onder de bewoners heeft voorgedaan. Voor elke geïdentificeerde overledene zijn gestructureerde vragenlijsten gestuurd naar de belangrijkste respondenten: de manager van het woonzorgcentrum, de verpleegkundige die het meest betrokken is bij de zorg (bij voorkeur een verpleegkundige) en de behandelende arts (een huisarts, geriater of een arts die in het woonzorgcentrum werkt). Voor elk deelnemend woonzorgcentrum is de manager ook gevraagd een vragenlijst in te vullen over de kenmerken van het woonzorgcentrum.

4 SAMENVATTING VAN DE BELANGRIJKSTE BEVINDINGEN

PALLIATIEVE ZORG IN WOONZORGCENTRA IN EUROPA

We stelden vast dat rusthuisbewoners vandaag de dag op zeer hoge leeftijd sterven, gemiddeld rond de 85 jaar, behalve in Polen waar de gemiddelde leeftijd op het moment van overlijden 81 jaar was (Hoofdstuk 1). Het percentage bewoners dat in het woonzorgcentrum overleed telt 80% in Polen, 82% in Engeland en België, 85% in Finland, 87% in Italië en 89% in Nederland. Een groot deel van de bewoners leed aan co-morbiditeit aan het levenseinde (47% - 74%) en ten minste 60% had de diagnose dementie op het moment van overlijden, vaak in een zeer ernstig of vergevorderd stadium. Klinische complicaties tijdens de laatste levensmaand kwamen vaak voor en bestonden voornamelijk uit eet- of drinkproblemen (51.9% in Engeland; 66.4% in Finland en Polen). De gemiddelde duur van het verblijf in het woonzorgcentrum was in alle landen relatief kort en varieerde tussen zes maanden in Polen en Italië en twee jaar in België. Het hoogste aantal bewoners met een zwakke cognitieve en functionele status één maand voor het overlijden vonden we in Polen en Italië, waar de bewoners ook de kortste verblijfsduur hadden. In alle landen zagen we een grote heterogeniteit in de mate waarin verpleegkundigen en zorgassistenten het eens waren met de basisprincipes van palliatieve zorg – gemeten met de Rotterdamse Move2PC-vragenlijst – maar met ruimte voor verbetering in alle landen (Hoofdstuk 2). Het zorgpersoneel in Engeland was het vaker eens met de principes, terwijl ze het in Italië en Polen minder vaak eens waren met de principes dan in de andere landen. De mate van overeenstemming hing sterk samen met het land, de leeftijd, de professionele functie en de formele opleiding. Oudere medewerkers hadden een hogere score voor overeenstemming dan jongere medewerkers, evenals verpleegkundigen in vergelijking met zorgassistenten en medewerkers die een opleiding in de palliatieve zorg hadden gevolgd in vergelijking met medewerkers die dat niet hadden gedaan. Tenslotte, identificeerden we verschillende verbeterpunten voor de organisatie van de palliatieve zorg in woonzorgcentra in de zes Europese landen, met behulp van de structurele IMPACT indicatoren van palliatieve zorg (hoofdstuk 3). Toegewijde palliatieve zorgfuncties, gespecialiseerde palliatieve zorgteams en een toegewezen contactpersoon die regelmatig contact onderhoudt met de bewoner en familieleden waren in de meeste landen, met name in Finland en Polen, vaak niet structureel ingebed in de organisatie van het woonzorgcentrum. In Finland, Italië en Polen toonden woonzorgcentra weinig beschikbaarheid van gespecialiseerd advies voor professionals in de palliatieve zorg. De beschikbaarheid van opioïden was beperkt in woonzorgcentra in Polen. Bijna alle structurele indicatoren voor de kwaliteit van palliatieve zorg verschilden aanzienlijk tussen de landen.

POTENTIEEL ONGEWENSTE BEHANDELINGEN EN HOSPITALISATIES AAN HET LEVENSEINDE

Kunstmatige beademing, reanimatie, bloedtransfusies, chemotherapie en radiotherapie, dialyse en chirurgie werden zelden gebruikt in de laatste levensweek van rusthuisbewoners in de meesten van de bestudeerde landen (Hoofdstuk 4). De prevalentie van de meeste behandelingen verschilde echter statistisch significant tussen de landen. Polen had het hoogste percentage bewoners die in de laatste levensweek ten minste één potentieel ongewenste behandeling kregen. Kunstmatige toegediende voeding en/of vochttoediening waren gangbare praktijken in Polen en Italië, met name het toedienen van kunstmatige vloeistoffen, zelfs bij bewoners met gevorderde dementie. Antibiotica werden vaak toegediend in alle landen, zij het met de hoogste percentages in Polen en Italië, en antidiabetica werden het vaakst toegediend in Polen. Bovendien bleek uit onze resultaten dat tussen 12% (Italië) en 26% (België) van de bewoners in de laatste levensmaand in het ziekenhuis werd opgenomen – met 16% in Nederland, 22% in Finland, 23% in Engeland en 25% in Polen – waarbij de meesten van deze bewoners slechts één keer werden opgenomen (Hoofdstuk 5). Er was minder kans op ziekenhuisopnames indien bewoners een wilsverklaring hadden met betrekking tot ‘niet hospitaliseren’ en als de verpleegkundige met een familielid sprak over de voorkeuren rond medische behandelingen en het verloop van de zorg. De beschikbaarheid van de arts in de laatste levensweek verminderde ook de kans op ziekenhuisopname. Het percentage van de bewoners dat in het ziekenhuis overleed was 6% in Nederland, 9% in Engeland en Finland, 13% in Italië, 18% in België en 19% in Polen. Als de bewoner uiteindelijk in het ziekenhuis overleed, was de reden voor de laatste ziekenhuisopname meestal een plotseling optreden of verergering van de symptomen of een levensbedreigende situatie. De arts en de verpleegkundige waren meestal degenen die de laatste opname aanvroegen, in Nederland was dit ook vaak op verzoek van de bewoner. Als de arts het overlijden van de bewoner verwachtte, was de kans op overlijden in het ziekenhuis kleiner. Een zwakkere functionele status ging gepaard met een verminderde kans op zowel ziekenhuisopname als op overlijden in het ziekenhuis.

EVALUATIE VAN EEN PALLIATIEF ZORGPROGRAMMA VOOR WOONZORGCENTRA IN EUROPA

We hebben het effect van het PACE-programma – een eenjarige multi-component interventie om niet-gespecialiseerde basis palliatieve zorg in woonzorgcentra te integreren – vergeleken met de normale zorg in woonzorgcentra via een cluster-gerandomiseerde klinische PACE-studie in meerdere faciliteiten in België, Engeland, Finland, Italië, Nederland, Polen en Zwitserland. We analyseerden het effect van het programma op uitkomsten op niveau van de bewoners, zoals gerapporteerd door het personeel, inclusief het comfort in de laatste levensweek (primaire bewonersuitkomst; gemeten met de EOLD-CAD), en de kwaliteit van de zorg in de laatste levensmaand (secundaire bewonersuitkomst; gemeten met de QOD-LTC). Daarnaast is onderzocht of het programma invloed had op de uitkomsten op niveau van het personeel, inclusief kennis van palliatieve zorg (primaire uitkomst personeel; gemeten met de Palliative Care Survey), zelfredzaamheid van het personeel, onderwijsbehoeften en meningen over palliatieve zorg (secundaire uitkomsten personeel; gemeten met respectievelijk de S-EOLC, de EPCS en de Rotterdam Move2PC). Het RCT toonde aan dat het PACE 'Steps to Success Programme' het comfort van de bewoners in de laatste levensweek, zoals gerapporteerd door het personeel, niet verbeterde. De resultaten duiden op een significant verschil tussen interventie- en controlegroepen omtrent kennis van het personeel over palliatieve zorg, dit verschil was echter zeer klein en waarschijnlijk niet klinisch significant. Verder verschilde de door het personeel gerapporteerde kwaliteit van de zorg voor bewoners in de laatste levensmaand aanzienlijk tussen de interventie- en controlegroepen. We ontdekten een significant verschil tussen de interventie- en controlegroepen op de QOD-LTC subschaal *voorbereidende taken*. We stelden daarom dat stap één – die focust op voorafgaande zorgplanning– resulteerde in een conversationele verandering met betrekking tot beslissingen over het levenseinde in woonzorgcentra. We veronderstelden dan ook dat de verbetering van de kwaliteit van de zorg in de laatste levensmaand die we vonden, invloed zou kunnen hebben gehad op het gebruik van het ziekenhuis en de plaats van overlijden. We hebben daarom een secundaire analyse uitgevoerd om te onderzoeken of het PACE-programma een effect had op het ziekenhuisgebruik in de laatste levensmaand van rusthuisbewoners in termen van het aantal spoedbezoeken, ziekenhuisopnames en verblijfsduur na opname, en of het programma een effect heeft op de plaats van overlijden van rusthuisbewoners. De resultaten tonen geen statistisch significant effect van het PACE-programma op de bezoeken aan de spoedafdeling, ziekenhuisopnames, de duur van het verblijf in het ziekenhuis in de laatste levensmaand of de plaats van overlijden. We vonden wel een kortere gemiddelde verblijfsduur na de interventie; dit was echter niet statistisch significant.

5 BESPREKING VAN DE BELANGRIJKSTE BEVINDINGEN

DE COMPLEXITEIT VAN PALIATIEVE ZORG IN WOONZORGCENTRA IN EUROPA: POPULATIE, PERSONEEL EN ORGANIZATIE

Evolueert het woonzorgcentrum naar "een plek om te sterven"?

Onze bevindingen bevestigen dat woonzorgcentra meer en meer plaatsen worden waar mensen aan het eind van hun leven gaan wonen als ze sterk afhankelijk zijn en complexe gezondheidsproblemen hebben, waardoor palliatieve zorg de meest geschikte zorgaanpak is om de kwaliteit van leven en sterven voor deze populatie te verbeteren gedurende het hele ziektetraject. Er zijn echter problemen bij het implementeren van een adequate palliatieve zorgaanpak die geschikt is voor alle bewoners. De uitdaging om een thuis te bieden aan langdurig inwonenden en tegelijkertijd palliatieve zorg te bieden aan kortverblijvers, heeft een grote invloed op de manier waarop palliatieve zorg wordt ontwikkeld, geleverd en ontvangen.

Aangezien steeds meer ouderen verpleegkundige zorg nodig zullen hebben in de toekomst, is de tijd gekomen om palliatieve zorg actief te promoten als de voorkeursbenadering binnen de zorg en om zich te concentreren op de integratie van palliatieve zorg in woonzorgcentra. Omdat de rusthuispopulatie evolueert naar een zwakkere en instabielere populatie, is het belangrijker om palliatieve, geriatrische en hospice zorg te verenigen dan te op te delen. De gezondheidszorg staat al enige tijd onder druk om alternatieven voor de huidige institutionele zorg te ontwikkelen, waardoor er een belangrijke verschuiving in de structuur, verantwoordelijkheid en functie van woonzorgcentra wordt verwacht. Als daarbij – zoals voorspeld – het aantal rusthuisbewoners inderdaad zal toenemen, zal ook de behoefte aan rusthuisbedden toenemen. Daarom moeten woonzorgcentra worden ondersteund bij het uitbreiden van hun functie, zodat ze in staat zijn om aan de behoeften van hun bewoners te voldoen. Woonzorgcentra vereisen een evolutie van geïsoleerde mono-centrische zorginstellingen naar uitgebreide geriatrische centra met een brede structuur die wordt ondersteund door een netwerk van diverse zorgteams. We moeten ons dus afvragen "*Wat kunnen we doen om te voorkomen dat woonzorgcentra evolueren naar een plek om te sterven*".

Zijn woonzorgcentra en hun personeel aangepast om deze evolutie te ondergaan?

Op dit moment is de integratie van palliatieve zorg in woonzorgcentra in sommige Europese landen zeer beperkt. De kwaliteit van de zorg – een belangrijk aandachtspunt in woonzorgcentra – is sterk afhankelijk van zowel het personeel als de organisatie in deze centra. Er bestaat een grote diversiteit aan levenseindezorg in woonzorgcentra, wat verder betekent dat ze sterk verschillen in toegang tot medische zorg of personeel. De zorg in de verschillende landen wordt echter ook geconfronteerd met veel van dezelfde uitdagingen: een gebrek aan (goed opgeleid) personeel, tijd en financiële middelen in combinatie met een hoog personeelsverloop, concurrerende prioriteiten van het personeel en beperkte opleidingsmogelijkheden. Verder blijkt uit een eerdere PACE-studie over personeelskennis dat de kennis van verpleegkundigen en zorgassistenten in woonzorgcentra in verschillende Europese landen onvoldoende is. Het is duidelijk dat de voorzieningen in woonzorgcentra en niet navenant de bevolkingsevolutie aangepast zijn. Immers, om palliatieve zorg aan rusthuisbewoners te kunnen verlenen, heeft het personeel bepaalde voorzieningen nodig en inzicht in de basisprincipes van de palliatieve zorg. Wij constateerden dat verpleegkundigen en zorgassistenten in Europese woonzorgcentra aanzienlijk verschillen in de mate waarin zij het eens zijn met de basisprincipes van de palliatieve zorg. Toch is er in alle zes landen ruimte voor verbetering; een kwart van het verplegend personeel ziet palliatieve zorg nog steeds als "terminale zorg" die begint in de laatste week van het leven, wat betekent dat de meeste verpleegkundigen het niet eens zijn met of niet bekend zijn met de essentie van wat palliatieve zorg inhoudt. Een gebrek aan inzicht in de betekenis van palliatieve zorg kan negatieve gevolgen hebben voor de kwaliteit van de zorg voor oudere bewoners met ernstige aandoeningen. We concluderen dat opleiding en training belangrijke factoren zijn die een rol spelen in de verschillende benaderingen van de palliatieve zorg.

Om de verschillen in personeelskennis tussen landen en woonzorgcentra te egaliseren, is het belangrijk om eerst bepaalde basisstructuren in elk woonzorgcentrum te voorzien. We stelden echter verschillende aandachtspunten vast betreffende de organisatie van palliatieve zorg; vooral met betrekking tot de beperkte beschikbaarheid en toegang tot gespecialiseerde palliatieve zorg in alle landen en de lage beschikbaarheid van opioïden in Polen. Polen, Finland en Italië bleken meer verbeterpunten te hebben aangaande de organisatie van de palliatieve zorg dan België, Engeland en Nederland, waar de basisvereisten voor palliatieve zorg beter gewaarborgd waren. We concludeerden dat de kwalificatie van het personeel en de organisatie van de palliatieve zorg in woonzorgcentra een internationale uitdaging blijft. Binnen het domein van de palliatieve zorg blijft de focus vandaag de dag vooral liggen op ziekenhuizen, hospices en thuiszorg. Ook op gebied van medische zorg en het welzijn van de bewoners is de woonzorgsetting nog steeds onderbelicht. Een betere training en opleiding van het personeel in palliatieve zorg en beleidsinvesteringen in de basisstructuren zijn een eerste stap om de woonzorgcentra en hun personeel voor te bereiden op de noodzakelijke evolutie naar een meer omvattende palliatieve zorgaanpak.

ONGEWENSTE BEHANDELINGEN EN HOSPITALISATIES AAN HET LEVENSEINDE

Een algemene focus op behandeling in woonzorgcentra

De uitdaging om dood bij ouderen te voorspellen bemoeilijkt de beslissing of een behandeling nog gepast is. Bepaalde behandelingen, medicijnen en transfers zijn mogelijks ongewenst wanneer ze aan het levenseinde aan ouderen worden toegediend. Hoewel ze soms nodig zijn, hebben ze een aantal nadelen, met name voor mensen met dementie en voor mensen die in woonzorgcentra wonen, en daarom moeten ze zorgvuldig worden overwogen of indien mogelijk worden vermeden wanneer er geen sterke klinische indicatie voor is.

We stelden vast dat veel potentieel ongewenste behandelingen – kunstmatige beademing, reanimatie, bloedtransfusies, chemotherapie of radiotherapie, dialyse en chirurgie – zelden werden voorkwamen in de laatste levensweek van de rusthuisbewoners. In alle zes landen werden echter vaak antibiotica toegediend (10% - 40%). Het percentage bewoners dat in de laatste levensweek ten minste één mogelijks ongewenste behandeling kreeg, was het hoogst in Polen. Het gebruik van antibiotica en kunstmatige voeding en/of vochttoediening was gebruikelijk in Polen en Italië – in het bijzonder het toedienen van kunstmatige vloeistoffen – zelfs bij bewoners met gevorderde dementie. Naast de behandelingen die in het woonzorgcentrum worden toegediend, zijn transfers vanuit het woonzorgcentrum naar ziekenhuizen aan het levenseinde mogelijk ongewenst. We ontdekten dat tot een kwart van de bewoners in de laatste levensmaand in het ziekenhuis werd opgenomen en dat tussen 6% en 19% van de bewoners in het ziekenhuis stierf. De bewoners werden in de laatste maand van hun leven vaker in het ziekenhuis opgenomen als ze een betere gezondheidstoestand hadden en het personeel was meer geneigd om de bewoners naar een ziekenhuis over te brengen als ze veronderstelden dat hij of zij niet stervende was. Artsen en verpleegkundigen waren degenen die meestal de aanvraag deden voor de laatste ziekenhuisopname en gaven aan dat de belangrijkste reden voor de laatste opname van bewoners die uiteindelijk in het ziekenhuis stierven 'een plotseling begin of verergering van de symptomen' of 'een levensbedreigende situatie' was. Er was meer kans op ziekenhuisopnames en overlijden in het ziekenhuis indien het gesprek over zorgvoorkeuren tussen de verpleegkundige en een familielid niet plaatsvond. Ook waren ziekenhuisopnames waarschijnlijker als er geen wilsverklaring was opgesteld met betrekking tot ‘niet hospitaliseren’. Opmerkelijk is dat het al dan niet hebben van een wilsverklaring niet geassocieerd werd met ziekenhuissterfte. Deze bevindingen impliceren dat, hoewel de betrokkenheid van het personeel en het begrip van de voorkeuren van de bewoners een sterke invloed hebben op ziekenhuissterfte, het hebben van een wilsverklaring niet de belangrijkste factor lijkt te zijn die hieraan bijdraagt. Ook al geeft de bewoner er de voorkeur aan niet naar het ziekenhuis te worden overgeplaatst, toch moet het verplegend personeel zich bekwaam voelen om de nodige zorg te verlenen, waardoor ziekenhuisopnames soms toch nodig blijken om de kwaliteit van de zorg te waarborgen. Dit wijst erop dat in acute situaties zeer complexe besluitvorming plaatsvindt waarbij de voorkeur van de bewoner moet worden afgewogen tegen wat er qua zorg in het woonzorgcentrum mogelijk is.

Nood aan een minder behandelingsgericht, minder ziekenhuis - gericht beleid?

Ons onderzoek heeft aangetoond dat wetgeving, zorgbeleid en zorgcultuur een belangrijke rol spelen bij de wenselijkheid van levenseindezorg bij rusthuisbewoners. Met name in Polen en Italië is de voorafgaande zorgplanning in vergelijking met de andere landen minder sterk geïntegreerd in de zorgcultuur. Dit associëren we met het cultureel taboe rond dood dat in die landen nog steeds heerst, waarbij het verplegend personeel zich vaak incompetent voelt om een gesprek te voeren rond levenseinde en meer moeite heeft om de terminale fase te herkennen. Behandelingsbeslissingen aan het levenseinde blijven daarom vaak onbesproken, wat ertoe kan leiden dat familieleden deze beslissingen alleen nemen en aandringen om alle mogelijke behandelingen uit te voeren.

In België – het land met het hoogste percentage ziekenhuisopnames – wordt van huisartsen meestal verwacht dat ze de levenseindezorg van hun patiënten coördineren, wat hen essentieel zou maken in het vermijden van ziekenhuisopnames in de laatste levensmaand. Veel familieleden vragen echter om opname in het ziekenhuis zonder de arts te raadplegen. In Nederland – het land met de laagste hospitalisatiecijfers en sterfgevallen in het ziekenhuis – wordt de zorg in het woonzorgcentrum opgevolgd door de geriater in het woonzorgcentrum zelf, een minder ziekenhuisgericht gezondheidsmodel. Bovendien hebben bewoners in Nederland – waar het stopzetten van levenslange medische behandelingen een geaccepteerde praktijk is en de kwaliteit van leven een belangrijk aspect is bij beslissingen over het levenseinde – vaker een palliatief zorgdoel op de dag van overlijden. In combinatie met deze studies suggereren onze bevindingen dat er in Nederland veel aandacht wordt besteed aan discussies over het levenseinde en aan de garantie dat rusthuisbewoners kunnen sterven in de huidige woonplaats.

RICHTING EEN UITGEBREIDE PALLIATIEVE ZORGAANPAK IN WOONZORGCENTRA?

Om de effectiviteit van het PACE 'Steps to Success Programme' – een multi-component zes-stappenprogramma dat gericht is op de integratie van niet-gespecialiseerde basis palliatieve zorg in woonzorgcentra in zeven landen: België, Engeland, Finland, Italië, Nederland, Polen en Zwitserland – te evalueren, werd een cluster gerandomiseerde klinische studie (RCT) uitgevoerd. Uit de RCT bleek dat het PACE-programma het comfort in de laatste week van het leven niet heeft verbeterd. De secundaire bewonersuitkomst – de kwaliteit van de zorg in de laatste levensmaand – is wel significant verbeterd. De verbetering van de kwaliteit van de zorg was het meest zichtbaar in de QOD-LTC subschaal '*voorbereidende taken*', waardoor we veronderstelden dat de voorafgaande zorgplanningsstap van het programma (stap één) resulteerde in een conversationele verandering met betrekking tot levenseindebeslissingen in woonzorgcentra. Om te onderzoeken of de verbeterde zorgplanning die voortvloeide uit het PACE-programma ook een effect had op ziekenhuisopnames in de laatste levensmaand en op de plaats van overlijden, hebben we een secundaire analyse uitgevoerd. Hoewel het vermijden van ziekenhuisopnames geen aparte stap van het programma was, beschouwden we dit als een onderdeel van de interventie in stap één – waar de voorkeuren voor behandeling en de plaats van overlijden werden besproken – en stap vijf, die zich richtte op de organisatie van de zorg tijdens de laatste levensdagen in het woonzorgcentrum. We veronderstelden dat de toename van de zorgkwaliteit in de laatste levensmaand die we vonden in het hoofdonderzoek en de training van het personeel tijdens stap één en vijf, invloed konden hebben op de plaats van overlijden en de ziekenhuisopnames in de laatste levensmaand op vlak van spoedopnames, ziekenhuisopnames en de duur van het verblijf in het ziekenhuis na de opname. In tegenstelling tot onze hypothese vond de secundaire analyse geen statistisch significant effect van het PACE-programma op een van de drie ziekenhuis-gerelateerde uitkomsten of plaats van overlijden.

In een PACE-studie die de kosteneffectiviteit van het PACE ‘Steps to Success programme’ evalueerde, werden aanzienlijke medische kostenbesparingen genoteerd na de interventie, voornamelijk door lagere ziekenhuiskosten – een daling van ongeveer 1000 euro per bewoner – als gevolg van een kortere verblijfsduur in het ziekenhuis. De conclusie van het onderzoek was dat het PACE-programma er mogelijks toe heeft geleid dat bewoners eerder naar het woonzorgcentrum zijn teruggekeerd, wat insinueert dat het programma langdurige ziekenhuisopnames heeft kunnen voorkomen en dat de integratie ervan in de woonzorgcentra kosteneffectief zou kunnen zijn. Het aantal ziekenhuisopnames was nog steeds voor verbetering vatbaar.

Voor het uitblijven van de verwachte effecten van het PACE-programma geven we meerdere mogelijke verklaringen.

Om te beginnen zouden er een discrepantie kunnen zijn tussen de verschillende onderdelen van het programma en de primaire uitkomst op niveau van de bewoners – het comfort in de laatste levensweek. De zes stappen waren gericht op het hele traject dat een bewoner doorloopt, van de opname tot overlijden. Slechts één van deze stappen (stap vijf) richtte zich op de zorg in de laatste levensdagen en werd pas aan het eind van het programma, op maand zeven, uitgevoerd. Daarnaast was het programma meer gericht op het beoordelen van de symptomen dan op de daadwerkelijke behandeling van de symptomen aan het levenseinde. Het includeren van artsen of gespecialiseerde palliatieve zorgdiensten kan nodig zijn om het comfort aan het levenseinde te verbeteren.

Wanneer een interventie faalt, moet men niet alleen de doeltreffendheid van het programma zelf in twijfel trekken, maar ook de uitvoering, de setting - wie heeft het uitgevoerd, wie heeft het ontvangen, hoe is het geïmplementeerd en afgeleverd. Vooral bij interventies in de gezondheidszorg zou het gebrek aan effect eerder te wijten kunnen zijn aan de context dan aan de interventie op zich. Het PACE-programma kan te complex zijn geweest, met te veel onderdelen om binnen de periode van een jaar uit te voeren, waardoor de implementatie in bepaalde woonzorgcentra ondermaats was. Hoewel we de interventie hebben afgestemd op de verschillende culturen en we bepaalde interventiematerialen hebben laten aanpassen om ze praktisch te maken in elke context, kan het programma te gestandaardiseerd geweest zijn om een optimale implementatie in alle woonzorgcentra te garanderen, waardoor een adequate aanpassing van de programmaonderdelen aan de lokale context niet mogelijk was. De procesevaluatie (geen onderdeel van dit doctoraat) duidde op een lage implementatiescore voor 5.4% van de woonzorgcentra, een gemiddelde implementatiescore voor 64.9% van de woonzorgcentra en een hoge implementatiescore voor 29.7% van de woonzorgcentra. Zij suggereerden dat kenmerken van de PACE-coördinatoren en -trainers of land-specifieke problemen – werktijden, constante reorganisaties, grote personeelsaantallen, personeelsverwachtingen en -attitudes en culturele taboes – mogelijk hebben geresulteerd in een zwakkere implementatie.

Wat de secundaire analyse betreft: hoewel het PACE-programma verschillende zorgelementen bevatte, waren deze misschien niet voldoende gericht op het daadwerkelijk voorkomen van ziekenhuisopnames in de laatste levensmaand. In het bijzonder was het programma onvoldoende gericht op het betrekken van artsen of gespecialiseerde palliatieve zorgdiensten en ontbrak het aan klinische of farmacologische richtlijnen voor de feitelijke behandeling van symptomen van sterven. Voor bewoners met complexe zorgnoden is het echter vaak nodig om gespecialiseerde palliatieve zorg in te schakelen. Verder is het mogelijk dat, hoewel familieleden als belangrijke factoren in het hele programma zijn opgenomen (met name in stap één en vijf), zij niet goed of niet systematisch genoeg zijn betrokken. Wanneer er sprake is van een acute medische aandoening in een woonzorgcentrum, hebben familieleden de neiging om met of zonder overleg met het verplegend personeel aan te dringen op een ziekenhuisopname, vaak uit angst voor een naderende dood.

De resultaten van de PACE-studie benadrukken nogmaals de moeilijkheid om uitkomsten op niveau van de bewoner te bepalen binnen het palliatief onderzoek, vooral gezien de complexe omgeving van een woonzorgcentrum. Bij de uitvoering van een complexe interventie moet rekening worden gehouden met de context van het woonzorgcentrum. Context heeft namelijk een sterke invloed op de manier waarop woonzorgcentra innovatieve programma's implementeren, ongeacht hun specifieke doelstelling of focus. Het blijft een vraagteken welk palliatief zorgmodel het meest gunstig is en welke tijd en plaats optimaal zijn voor de uitvoering ervan.

6 IMPLICATIES VOOR PRAKTIJK, BELEID EN TOEKOMSTIG ONDERZOEK

IMPLICATIES VOOR PRAKTIJK

Een eerste belangrijke aanbeveling voor alle woonzorgcentra in Europa is het bewerkstelligen van een culturele verschuiving op het gebied van palliatieve zorg: het is belangrijk om palliatieve zorg te erkennen en te beschouwen als een adequate en noodzakelijke zorgaanpak. Daarom raden wij woonzorgcentra aan om palliatieve zorg vroeger in het ziektetraject te integreren met naadloze overgangen naar gespecialiseerde zorg indien nodig. Dit kan bijdragen aan het garanderen van kostenefficiënte en tijdige toegang tot kwaliteitsvolle zorg voor alle rusthuisbewoners gedurende het gehele ziektetraject. Om de palliatieve zorg te integreren in de woonzorgcentra hebben verschillende zorgonderdelen aandacht nodig. Ten eerste worden woonzorgcentra aangemoedigd om meer aandacht te besteden aan voorafgaande zorgplanning, omdat dit de bewoners kan helpen om hun zorgdoelen en -voorkeuren uit te drukken. Ten tweede geven we aan dat het nodig is om acute veranderingen in de symptomen nauwgezet op te volgen voordat deze verergeren en leiden tot een hospitalisatie of een zware behandeling. We raden woonzorgcentra aan om (1) gesprekken aan het levenseinde tussen zorgpersoneel, bewoners en hun familieleden mogelijk te maken en (2) meer aandacht te besteden aan de laatste levensdagen, bijvoorbeeld door middel van een behandelplan voor het optreden van symptomen aan levenseinde. Ten derde zijn cursussen voor alle medewerkers in de palliatieve zorg een belangrijke verbeterpunt en kunnen ze de implementatie van bovengenoemde aanbevelingen vergemakkelijken. Initiatieven op het gebied van palliatieve zorg, zoals het PACE 'Steps to Success Programme', kunnen helpen om deze verschillende zorgonderdelen aan te pakken en kunnen het bewustzijn over palliatieve zorg bij het personeel in het woonzorgcentrum, maar ook bewoners en hun families vergroten. Dergelijke initiatieven moeten voldoende flexibel zijn om af te stemmen op de lokale cultuur en de context tijdens de implementatie, ze moeten specifiek en doelgericht genoeg zijn en alle belangrijke belanghebbenden in het woonzorgcentrum op de juiste manier betrekken: bewoners, personeel, artsen, gespecialiseerde palliatieve zorgdiensten en familieleden. Om de implementatie van palliatieve zorginitiatieven in woonzorgcentra beter uitvoerbaar te maken, bespreken we drie implementatiestappen. Ten eerste moet er aan bepaalde voorwaarden, zoals organisatorische gereedheid, voldaan zijn voordat een interventie kan worden ingevoerd. Ten tweede moeten palliatieve zorg en voorafgaande zorgplanning ingebed zijn in de routine, de dagelijkse praktijk, waarvoor de PACE Steps of andere materialen kunnen worden gebruikt. Ten derde, als de interventie niet wordt opgenomen in de dagelijkse praktijk, kunnen verbeteringen in de loop van de tijd, vooral na de implementatie, afnemen. Als zorgverlener of directeur zal het belangrijk zijn om de opleiding voort te zetten en manieren te vinden om de palliatieve zorg als cultuur te verankeren in het woonzorgcentrum, op een duurzame manier.

IMPLICATIES VOOR BELEID

De resultaten van dit proefschrift kunnen door beleidsmakers en andere bevoegden worden gebruikt om beleid en interventies op het gebied van de volksgezondheid te ontwikkelen, om de ontwikkeling van adequate palliatieve zorg in woonzorgcentra te verbeteren en de uitwisseling van goede praktijken over nationale grenzen en woonzorgcentra heen mogelijk te maken. We benadrukken de nood aan een gezondheidszorgbeleid dat zorgt voor gelijke toegang tot palliatieve zorg voor alle zorginstellingen, voor alle bewoners, met een gedetailleerd overzicht van de materialen die in woonzorgcentra beschikbaar zouden moeten zijn en de financiële middelen die nodig zijn om deze aan te leveren. We bevelen ook aan dat het beleid hierbij de nadruk legt op de nood aan integratie van hoogwaardige palliatieve zorg in combinatie met hoogwaardige dementiezorg, waardoor woonzorgcentra dementie-expertisecentra kunnen worden wat betreft palliatieve zorg. Het beleid dat woonzorgcentra ondersteunt om een palliatieve zorgaanpak te integreren kan de sector aanzienlijk voordeel opleveren. Het is belangrijk dat beleidsmakers – in samenwerking met de palliatieve en woonzorgsector – een plan ontwikkelen voor een effectieve uitbreiding van palliatieve zorg in woonzorgcentra. Er is meer en betere scholing en training nodig om kennis rond palliatieve zorg te bevorderen en het tijdige gebruik ervan te stimuleren. Vooral gezien de verschillende complexe gezondheidsproblemen van rusthuisbewoners zou onderwijs een hoge prioriteit moeten hebben op het gebied van de volksgezondheid. Potentieel ongewenste behandelingen aan het levenseinde vereisen bijzondere aandacht, met name met het oog op het huidige beleid in sommige landen. Aanzienlijke verschillen tussen landen vragen om de ontwikkeling van internationale richtlijnen om zorgpersoneel en artsen te helpen bij de besluitvorming over de behandeling, rekening houdend met culturele verschillen, en bij de herkenning van de terminale fase. Ten slotte moeten in de kwaliteitsindicatoren en de regelgeving voor woonzorgcentra parameters worden opgenomen met betrekking tot het levenseinde en de palliatieve zorg voor rusthuisbewoners.

IMPLICATIES VOOR TOEKOMSTIG ONDERZOEK

We moeten blijven investeren in grondig en nauwkeurig onderzoek dat de bewoners van een woonzorgcentrum ondersteunt om hun laatste maanden en jaren comfortabel en waardig door te brengen. Dit proefschrift illustreert dat de behandelingen in de laatste levensmaand bij rusthuisbewoners sterk verschillen tussen landen. Voor veel behandelingen bestaan nog geen internationale richtlijnen. Er is dus meer onderzoek nodig om de toediening van behandelingen aan het levenseind van rusthuisbewoners te begeleiden. Bovendien is het, ondanks de uitdagingen die samenhangen met de uitvoering van palliatief zorgonderzoek in de complexe omgeving van woonzorgcentra, essentieel dat we blijven proberen om de palliatieve zorg voor de bewoners en de uitkomsten rond levenseinde in deze omgeving te verbeteren. Daarom moeten we verdergaan met het evalueren van verschillende palliatieve zorginterventies in woonzorgcentra. In toekomstige interventies zouden we kunnen onderzoeken of een meer flexibele interventie die specifiek gericht is op het verbeteren van de laatste levensweek, d.w.z. het verbeteren van het comfort tijdens het sterven en het voorkomen van onnodige ziekenhuisopnames aan het einde van het leven, een betere uitkomst zou kunnen hebben dan de PACE-studie. Dergelijke interventies zouden echter ook gericht moeten zijn op de gehele woonzorgcontext. In termen van evaluatiemethoden zijn gerandomiseerde klinische studies van onschatbare waarde in dit onderzoeksgebied, omdat ze noodzakelijk zijn om kwaliteitsvol hoogstaand causaal bewijs te leveren. Het is echter belangrijk om de toegevoegde waarde van andere complementaire evaluatietechnieken te onderkennen. Toekomstige studies moeten de langetermijneffecten en de duurzaamheid van palliatieve zorginterventies in woonzorgcentra onderzoeken. Representatief observationeel onderzoek dat zorgprocessen en -uitkomsten op langere termijn opvolgt, waarbij kwantitatieve en kwalitatieve gegevens worden gecombineerd, zullen belangrijke informatie opleveren over de ontwikkeling van woonzorgcentra. Ten slotte moet in toekomstige studies worden nagegaan hoe de interventie en de uitkomstmaten beter op elkaar kunnen worden afgestemd. Dit kan worden gerealiseerd door niet alleen vooruit te denken in termen van het identificeren van de uitkomsten (d.w.z. wat men hoopt te bereiken), maar ook andersom te denken – een proces dat 'backward outcome mapping' wordt genoemd – om na te gaan of de uitkomst alleen door de interventie wordt beïnvloed of dat er andere interventiecomponenten nodig zijn om de uitkomst te bereiken.

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Elisabeth (°1994) obtained her master's degree in Clinical Psychology (KULeuven) in 2016. After she completed a second master in Neuropsychology (Maastricht University) in 2017, she started as a junior PhD researcher at the End-of-Life Care Research Group (VUB-UGent), working on the PAlliative Care for older people in nursing homes in Europe (PACE) Project. PACE is a European funded project (FP7, 2014-2019) comparing the effectiveness of palliative care for elderly people in care or nursing homes in seven European countries and aiming to advise policymakers on optimal palliative care practices. Elisabeth was supervised by Prof Dr. Tinne Smets, Prof. Dr. Ruth Piers, Prof. Dr. Lieve Van den Block and Prof. Dr. Luc Deliens. She presented her work at national and international conferences and was chosen as one of the four highest scoring oral abstracts at the World Research Congress of the European Association for Palliative Care in 2020.

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