

The End of Life in Different Healthcare Settings: Looking for a Palliative Approach

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Chapter 1

Introduction

Background

As demographics change across Europe and the population ages, increasing numbers of people will die with chronic illnesses and multiple co-morbidities ^{1, 2}. It is currently estimated that approximately two-thirds of people who die are likely to benefit from palliative care, as their deaths are not unexpected or sudden ³. However, where patients die still has a marked influence on receipt of palliative care at the end of life ⁴. Patients whose deaths can be anticipated are cared for across the full spectrum of healthcare settings, and access to palliative care across the board has the potential to best serve their diverse end-of-life care needs.

The Palliative Approach

The World Health Organisation (WHO) defines palliative care 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” ⁵. This definition can cover care delivered in any setting, and delivered by any combination of generalist and specialist carers and professionals. Specific goals of palliative care, according to the WHO guidance, includes a number of aims – medical, practical and psychosocial, which come together to indicate a broad idea of what the palliative approach should deliver for patients and families. In practice, this can be signalled in a number of ways, including the cessation of certain active treatments, a shift in the aim of treatment and an increased concentration on psychosocial and spiritual care ^{6, 7, 8}. As palliative and

end-of-life care has developed as a specific care approach, both inside and outside of the hospice setting, the range of terms used to refer to this type of care has also grown^{9, 10}. There is considerable variation between how terms are used, and the type of care that they refer to¹¹. In this thesis, “palliative care” and “the palliative approach” are used to refer to a structured approach based on symptom palliation regardless of physical setting. The European Association for Palliative Care estimates that at any given time there are over 600,000 patients who would benefit from specialist palliative care across Europe.

Development of the Palliative Approach

Palliative care as a movement developed from inpatient hospice facilities. The catalyst for the modern development of palliative care came from the establishment of St Christopher’s Hospice in southeast London¹². St Christopher’s was built to marry a total-institutional philosophy encompassing medical, psychosocial and spiritual care of dying patients with scientific advances in pain and symptom control. Now, the palliative care movement has diversified from the inpatient hospice model pioneered by Cicely Saunders, and hospice-type care can be found across many settings¹³.

Palliative care has developed differently between countries as the discipline has grown, and reflects the structure of different healthcare systems and incorporates relevant societal norms related to ideas of care and of death¹⁴. In some countries the emphasis has been on developing standalone palliative care facilities, whilst in others integrating palliative care into hospitals, nursing homes and home care services has taken priority¹⁵.

Across Europe, many models of palliative care exist, thus defining and assessing palliative care and the differences between settings can be difficult.

Institutional Settings of Care

This thesis will first explore care as delivered in the inpatient setting in comparison with other environments where people commonly die - such as hospitals, nursing homes and homes. There is considerable variation across countries and regions as to the specific definitions and make-up of different models of care, but institutional settings generally fit into the three variations detailed below:

Inpatient Hospice Facilities

The concept of hospice has been developing since the 15th century, when the word was used to refer to a place of care for travellers on religious pilgrimages who were not expected to survive their journey. Over time this concept has developed to refer to a place of care where the focus was on relief of symptoms, and not cure. The modern hospice movement was pioneered by Cicely Saunders' research from the 1950's onwards; culminating in the creation of St Christopher's Hospice in Sydenham, London in 1967¹². Across Europe, up to 10% of deaths occur in the inpatient hospice setting - though there is significant variation in this rate between countries¹⁶.

Inpatient hospice care has diversified since the establishment of St Christopher's, and can be used as a term to refer to many different types of

care across countries and across settings. Many inpatient hospices now provide respite or temporary care through day clinics and other initiatives, as well as different models of inpatient care. Though inpatient hospice care is widely available across much of Europe, the accessibility of inpatient hospice care has been questioned. Inpatient hospices were first developed to care for cancer patients, and this bias is still reflected in inpatient hospice populations across Europe ¹⁷.

Throughout this thesis, the phrases “inpatient hospice care” and “inpatient hospice facilities” will be used to refer to end-of-life care institutions that exist as physically defined specialist facilities for end-of-life care. With regards to the three models of hospice in the Netherlands; “standalone hospice” will refer to the medically-focussed hospices staffed by physicians and nurses, “palliative care units” will refer to specific units embedded in nursing homes and “bijna-thuis-huizen” refers to volunteer-staffed care-focused hospices with peripatetic medical and nursing staff.

Hospitals

Hospitals provide a diverse range of treatment, from acute care to outpatient clinics and referral services. Hospitals have traditionally been focused on curative medicine, and this can affect the way in which palliative care is delivered and experienced by patients and their families ¹⁸. Between 33%-63% of predictable deaths across Europe currently happen in the hospital setting, however as an environment that largely exists for curative or life-prolonging care dying in hospital may be perceived as a failure of continuing care as opposed to an expected outcome ¹⁹. A number of initiatives including care pathways and guidelines have been developed to

better integrate palliative care into the acute hospital setting, though there are significant institutional cultural barriers to the use of such tools and interventions even when they are readily available^{20, 21}.

Residential and Nursing Homes

As the population across Europe ages, the need for residential and nursing homes will increase. The percentage of people living with chronic illness and multi-morbidities will require both medical and psychosocial attention – suggesting an increase in need for comprehensive care facilities in this model². Broad et al. recorded 12% of deaths worldwide as taking place in residential or nursing homes²².

The level of palliative care provided by nursing homes can differ substantially between institutions and between countries, with some having staff or schemes with a specialist palliative care status but others operating on a strictly generalist basis.

Aims and Objectives

This thesis aims to explore the ways in which palliative care varies according to the setting that it is delivered in, with particular regard to differences between care in inpatient hospice facilities and non-hospice settings. In order to thoroughly investigate the diversity of end of life care, it is important to identify the dimensions of difference between different models with the aim of helping care be better directed towards the populations that it must serve.

The thesis explores these subjects using a variety of existing data sources. The structure of the thesis will take two parts, with complementary research aims, methodologies and questions.

Part I

The main aim of part one is to compare inpatient hospice facilities to other palliative care settings by investigating end-of-life care across different settings, and analysing the differences in care received and populations admitted. Specific objectives include:

- a) Investigating the philosophy of inpatient hospice facilities through physical space and social organisation.
- b) Assessing and comparing the palliative approach in hospital and inpatient hospice facilities by looking at drugs and procedures administered during the last three days of life, and investigating the role played by patient characteristics.
- c) Investigating characteristics of end-of-life care delivered in four settings, in terms of the type of patients in different settings, differences in process of care and in end-of-life decisions.

Part II

Part two will concentrate specifically on the Dutch inpatient hospice setting, with a primary aim of investigating the differences between who applies and who is admitted to inpatient hospice care, and then focusing on the specifics of care received in inpatient hospices. Specifically, this will be achieved through:

- d) Investigating the differences between populations who are admitted to inpatient hospice care or not following application, and how the spread of diagnoses and characteristics of people who apply for care in inpatient hospice facilities compares to the general end of life population.
- e) Studying patients who are admitted to each of the three types of Dutch inpatient hospice facilities and comparing patient characteristics and process of care between settings.
- f) Comparing patient characteristics and processes for patients admitted to inpatient hospice care with the three most-common diseases at the end of life.

Methods

For part I three different studies were performed, with inpatient hospice care as a comparator to other common end-of-life settings. The methods used were varied, in order to provide a broad scope of investigation.

Objective a - Qualitative Analysis

To investigate the development of the philosophy of inpatient hospice care as a distinct model, we performed a qualitative study utilising data from the Cicely Saunders archive at King's College London – a repository of published works, notes, pictures and slides collected and produced by Cicely Saunders throughout her life and archived after her death. The archive comprises 81 boxes of archived material.

Analysis was undertaken using a grounded-theory influenced approach. Themes were isolated and assessed iteratively to explore the philosophy of St Christopher's Hospice and its design and development. The analysis focussed on considerations concerning the physical environment of the institution during the development phase and, in particular, how the environment should differ from that of a conventional hospital.

Objective b - The Liverpool Care Pathway Cluster Controlled Trial

In order to compare care delivered in inpatient hospice facilities and in hospital, we used baseline data from the cluster-controlled trial of a modified version of the Liverpool Care Pathway for the Dying Patient across Italy. The study population consisted of patients in 16 hospital general-medicine wards (n= 145) and five inpatient hospice facilities (n= 127) across a number of regions within Italy. At baseline, patients in all general-medicine wards received standard generalist end-of-life care.

Nursing staff affiliated with the research team recorded data via retrospective medical chart review using a standardised form after the death of the patient. The form recorded all drugs administered and procedures undertaken during the patient's final three days of life, or part thereof. Information was demarcated into three different time points during the stay of the patient to give an indication of administration and usage patterns longitudinally, and information concerning the demographic characteristics of patients and the characteristics of their final stay was also recorded on the standardised form.

Objective c – The Dutch Death Certificates Database

To investigate care delivered across four common end-of-life settings, we used data gathered through a nationwide survey of death certificates in the Netherlands in 2010 (n = 5448). Deaths were separated into five strata based on cause of death and whether end-of-life decision-making could have been made before death.

Questionnaires were then sent out to all attending physicians of deaths. Patient demographics and the cause of death were recorded from the municipal registries. The questionnaire then explored characteristics of the end of life including care characteristics – such as a palliative treatment aim, hospitalisation history and the involvement of different health professionals in the final month of life – and end-of-life decisions were recorded.

Objectives d, e and f - IKNL hospice database

Part II is focussed on the Dutch inpatient hospice setting, and variances in admission and care within this. Information from a database of patients who applied for inpatient hospice care between 2007 – 2012 (n= 10254) was used. The database is managed by the comprehensive cancer center of the Netherlands (IKNL) and represents ~25% of hospices in the Netherlands.

Healthcare professionals recorded data on demographic and application characteristics of all patients applying for care, and characteristics of care received by those who were subsequently admitted.

Data were then compared to the main diagnosis of all persons in the Netherlands who died non-suddenly by utilising data from a previous national death certificate study.

This database was first used to study differences in the whole population for those who were admitted and not following application, and then split into more specific populations who represented the three main disease groups cared for – namely cancer, heart failure and lung disease - and patients who were admitted into each of the three models of inpatient hospice care in the Netherlands.

Content Outline

Chapter 2

Keep all thee 'til the end – reclaiming the lifeworld for patients in the hospice setting

An investigation of how inpatient hospice facilities developed, with particular emphasis on the physical space and social organisation of St Christopher's Hospice in London – widely considered to be the first modern inpatient hospice.

Chapter 3

A comparison of drugs and procedures of care in the Italian hospice and hospital settings: the final three days of life for cancer patients

An analysis of how often potentially appropriate and inappropriate drugs and procedures are given in inpatient hospice facilities and in hospitals; and whether they are stopped, started or maintained throughout the patient's final three days of life.

Chapter 4

Characteristics of the end of life in four settings in the Netherlands: care and decisions

Investigating the characteristics of end-of-life care and populations delivered across four settings in the Netherlands – hospital, inpatient hospice facility, home and nursing home.

Chapter 5

Hospice care in the Netherlands: who applies and who is admitted to inpatient care?

An analysis of the differences between populations who are admitted or not following application to inpatient hospice care, and how diagnoses compare to the population at large.

Chapter 6

Does hospice care vary for patients admitted to the three types of inpatient hospice facility in the Netherlands?

An investigation of differences in sociodemographic and disease characteristics between patients who are admitted to three types of

inpatient hospice facility in the Netherlands, and a comparison of care received in each setting.

Chapter 7

Does hospice care vary between patients with cancer, heart failure and lung disease?

An assessment of the differences in admittance between patients with cancer, heart failure and lung disease – the three most numerous groups cared for in inpatient hospice facilities in the Netherlands – and the differences in care received following admittance to inpatient care.

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Part One

“If man is shaped by his environment, his environment must be made human.”

Karl Marx and Friedrich Engels

Chapter 2

“Keep all thee ‘til the end”: Reclaiming the lifeworld for patients in the hospice setting

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Abstract

Background: St Christopher's Hospice, London was founded to provide specialist care to the incurably ill.

Aim: We studied the dimensions of difference that set St Christopher's Hospice apart from hospital care of the dying, focusing on physical space and social organisation.

Design: Material (notes from meetings, speeches and reports) from 1953 - 1980 from the Cicely Saunders Archive was analysed qualitatively. Of 81 boxes, 31 with information on considerations of the physical environment of St Christopher's Hospice were selected. Through thematic analysis, quotes were found and analysed using open coding.

Results: Five themes were developed by EW, and corroborated with HRWP and BP. Data were gathered from 15 of 31 boxes. Themes emerged from the analysis, linking physical/social space with the philosophy of palliative care. Next to the overarching theme "home/homelike" these were: "community": *"We have planned wards rather than single rooms, for we want there to be a community life for the patients."* "consideration of others": *"relatives might be enabled to stay and carry out quite extensive care for the patient."* "link with outside world": *"Good public transport and a feeling of openness to the world outside are chief among the needs of any unit for terminal care."* "privacy": *"Space is planned for a change of scene for the patients, for silence and privacy."*

Conclusion: The hospice philosophy functioned as the catalyst for the development of the physical environment of St Christopher's Hospice. Taking Habermas' concept of lifeworld it seems that, in contrast to acute care, the need for inpatient hospice facilities to formulate their own lifeworld to support and fully engage patients was central. As lifeworlds are culture-sensitive, this underlines the need for variation in design and organization of inpatient hospice facilities across the world.

Background

The word hospice has its root in the Latin “hospes”, used initially to describe both the giving and receiving of hospitality. “Hospice” first appeared in usage in the 15th century to indicate a place of rest for pilgrims, many of whom were not expected to survive their travels. Over time this idea developed to indicate a place for the long term ill and dying - with a focus on care as opposed to cure ¹.

Cicely Saunders was a nurse, social worker and then physician in England who is widely accepted to be the founder of the modern inpatient hospice movement. In 1967, she founded St Christopher’s Hospice in South East London, after having gained experience caring for the dying at St Joseph’s Hospice in Hackney and St Luke’s Home for the Dying Poor ². Saunders identified a need for an institution in South East London, both where care under this philosophy could take place, and where the scientific study of the care of the dying could be furthered – an opportunity not available in the existing institutions of the time. She had learnt about the use of morphine whilst working at St Joseph’s, and this was an avenue of study that she was keen to explore further.

St Christopher’s Hospice was intended as a place that would provide specialist care to those suffering from incurable illnesses with sensitivity to the needs of these patients and their families in a wider sense. Much of the philosophy of what a palliative care institution should be like was developed from the idea of total pain, as explored in Saunders’ early work. This idea recognises that pain is not only a physiological experience, but encompasses spiritual, psychological and social dimensions and St

Christopher's Hospice was developed with careful consideration to this philosophy³.

From the very beginning, St Christopher's Hospice set out to develop a different way of dying for its patients, and to spread this new philosophy of death in inpatient hospice facilities. As palliative care has developed as a speciality it has become integrated into many different care environments with differing organisational structures and physical properties. The general philosophy developed by Cicely Saunders has been taken and adapted to the environments – fiscal, political and structural – that different health systems operate within, but the concentration on shaping the patient experience through a distinct physical setting has not always been considered a vital part of this care.

In his historical analysis, Clark⁴ identifies that the space of St Christopher's Hospice, and how people could interact within the institution was quite different to the hospitals of the time. The institution was developed as a “home from home”, and the community and environment was seen to be a very important part of this philosophy.

With this paper, we aim to investigate the dimensions of difference that set St Christopher's Hospice apart from hospital care of the dying, and reflect the philosophy of modern inpatient hospice care through physical space and social organisation.

By identifying the reasoning behind the original aim to differentiate the environment of St Christopher's Hospice from the general hospitals that

existed at the time we can explore the roots of the philosophy of palliative care and discuss this in light of how care is delivered in different settings.

Methods

A qualitative thematic analysis was undertaken on material from the Cicely Saunders Archive held at King's College London, focusing on considerations of the development of the physical environment of St Christopher's Hospice.

This study utilised data from the Cicely Saunders archive at King's College London. The archive consists of published works and notes, pictures, slides and photographs kept by Cicely Saunders throughout her life and archived after her death. The scope of the archive echoes the full scope of Saunders' work – from the development of her interests in how best to care for the dying medically through to legal and publicity documents surrounding the construction and continued running of St Christopher's Hospice. The archive consists of 81 boxes which are categorised according to time period, material type, topic and geographic area. The time range of data available in the archive was 1953 – 2005. Material took the form of manuscript notes, transcripts of oral presentations, letters and notebooks – for example, notes from meetings with architects and oral presentations to potential benefactors of the hospice.

Selection

Selection of boxes

For this study, data from up to 1980 were selected from the full archive. This was to keep the focus on the development phase of St Christopher's Hospice. To focus the data geographically, only boxes that were labelled "UK" were chosen for analysis. This resulted in thirty-one boxes being selected.

Of these 31 boxes, a selection was made based on their title and description, and selection was based around the themes of "development" "environment" "philosophy" "need" and "aim". A broad selection strategy was used at this stage in order to include anything potentially relevant. After selection, fifteen of the thirty-one boxes were found to contain relevant information.

Selection of material within boxes

Material concerning the environment of St Christopher's Hospice was gathered from documents - environment was parsed as both the physical construction of the building and interior spaces, and the organisation of time and people inside of it. Material that corresponded to these themes were gathered and recorded in a single document. This selection process was done by two researchers (EW and HRWP)

Analysis

An iterative process was used to define themes and extract data from the full range of material available. Quotes found were analysed to generate themes using open coding⁵. Quotes gathered came from both formal and informal source material – the majority being from letters, notes for speeches or meetings and preparation for published pieces. As themes emerged, data were grouped accordingly. Groups were then analysed and, in cases, combined to form strong categories with ample data in each. Themes and validity of data were corroborated throughout by EW and HRWP.

Results

Five themes emerged from the analysis of recurring text motifs – (1) home/homelike – which served as an overarching theme, of which - (2) link with outside world (3) consideration of others (4) community/normality (5) privacy were sub-specifications.

Home/homelike

An often-recurring theme identified during analysis was that of the environment of St Christopher's Hospice being compared to a "home" environment. It was very clear that this was considered to be different to the care environment provided in a hospital, and was often posited to be the direct opposite to "home" - *"It has to replace home as well as hospital and the buildings should be designed with this in mind"* (Box 1/3/2/87; from a 1964 oral presentation). The idea of the care environment reflecting that of a home was seen to be beneficial for the patients for their wider

psychosocial care; *"We believe that it is essential that these people should be welcomed into some kind of community that can replace their homes"*(Box 1/2/86, from typed document "St Christopher's Hospice", date unspecified). This was noted as being an inspiration taken from some smaller hospitals that existed at the time and were perceived to be good providers of care for those at the end of life- *"By and large, the most enthusiastic supporters of hospitalisation were those doctors with access to a GP or local cottage hospital - described by one as a "home from home" for patients and their families"* (Box 1/1/42, Notes from reading "Narphen Promotional Studies" 1969).

Time and control was also explored within this theme; with comments on regulation and rigidity with regards to both planning; *"It is planned as something between a hospital and a home - combining the skills of one with the warmth and welcome, the time available and the beds without invisible parking meters beside them that belong to the other"* (Box 1/2/9, draft of "St Christopher's Brochure, 1964/5) and, in a more abstract sense, as part of the philosophical aims of the institution - *"This time that can be so hard or so dreary will be changed into one of peace, security and meaning, a sort of homecoming"*(Box 1/2/9, draft of "St Christopher's Brochure, 1964/5). This was then developed for the St Christopher's Hospice "Aims and Basis" document to reflect the medical focus of the institution as well as its religious founding; *" 'Hospice' means a 'house of rest for travellers' a 'stopping place for pilgrims'. It means something between a hospital and a home"* (Box 1/2/9, draft of "St Christopher's Brochure, 1964/5). "Homelike" proved to be a major influence on the other

themes, all of which reflect and amplify certain specific elements of this idea.

Community

In notes there was a great deal of thought on creating a community feel, and the idea of new bounds of normality was at the forefront of planning. This theme also incorporates quotes that were gathered under “normality”, as these generally addressed the feeling that patients should be able to feel “normal” in St Christopher’s Hospice, regardless of diagnosis or illness stage. This was taken to be key in creating the “community” of St Christopher’s Hospice, and so was combined to create a cohesive and well-populated theme.

At the time that St Christopher’s Hospice was being developed, patients with terminal illnesses were considered to be outside the remit of acute care hospitals and could find that they faced isolation from staff who considered them to be beyond help; “[...]a general ward is rarely the right place for them. The sight of them may frighten and depress others, and they become miserable as they see their neighbours improving while their own hopes are continually deferred. They are often correct in thinking that doctors pass by the end of their bed and leave them alone with their questioning. It is not the answer to put up screens or curtains.” (Box 1/2/5, Notes “The Management of Patients in the Terminal Stage”, between 1960-66).

The recognition of particular needs of terminal patients thus greatly influenced the planning of the community element of St Christopher’s

Hospice; *"There is great strength to be gained in the community of suffering and where patients are wisely placed they are often able to help one another"* (Box 1/2/30, Notes "The Need", between 1960-67). / *"We have planned wards rather than single rooms for we want there to be a community life for the patients. Man is a social being and he needs to see life going on, to have ordinary social talk and to see the world from his window, however ill he is"* (Box 1/2/9, draft of "St Christopher's Brochure", 1964/5).

This was reflected in notes concerning the design of inpatient hospice facilities with sensitivity to medical requirements – *"The emphasis was placed on the ability to retain normal relationships without in any way compromising on the need for continuous and, where necessary, intensive care of the patient"* (Box 1/1/42, Notes from reading "Narphen Promotional Studies" 1969)- and ideas surrounding socialising and activities within the facility; *"This is almost certainly the last place in which a patient will live and he should be able to sit or go out, wander around and enjoy his family and suitable activity as long as he can and as he wishes"* (Box 1/3/2/87; from a 1964 oral presentation). Different facets of how such normal relationships may be maintained were extensively considered in planning notes - *"For the body: we strive for growing understanding and expertise in symptom control, for due regard to appearance and self esteem...Resources are available to enable the dying person to live until he dies, at his own maximum potential, performing to the limit of his physical activity and mental capacity, with control and independence wherever possible"* (Box 1/3/2/87, notes for "Pamphlet – Spiritual Pain, between 1959-88).

Consideration of others

The role of relatives and friends was considered in planning St Christopher's Hospice from the very beginning. Planning documents discussed enabling and even encouraging the inclusion of informal caregivers in the day-to-day life of the facility, a contrast to the very hierarchical hospital system; "*Relatives might be enabled to stay and carry out quite extensive care for the patient (comparable to the admission of a mother with her child)*" (Box 1/2/30, Notes "The Need", between 1960-67). Their role was reflected in thinking about the physical space of the facility, the way in which time would be organised and even the impetus for developing such an institution; "*While it is important that most people should remain at home as long as possible and true that many families will manage to take charge if the situation most adequately, it is evident that many are staying when they already need skilled institutional care, and that one of the main reasons for this is lack of proper accommodation*" (Box 1/2/30, Notes "The Need", between 1960-67).

The recognition of the involvement of friends and relatives even as a possibility shows a marked difference in philosophy from hospital care. That this would affect spatial planning influenced decisions surrounding space between beds in wards and numbers of beds per ward or unit "*Some way of drawing the relatives into the patient's care may be found, and this may affect planning*"(Box 1/3/2/87, Notes from "The Need for Institutional Care for the Patient with Advanced Cancer", 1964)

It was recognised very early in the planning process that the facility would, therefore, have to provide a support structure for families, carers and other

visitors. This included such measures as instigating a “no visiting day” to allow visitors to take time off for respite; *“We might keep one day free each week so that relations have no conscience at having a ‘day off’ ”* (Box 1/2/30, Notes “Family Wing”, between 1960-67). However, it was noted that this and other rules should never be so inflexible that they should have negative effects on visitors – *“Mollie’s brother was over from Holland in a Monday [non visiting day] he was welcomed as on any other day, given lunch and allowed to stay as long as he wanted. This was typical of how there were rules and no rules”*. (Box 1/3/2/87, Notes from “Motor Neurone Disease in a Hospice, 1981)

Link with outside world

The idea of the inpatient hospice facility providing a link to the outside world was prevalent in the archive material. This was often related to the idea of a “homelike” environment, in contrast to hospitals. The physical construction of the building was the main concern within this theme, and in particular providing an environment where even bed-bound patients would not feel isolated from day-to-day activities or the world outside of St Christopher’s Hospice. In some cases this was as simple as planning the layout of the wards; *“Terminal Unit of about 60 beds: These would be planned in three wards of about 20 each. There would be a ward of 16 beds, possibly divided by half glass screens into two six-bedded cubicles, and one with four beds, all planned so that patients can see the life of the world outside and yet not have the light directly in their eyes”* (Box 1/2/30, Notes “The Need”, between 1960-67). More abstract concerns were also addressed to take into account the needs of those accessing the facility as ambulatory patients or visitors, and thus providing the fluid contact with the

outside world; *“Good public transport and a feeling of openness to the world outside are chief among the needs of any unit for terminal or long term care”* (Box 1/3/2/87, Notes from “A Philosophy of Terminal Care, between 1959-88). This reflected a fundamental concern found in many iterations throughout the archive notes; the consideration of the patient within the social realm - *“We would like to remember the original emphasis and that the care given by a Hospice was very much a part of life”*(Box 1/2/9, draft of “St Christopher’s Brochure, 1964/5).

Privacy

Though community and activity was an important concern in developing the workings of St Christopher’s Hospice, so too was privacy. This was mostly explored through notes concerning the physical characteristics of the wards in terms of size and layout; *“Space is planned for a change of scene for the patients, for silence and for privacy. Beds can be pushed right up to the bay windows with their splendid view”* (Box 1/2/9, draft of “St Christopher’s Brochure, 1964/5). This is then taken further to apply to other spaces within the facility away from the bedside; *“Emphasis should be given to the need for spaces for private talk; these must be found”* (Box 1/3/2/87, Notes from “A Philosophy of Terminal Care, between 1959-88). As well as spatial considerations, thought was given to the wider idea of dignity and what is acceptable within the social arena; *“Preservation of the patient’s dignity and self-respect, with privacy, are essential to all, but especially to him whose illness subjects him to humiliating experiences. Bed curtains are absolutely necessary but are not soundproof, and can seldom be drawn by the patient himself whenever he wants to”* (Box 1/2/95, Notes from a letter to Nursing Times, 1965) / *“The rest of the beds should be in single rooms so that other*

patients need not see anyone dying in the ward, and so that those who love and need privacy may have it" (Box 1/2/30, Notes "Family Wing", between 1960-67).

Discussion

The carefully controlled structure of medical clinics has long been recognised as being intrinsic to the ability to treat – to allow patients to relinquish their outside social role and become subject to treatments, therapies and examinations ⁶. The construction of healthcare spaces has a distinct effect on patient care, and this has recognised repercussions in shaping the intended patient experience. Hospitals are recognised as being a form of Foucauldian heterotopia; housing those who are considered to be deviant within "normal" society ⁷. If hospitals are heterotopias that house the bodily unwell, who are temporarily excluded from normal social life whilst cure is pursued, then inpatient hospice facilities take this further still and act as a heterotopia for the hospital population in housing those who will not be cured.

Philipsen ⁸ highlights the difference in need between patients who require sustained continuity of care for chronic conditions and those accessing acute medical care for diagnosis and short term treatment when considering environment and its effects. Taking Habermas' concept of the lifeworld, Philipsen differentiates between those who engage with an acute medical system, that does not seek to replace or alter the lifeworld of the patient and the type of long term chronic care that needs to formulate its own lifeworld in order to support and fully engage the patients within its care. This can be seen as an extension of the idea of heterotopia – the

separation of patient populations allows the construction of a different type of lifeworld.

In the case of St Christopher's Hospice this closely echoes that of Philipsen's concept of the chronic illness lifeworld. The construction of St Christopher's Hospice and the themes represented within the analysis illustrate the different needs of patients at the end of life and how this is reflected through the institution's physical space. This creation of a new type of lifeworld reflected the social tenet of the concept of total pain⁹ by enabling "as full as possible" patient participation in the social sphere.

The same needs and processes are reflected in similarly total institutions. Oosterveld-Vlug¹⁰ explores the concept of dignity as experienced by patients in Dutch nursing homes. Such institutions also serve the long-term and end-of-life patient population, and have similarly developed lifeworlds specific to these needs. Societal engagement is posited to be an integral part of maintaining dignity in this enclosed and dependent environment, and this included relationships with formal caregivers as well as within the patient population.

An acknowledgement of, and drive to incorporate, the need for facilities such as quiet rooms to spend time with families after a diagnosis or bereavement is increasingly found not only in inpatient hospice facilities but also general hospitals. Increasingly, facilities for longer-term visitors are also found and are constructed to mimic the scale and function of domestic homes¹¹. The modern patient with a terminal illness is likely to receive treatment and advice from a number of settings – hospital clinics, informal advice centres, respite or day care at an inpatient hospice facility – and this

adoption of Saunders' environmental values across institutions allows continuation of the chronic or terminal illness lifeworld beyond the boundaries of any one given institution.

Inpatient hospice facilities today do not operate solely for the dying. Patients may use an inpatient hospice facility for defined periods of respite or symptom control before returning home or to another care institution, or may visit regularly as a day patient but never occupy the space as an inpatient. Whilst the patients overall level of exposure to a given environment is lessened in these circumstances, the need for the institution to provide a structure in which the patient can occupy their role as patient does not change. Disease specific centres such as the Maggie's Cancer Centres initiative ¹² – which provide a space that is separate from hospital facilities to explore information or seek help informally for patients – incorporate many of Saunders' ideas that an inpatient hospice facility should reflect the home environment, but are used only on an outpatient basis.

In recent years, the preference when building new facilities has been for single rooms with en-suite bathroom facilities, and separation from admission has been seen as a positive experience. Worpole ¹¹ highlights the reflection of consumer culture through these cellular environments, where each patient and their family are able to control the temperature, light and airflow within their territory – an idea very much linked to ideas of life and autonomy. However there remains, in facilities that are not solely comprised of single rooms, the fear that a patient enters a single room to die. When a patient has spent the dying phase in a shared space, but is

removed to die, death is posited as something to be feared ¹³ – the meaning of separation, and when it occurs in the dying process.

A 2011 systematic review concerning the environment of elderly adults who die as inpatients ¹⁴ identified similar themes of interest – namely privacy as needed, proximity (physically/emotionally to loved ones, home and nature), satisfaction with the physical environment and deficiencies with the physical environment from a selection of ten articles. Several included articles stressed the undesirability of large, old-fashioned “nightingale wards” with many inhabitants, but there were also positive comments on small-scale shared rooms, which helped to maintain a sense of the social self. Rowlands and Noble ¹⁵ found that patients with advanced cancer appreciated a mix of single rooms and four-bedded cubicles depending on changing needs over time, and Oosterveld-Vlug ¹⁰ found that frail elderly patients in shared rooms reported feeling more secure than when they stayed alone.

Conclusion

An institution of healthcare as a system is universalistic, and by nature directed to a high degree of instrumental rationality. As a lifeworld, an inpatient hospice facility is particularistic by nature – creating expressive personal relations within a framework of home and belonging. These processes are reflected in cultural frameworks and differences, and lead to unique environments in inpatient hospice facilities across the world. In general it must be noted that in the planning of inpatient hospice care in different countries and cultures, lifeworld characteristics vary more from one situation to another than the system characteristics.

Concerns about the environment of inpatient hospice facilities have been instrumental in the evolution of palliative care. The physical environment signifies much wider concerns about patients. For St Christopher's Hospice, the ideas of total pain and holistic care functioned as the catalyst for the development of the physical space of the institution. Contemporary patient experience is still very much linked to how an environment is constructed that creates this type of lifeworld, even as the location and function of palliative care continues to evolve, and St Christopher's Hospice provided important groundwork for the continued development of the palliative approach as a model of care.

Saunders' original concerns and ideas surrounding suitable environments for terminally ill patients have been developed and adapted to fit today's more flexible culture of care between institutions, but certain modern foci – such as the growing move towards providing single rooms ¹⁶ – represent a fundamental departure from the way that St Christopher's was designed to deal with the dying patient. This may be a reflection of modern society - a nod towards the consumer-led, customisable culture of current society, but the impact of separating dying patients further must continue to be assessed within the scope of the holistic dying experience.

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Chapter 3

A comparison of drugs and procedures of care in the Italian hospice and hospital settings: the final three days of life for cancer patients

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Abstract

Background: A palliative approach at the end of life typically involves forgoing certain drugs and procedures and starting others - weighing burden against potential benefit. An assessment of the palliative approach may be undertaken by investigating which drugs and procedures are used in the dying phase, and at what frequencies.

Methods: Drugs were classified as potentially (in)appropriate based on expert classification. Procedures were classed as therapeutic or diagnostic. 271 consecutive cancer deaths from across 16 hospital general wards and 5 inpatient hospice facilities in Italy gathered data on drugs and procedures in the final three days of life through a standardised form. Differences between the two groups were tested using chi-square testing, and logistic regressions were performed to control for patient characteristics.

Results: 75.0% of patients in hospital received 3 or more potentially inappropriate drugs in their last three days of life, against 42.6% in inpatient hospice facilities. Diagnostic procedures were carried out more frequently in hospital. Multivariate logistic regression showed that when data were controlled for patient characteristics, setting had a unique contribution to the differences found in use of drugs and procedures.

Conclusion: The data indicates a need for improvement in the hospital setting concerning recognising the need for palliative care, and ensuring a timely introduction of this approach.

Introduction

Palliative care is vital to optimise both patients and caregivers' wellbeing in advanced stages of disease ¹. End of life care can be delivered in many settings, from the traditional inpatient hospice facility to care delivered at home or in hospital. The inpatient hospice model of care was initially developed to cater exclusively to the palliative approach, whereas hospital has typically been focused on curative medicine. This can particularly affect the dying phase of those cared for in hospital, as well as their families ^{2,3}. The majority of deaths in Europe occur in the hospital setting ⁴, and this rate is expected to rise in light of changing demographics ⁵. Thus it is important to assess the extent to which the palliative care approach is taken in different settings.

One way of looking at the palliative care approach might be to assess drugs and procedures received by patients in the dying phase. The palliative approach typically involves forgoing certain drugs and procedures, and initiating others, when burden is weighed against potential benefit in the remaining lifetime of the patient ^{6,7,8}. A change of routes of administration may also be considered in this phase, as patients' tolerance of swallowing medications, for example, lessens. However, there is no strong consensus on what drugs or procedures may be appropriate or inappropriate at the end of life. Recently a start has been made for drugs by Raijmakers et al ⁹, who surveyed an international cross-section of palliative care experts and created a list of drugs deemed to be potentially appropriate or inappropriate for use at the end of life.

Judging the potential appropriateness of procedures is less certain, but dichotomising procedures into “therapeutic” or “diagnostic” can be helpful. Coackley and Ellershaw ¹⁰ highlight blood tests and measurement of vital signs as potentially inappropriate procedures for patients in the final days of life. This might then be extrapolated to include other procedures with diagnostic or investigative aims, rather than procedures aimed at the alleviation of symptoms. For therapeutic procedures, assessing appropriateness is more difficult still. Treatments that can be curative at another point in the disease trajectory may acquire a palliative intent – for example the use of radiotherapy to alleviate pain.

Studies comparing care given in inpatient hospice facilities and hospitals are scarce and generally do not include assessment of process of care ¹¹, ¹². In this study we therefore aim to assess and compare the palliative approach in hospitals and inpatient hospice facilities by looking at drugs and procedures administered during the last three days of life. The aims of this study are to investigate how often potentially appropriate and inappropriate drugs are administered in the final three days of life in inpatient hospice facilities and in hospitals; whether drugs administered in the last three days of life are given continuously, stopped or started; how often diagnostic and therapeutic procedures are used in the final three days of life in inpatient hospice facilities and in hospitals. Finally, a multivariate analysis was performed to study the association between use of drugs and procedures and setting after adjusting for patient characteristics.

Methods

Design and Population

This study utilises data gathered at baseline of a cluster-controlled trial, which introduced a modified version of the Liverpool Care Pathway for the Dying Patient in 16 hospital general-medicine wards and 5 inpatient hospice facilities across different regions in Italy ¹³. At baseline, patients in general medicine wards received standard end-of-life generalist care. Data were collected through a retrospective chart review by nursing staff affiliated with the research team. Data were collected using a standardised form, completed from the patient's medical records after death. Data were gathered concerning the final three days of life, as this is the scope of the Liverpool Care Pathway as an intervention.

351 consecutive deaths in the study wards and inpatient hospice facilities during a three-month data collection period formed the study population. Deaths were excluded if the patient was a relative of a member of staff, or if the cause of death recorded was not cancer. One patient was excluded from this analysis due to no values for drugs or procedural data being recorded. This resulted in 271 patients for whom the data on drugs and procedures were complete, 144 hospital patients and 127 inpatient hospice facility residents.

Measurement Instrument

The registration form recorded all drugs administered and procedures (therapeutic and diagnostic) undertaken in the final three days of life. Drugs were grouped into categories organised by classification of type of drug.

Data were entered as “Yes” or “No” for each category of drugs or type of procedure listed on the form for three different time points - covering the final three days of life, or part thereof, spent as an inpatient. Data on the demographic information of patients, and information concerning the final stay in hospital was also collected through the standardised form.

Ethics

The hospital cluster trial ¹⁴ received ethical approval from the Ethics Committee of the National Cancer Research Institute of Genoa (Italy) on September 14th 2009 (Reference: CCP09.001) and subsequently from the six Local Ethical Committees where the hospitals were allocated. The inpatient hospice facility cluster trial received ethical approval from the Ethics Committee of the National Cancer Research Institute of Genoa (Italy) on July 5th 2010 (Reference: CCP10.001) and subsequently from the four Local Ethical Committees where the inpatient hospice facilities were allocated.

Analysis

The study population was dichotomised into inpatient hospice facility and hospital patients. Differences between the two groups were tested using chi-square testing, Fisher’s exact test was used on cells where the expected value in cells was lower than 5. Drugs were classified as potentially inappropriate or potentially appropriate for end-of-life care based on the classification from expert opinions described by Raijmakers et al ⁹. Procedures were classed as either diagnostic or therapeutic.

To assess whether drugs that were administered were given continuously, stopped or started in the final three days of life, we selected all patients that were inpatients for at least the final three days of life (106 hospital and 107 inpatient hospice facility patients).

Looking at the data gathered for the three time-points, we sorted patients into the following categories per type of drug: drug not given, drug given continuously (= all three days), drug stopped in the final three days, drug started in the final three days, and a category 'other' (for rare cases with more fluctuating drug administration).

To study the association between setting and use of drugs and procedures we performed multivariate analyses after adjusting for patient characteristics. Dependent variables of 3 or more potentially inappropriate drugs (versus less) use of 3 or more potentially appropriate drugs (versus less), performance of one or more diagnostic procedures (versus none), and performance of two or more therapeutic procedures (versus less) were used. This was decided based on the distribution of values from initial analysis. Independent variable was setting (hospital versus inpatient hospice facility), and covariates were age, gender, years of education, marital status, setting the patient was referred from, primary tumour, and days as inpatient in hospital or inpatient hospice facility.

Results

Characteristics of Study Patients (table 1)

Of patients included in the study, the mean age was similar between settings (76 in hospital and 74 in inpatient hospice care) and length of stay showed little difference, with a stay of over 7 days the case for over 48% of patients in either setting. Data showed significant differences between inpatient hospice care and hospital populations in terms of demographic characteristics – 69.4% of patients in hospital were male compared to 55.1% in inpatient hospice facilities, and patients in hospital were more often found to be married than their counterparts in inpatient hospice care (67.4% versus 51.8%). Education level also differed significantly between settings with almost double the number of patients in inpatient hospice facilities having completed over 9 years of education when compared with hospital (36.4% versus 18.4%). In inpatient hospice care, more patients were referred from home (87.8% versus 40.2%) than in hospital.

Use of potentially inappropriate and appropriate drugs (table 2)

The mean and median number of all drugs received in inpatient hospice facilities was 5.95 and 6.00 respectively. In hospital this was 5.13 and 5.00. Table 2 shows that in hospital more potentially inappropriate drugs were used than in inpatient hospice facilities: 75.0% of patients in hospital received 3 or more potentially inappropriate drugs in their last three days of life as opposed to 42.6% in inpatient hospice care. A significant difference was observed for five of the potentially inappropriate classes of drugs: antibiotics (61.8% versus 14.2%; $P = .000$), anticoagulants (50.7% versus 33.9%; $P = .020$), supplements (36.1% versus 9.4%; $P = .000$),

antihypertensives (26.9% versus 9.4%; $P = .001$), and dopamine (6.2% versus none; $P = .016$). In contrast, potentially appropriate drugs were used less in hospital than in inpatient hospice care: 68.5% of patients in hospital received 1-2 potentially appropriate drugs as opposed to 88.1% in inpatient hospice facilities. A significant difference was seen in 4 of the 5 potentially appropriate drugs: opioids (66.9% versus 88.2%; $P = .000$), haloperidol (11.8% versus 63.8%; $P = 0.000$), midazolam (5.6% versus 71.7%; $P = 0.000$), and drugs for pulmonary secretions (4.2% and 47.2%; $P = 0.000$).

Pattern of drug use in the last three days (table 3)

Of potentially inappropriate drugs, many were used more widely in general in the hospital than inpatient hospice care setting, with less patients falling under the category of “Drug not given”. Hospital patients showed a much greater incidence of having certain potentially inappropriate drugs stopped within the final three days of life than inpatient hospice facility patients - including antibiotics (24.5% versus 8.4%), antihypertensives (17.9% versus 8.4%), anticoagulants (37.7% versus 19.6%), and supplements (28.3% versus 7.5%). Conversely, potentially appropriate drugs were found to be more likely to be given continuously in inpatient hospice care than the hospital setting. Opioids were delivered continuously at over twice the rate in inpatient hospice facilities than in hospital (65.4% versus 28.3%). These drugs were less frequently started in the final three days in inpatient hospice care (12.1% and 7.5%) than in hospital (20.8% and 13.3%). In contrast, midazolam, haloperidol, and drugs for pulmonary secretions were more frequently started in the final three days in inpatient hospice care (17.8%, 7.5% and 14.0%) than in hospital (3.8%, 1.9% and 1.9%).

Procedures undertaken in final three days of life (table 4)

The mean and median number of all procedures received in inpatient hospice facilities was 1.74 and 1.00 respectively. In hospital this was 2.58 and 2.00. Table 4 shows that diagnostic procedures were carried out more frequently in the hospital than inpatient hospice care setting: 38.9% of hospital patients had one or more diagnostic procedures in their last days of life against 15.0% of inpatient hospice facility patients. The largest difference between hospital and inpatient hospice facilities was found for analysis of arterial blood gases (16.7% versus 0.8%) and x-rays (13.9% versus 0.0%). No significant difference was found for the number of therapeutic procedures delivered between hospital and inpatient hospice care setting - 84.7% of hospital patients and 85.0% of inpatient hospice facility patients received one or more therapeutic procedures. For two therapeutic procedures - oxygen (63.2% versus 40.2%) and transfusion (11.1% and 0.0%) - it was found that they were delivered more in hospital than in inpatient hospice care.

Unique contribution of setting to use of drugs and procedures

Multivariate logistic regression analysis showed that when data were controlled for all patient characteristics described in Table 1, setting had a unique contribution to the differences found in drugs used and procedures delivered. In the hospital setting, patients had a higher probability of receiving three or more inappropriate drugs (OR= 3.52, 95% CI= 1.83 – 6.78), and were less likely to receive three or more appropriate drugs (OR= .08, 95% CI= .04 - .18) than in the inpatient hospice care setting. Furthermore, patients in hospital were times more likely to undergo one or

more diagnostic procedure (OR= 3.50, 95% CI= 1.15 – 7.88) than inpatient hospice facility patients. There was no difference in chance on receiving two or more therapeutic procedures between hospital and inpatient hospice care patients (OR= 1.46, 95% CI= .78 – 2.74).

Discussion

The analysis showed that, when looking at administration of potentially inappropriate and appropriate drugs and use of diagnostic and therapeutic procedures, inpatient hospice facilities use a more palliative approach than hospitals in patients' last three days of life, and less administration of potentially inappropriate drugs. A higher proportion of opioids are started in these final three days. Hospital patients more often receive potentially inappropriate drugs, such as anticoagulants and antibiotics, and less often receive potentially appropriate drugs, such as opioids, haloperidol and drugs for pulmonary secretions than inpatient hospice care patients. They also receive more diagnostic procedures such as analysis of arterial blood gases and x-rays. Analyses controlling for differences in patient characteristics in hospital and inpatient hospice facilities show that setting has a unique contribution to the differences found.

Strengths and Limitations

The study data were populated through clinical chart review, translated into a standardised form. This is an efficient and reliable means of research, as it relies on data that exists as part of the patient's care continuum. The study, however, has limitations. The categorisation of drugs into "potentially appropriate" and "potentially inappropriate" is based on one survey of experts, so cannot be taken to represent a wider consensus. Furthermore,

whether a drug is appropriate or inappropriate also depends on the situation of the patient. Similarly, the separation of procedures into “diagnostic” and “therapeutic” cannot be taken to infer an inherent validity of the use of any given procedure. As treatment options and symptoms differ so much between conditions there cannot be a proscriptive range of treatments that are deemed to always be “suitable” or “unsuitable” in end-of-life care. However, to use an analogy with quality indicators, one could consider that a low percentage of potentially inappropriate drugs and diagnostic procedures is a preferable outcome. Such indicators are currently used in wider hospital or system research, and may indicate a norm of drug use considered good, for example ¹⁴. Such norms do not exist yet for drugs and procedures in the last days of life. The concept of the dying phase is also the subject of much debate, though recent research ¹⁵ highlights the presence of certain physical signs present within the final three days of life for cancer patients. Finally, while the design allowed us to control for several patient characteristics in analysing the contribution of setting to use of drugs and procedures, it is possible that there are other patient characteristics that interfere in the found relationship.

Comparison with existing literature

Background research for the formulation of this paper highlighted a paucity of existing studies that assessed process of care as received by dying patients. Currently very little data exists to compare the use of drugs and procedures delivered at the end of life in different settings to provide a measure of process of care. Previous papers have explored assessments of quality of life and caregiver distress between different settings, but explicit data recording process of care remains scarce ^{16, 17}.

The difficult transition to palliation in hospitals

Results show that hospitals more often use potentially inappropriate drugs within the final three days of life than inpatient hospice facilities, but often stop these during this period. This may indicate that the palliative approach is recognised as appropriate, and that this is acted on, but at a much later stage than in the inpatient hospice care setting. Earle et al ¹⁸ found an increase in aggressiveness of treatment received by patients in an acute hospital setting over three years. This can be exacerbated by developments in technology and pharmacology, which encourage physicians to go to greater lengths to try to “save” a patient, and a prevailing culture that sees death in the acute setting as a failure of medical staff ⁸, potentially affecting the point at which the palliative approach is begun.

The patient perspective on appropriate care

The consideration of burden of care is important in making decisions at the end of life, and procedures must be assessed with the holistic needs of the patient in mind - not only medical aspects of care, but also psychosocial and spiritual needs ¹⁹. Fried ²⁰, in a study of elderly patients making end-of-life treatment decisions, found that burden of treatments was weighed by patients against anticipated outcomes and a more marginal outcome lead to less willingness to consider a treatment. This must be considered in the case of potentially inappropriate drugs and procedures, where the perceived benefit of a drug or procedure to the patient or family may be greater than the burden of administration. Thus a strictly scientific classification of appropriateness may be at odds with patient experience of

such drugs and procedures. The same is true for potentially appropriate drugs and procedures - for instance, it is known that some patients are reluctant to use opioids because of fears of becoming drowsy and unaware at the end of life ²¹. Solid information that allows patients to weigh benefits against burdens, and make informed and shared decisions alongside medical staff should be made available.

Conclusion

The data indicate a need for improvement in the hospital setting concerning recognising the need for palliative care, and ensuring a timely transition to this for the patient. It is not possible to say on an abstract level that any one type of drug or procedure is appropriate or inappropriate for any given patient, but the observation of data on this scale suggests that the process of care is not fitting the palliative needs of patients. Pathways such as the Liverpool Care Pathway have made steps towards introducing such a philosophy into hospital care, but a stronger evidence base must be built before introducing such initiatives in a widespread way ^{22, 12}.

Table 1: Characteristics of patients in hospital and inpatient hospice facilities

		HOSPITAL		HOSPICE		P-value
		N=144		N=127		
		n.	%	n.	%	
Age	(mean, range)	76	(46-97)	74	(43-96)	.324
Gender	Male	100	69.4	70	55.1	.017*
	Female	44	30.6	57	44.9	
Education (years)	9-13	21	18.4	35	36.4	.006
	6-8	26	22.8	23	24.0	
	0-5	67	58.8	38	39.6	
	Unknown	30		31		
Marital status	Single	42	32.6	55	48.2	.018*
	Married	87	67.4	59	51.8	
	Unknown	15		13		
Referred from	Home	122	87.8	51	40.2	.000
	Nursing home	7	5.0	8	6.3	
	Hospital	10	6.9	68	53.5	
	Unknown	5		-		
Primary tumour	Digestive system	44	30.6	41	32.3	
	Respiratory system	40	27.8	30	23.6	

	Genitourinary system	14	9.7	24	18.9	
	Haematological	27	18.8	7	5.5	
	Breast	8	5.6	5	3.9	
	Others	11	7.6	20	15.7	.003
Days as inpatient	0-3	37	25.7	20	15.7	
	4-7	37	25.7	29	22.8	
	7+	70	48.6	78	61.4	.066

P values marked * are results of Fisher's Exact Test (2-sided)

Table 2: Frequency of potentially inappropriate and appropriate drugs delivered in the final three days of life in hospital and in inpatient hospice facilities

	HOSPITAL		HOSPICE		P-value	
	N=144		N=127			
	n.	%	n.	%		
Potentially Inappropriate Drugs*						
Antiulcer Drugs	104	72.2	82	64.6	.398	
Antibiotics	89	61.8	18	14.2	.000	
Steroids	82	56.9	79	62.2	.668	
Anticoagulents	73	50.7	43	33.9	.020	
Supplements	52	36.1	12	9.4	.000	
Antihypertensives	39	26.9	12	9.4	.001	
Antiarrhythmics	25	17.4	10	7.9	.067	
Replacement Hormones	22	15.3	11	8.7	.251	
Vasodilator Drugs	16	11.1	5	3.9	.088	
Dopamine	9	6.2	0	0	.016	
Number of	0	8	5.6	20	15.9	
Inappropriate Drugs	1-2	28	19.6	53	42.1	
	3-4	66	45.8	46	36.5	
	5+	41	28.7	7	5.6	.000
Potentially Appropriate Drugs						
Opioids	97	66.9	112	88.2	.000	
Drugs for Nausea/Vomiting	22	15.3	27	21.3	.438	
Haloperidol	17	11.8	81	63.8	.000	

Midazolam	8	5.6	91	71.7	.000	
Drugs for Pulmonary Secretions	6	4.2	60	47.2	.000	
Number of	0	45	31.3	8	6.3	
Appropriate Drugs						
	1-2	98	68.5	111	88.1	
	3-4	-	-	7	5.6	
	5+	-	-	-	-	.000

*Use of bisphosphonates was also assessed, but no positive values were returned from either setting

Table 3: Longitudinal drug data for patients who stayed over 3 days in hospital and in inpatient hospice facilities

	HOSPITAL		HOSPICE N=107		P-value
	N=106		n.	%	
Potentially Inappropriate Drugs	n.	%	n.	%	
<i>Supplements</i>					
Drug not given	59	55.7	97	90.7	
Drug given continuously	14	13.2	1	0.9	
Drug stopped in final three days	30	28.3	8	7.5	
Drug started in final three days	1	0.9	1	0.9	
Other	2	1.9	-	-	.000
<i>Replacement Hormones</i>					
Drug not given	87	82.1	94	87.9	
Drug given continuously	12	11.3	1	0.9	
Drug stopped in final three days	7	6.6	10	9.3	
Drug started in final three days	-	-	-	-	
Other	-	-	2	1.9	.007
<i>Antiulcer Drugs</i>					
Drug not given	25	23.6	37	34.6	
Drug given continuously	27	25.5	23	21.5	
Drug stopped in final three days	50	47.2	41	38.3	
Drug started in final three days	1	0.9	2	1.9	
Other	3	2.8	4	3.7	.405
<i>Anticoagulents</i>					
Drug not given	45	42.5	73	68.2	
Drug given continuously	14	13.2	6	5.6	
Drug stopped in final three days	40	37.7	21	19.6	
Drug started in final three days	3	2.8	-	-	
Other	4	3.8	7	6.5	.001

Antihypertensives

Drug not given	71	67.0	97	90.7	
Drug given continuously	10	9.4	-	-	
Drug stopped in final three days	19	17.9	9	8.4	
Drug started in final three days	2	1.9	1	0.9	
Other	4	3.8	-	-	.000

Antiarrhythmics

Drug not given	86	81.1	97	90.7	
Drug given continuously	8	7.5	3	2.8	
Drug stopped in final three days	10	9.4	6	5.6	
Drug started in final three days	1	0.9	1	0.9	
Other	1	0.9	-	-	.295

Antibiotics

Drug not given	41	38.7	90	84.1	
Drug given continuously	25	23.6	5	4.7	
Drug stopped in final three days	36	24.5	9	8.4	
Drug started in final three days	1	0.9	3	2.8	
Other	3	2.8	-	-	.000

Steroids

Drug not given	44	41.5	39	36.4	
Drug given continuously	25	23.6	22	20.6	
Drug stopped in final three days	26	24.5	35	32.7	
Drug started in final three days	8	7.5	3	2.8	
Other	3	2.8	8	7.5	.174

Vasodilator Drugs

Drug not given	93	87.7	102	95.3	
Drug given continuously	5	4.7	2	1.9	
Drug stopped in final three days	5	4.7	3	2.8	
Drug started in final three days	-	-	-	-	

Other	3	2.8	-	-	.158
<i>Dopamine</i>					
Drug not given	100	94.3	107	100	
Drug given continuously	-	-	-	-	
Drug stopped in final three days	1	0.9	-	-	
Drug started in final three days	4	3.8	-	-	
Other	1	0.9	-	-	.101

Potentially Appropriate Drugs

<i>Opioids</i>					
Drug not given	31	29.2	9	8.4	
Drug given continuously	30	28.3	70	65.4	
Drug stopped in final three days	25	23.6	17	15.9	
Drug started in final three days	14	13.2	8	7.5	
Other	6	5.7	3	2.8	.001

<i>Midazolam</i>					
Drug not given	100	94.3	30	28.0	
Drug given continuously	2	1.9	39	36.4	
Drug stopped in final three days	-	-	14	13.1	
Drug started in final three days	4	3.8	19	17.8	
Other	-	-	5	4.7	.000

<i>Haloperidol</i>					
Drug not given	94	88.7	38	35.5	
Drug given continuously	6	5.7	46	43.0	
Drug stopped in final three days	2	1.9	12	11.2	
Drug started in final three days	2	1.9	8	7.5	
Other	2	1.9	3	2.8	.000

<i>Drugs for Pulmonary Secretions</i>					
Drug not given	102	96.2	54	50.5	

Drug given continuously	-0	-	27	25.2	
Drug stopped in final three days	2	1.9	5	4.7	
Drug started in final three days	2	1.9	15	14.0	
Other	-	-	6	5.6	.000
<i>Drugs for Nausea/Vomiting</i>					
Drug not given	90	84.9	81	75.7	
Drug given continuously	4	3.8	5	4.7	
Drug stopped in final three days	8	7.5	17	15.9	
Drug started in final three days	4	3.8	2	1.9	
Other	-	-	2	1.9	.166

Table 4: Frequency of diagnostic and therapeutic procedures delivered in the final three days of life in hospital and in inpatient hospice facilities

	HOSPITAL		HOSPICE N=127		P-value
	N=144				
PROCEDURES					
Diagnostic Procedures*					
ECG	31	21.5	19	15.0	.209*
Arterial Blood Gases	24	16.7	1	0.8	<.001*
X-ray	20	13.9	-	-	.000
Ultrasound	9	6.3	1	0.8	.022*
CT Scan	9	6.3	1	0.8	.022*
Biopsy	2	1.4	-	-	.500*
Number of	0	88	61.1	108	85.0
Diagnostic	1-2	47	32.6	18	14.2
Procedures	3-5	9	6.3	1	0.8
	5+	-	-	-	.000
Therapeutic Procedures**					
Oxygen	91	63.2	51	40.2	<.001*
1*Vesical Catheterisation	79	54.9	76	59.8	.461*
Artificial Hydration (or CVC)	22	15.3	31	24.4	.066*
Bronchial Aspiration	17	11.8	23	18.1	.171*
Transfusion	16	11.1	0	0	<.001*
Enema	15	10.4	10	7.9	.532*

CPR	4	2.8	0	0	.125*	
Chemotherapy	4	2.8	0	0	.150	
Drainage	3	2.1	3	2.4	1*	
Non-Invasive Ventilation	2	1.4	0	0	.500*	
Radiotherapy	1	0.7	0	0	1*	
Removal of faecal Impaction	-	-	2	1.6	.219*	
Intubation	-	-	1	0.8	.469*	
Number of	0	22	15.3	19	15.0	
Therapeutic	1-2	84	58.3	82	64.6	
Procedures	3-5	37	25.7	25	19.7	
	5+	1	0.7	1	0.8	.681

* use of MRI was also assessed, but no positive values were returned from either setting

** dialysis, invasive ventilation, tracheotomy and peritoneal catheterisation were also assessed, but no positive values were returned from either setting

P values marked * are results of Fisher's Exact Test (2-sided)

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Chapter 4

Characteristics of the end of life in four settings in the Netherlands: care and decisions

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Abstract

Background: Strong provision of palliative care is necessary across care settings to provide for the full spectrum of patients who could benefit from a palliative approach.

Aim: This paper aims to investigate differences in care delivery and end-of-life decisions across four common end-of-life care settings in the Netherlands – hospital, home, nursing home and inpatient hospice facilities.

Design: This study uses data gathered in 2010 through a nationwide survey of death certificate data in the Netherlands. Data were weighted to be representative of all 2010 deaths. Decedents were grouped according to place of death.

Participants: A questionnaire was sent to attending physicians to provide data on care characteristics and end-of-life decisions.

Results: 10% of deaths occurred in inpatient hospice facilities (including Palliative Care Units), 39% at home (including residential homes), 24% in nursing homes and 28% in hospital. Timing of palliative treatment aim differed significantly between settings - 71% of inpatient hospice facility patients had a long-term palliative care aim, compared to 12% of those in hospital. Opioids were given to the majority of patients in each setting (72% - 85%) though settings differed in how long before death opioids were started. In all settings most patients did not request euthanasia or physician-assisted suicide (85% to 98%). At home, about half of requests

resulted in euthanasia (or PAS), compared to one third in inpatient hospice facilities and hospital and 1 in 10 requests in nursing homes.

Conclusions: We found substantial differences in end-of-life care and decisions between settings - differences not only related to patient populations, but also care delivery between settings related to availability and culture.

Background

End-of-life care must be delivered across the full spectrum of care settings in any given system¹. Dutch palliative care policy follows the principle that palliative care should be delivered by generalists when possible, and by specialists when necessary. Physicians in all settings can turn to a palliative care team for consultation. A 2011 policy document issued by the Dutch Ministry for Health, Welfare and Sport confirmed this by putting onus on general practitioners, who attend people who die at home or at a residential home, to provide physical, psychosocial and spiritual palliative care for both patients and their carers². Yet many patients do not die at home, but in another setting. Of patients in the Netherlands whose deaths were not totally unexpected, in 2005 34% died at home or a residential home, 33% died in hospitals, 30% in nursing homes, and 5% elsewhere³ - this highlights the need for strong palliative care to be available in all settings.

While hospitals are primarily focused on cure and life-prolongation, in many hospitals have a palliative care consultation team. Dutch nursing homes provide a distinct medical speciality, where palliative and terminal care is a fundamental part of the function⁴. Nursing homes employ specialist physicians - elderly care physicians - who have undertaken three years of specific training for the role. This is designed to bridge the gap between the applicability of general practice and the high level of specific knowledge of hospital geriatricians⁵. Finally, inpatient hospice care is available, in standalone hospices or palliative care units in a nursing home or hospital. Whilst other settings serve a variety of purposes for diverse populations, these are specifically aimed at patients at the end of life. Inpatient hospice

facilities in the Netherlands are lead by the idea of reducing medical or technical dominance in the care of the dying⁶.

The type of patients that different settings are designed to cater for can vary in their own specialisms, and in demographic characteristics of patients served - though patients in each setting may share considerable similarities in terms of illness trajectory and medical needs⁷. The philosophies and care cultures of both individual institutions and types of institutions may shape the care that those who die in them receive. Some settings may have regular access to particular types of specialist caregivers – such as pain therapists or spiritual carers – whilst this may be more difficult in other settings that are traditionally focused on cure or rehabilitation. Priorities and culture may also be reflected in prescribing practices, for example regarding the use of morphine⁸. Different care characteristics may suggest a greater or lesser adherence to the philosophy of palliative care over curative treatment⁹.

In this study we aim to investigate characteristics of end of life care delivered in four settings – namely inpatient hospice facilities, home, nursing homes and hospitals. Research questions are: What percentage of patients die in the different healthcare settings in the Netherlands? What are the differences in characteristics between patients who die in hospice, (residential) home, nursing home, and hospital? How do care characteristics vary between the four settings? How do end-of-life decisions vary between patients in the four settings?

Methods

Design and population

This study uses data gathered in 2010 through a nationwide mortality follow-back study based on a sample of death derived from death certificate data in the Netherlands¹⁰. During a 3-month study period (August 1 through November 1) all registered deaths were recorded from the central death registry of Statistics Netherlands. On the basis of cause of death, deaths were assigned to one of five strata - with stratum one including causes of death that precluded end-of-life decision-making (e.g. instant death in a traffic accident) and strata two to four having diagnosis that have an increased likelihood of an end-of-life decision having been made (e.g. acute myocardial infarction in stratum 2, heart failure in stratum 3 and cancer in stratum four). Stratum five consisted of cases in which the physician had noted euthanasia or physician-assisted suicide on the death certificate. Cases in stratum one were retained in the sample, but no questionnaires were sent out. The final sampling contained 50% of cases in stratum five, 25% in stratum four, 13% in stratum three, and 8% in stratum one and two. A written questionnaire was sent to all attending physicians of the sampled cases in strata two to five, guaranteeing anonymity. Of the 8496 questionnaires that were mailed, 6263 were returned and eligible for analysis (response rate 74%).

In accordance with Dutch law, this study was exempt from seeking approval from an ethics committee since it did not involve any imposing interventions or actions¹¹.

Questionnaire

The questionnaire was similar to the questionnaires used in earlier death certificate studies ¹⁰. Patient demographics - age, sex, and marital status - and cause of death were derived from the death certificate and municipal registries. The questionnaire looked at different characteristics of the last phase of life. The setting in which the patient died was derived from the specialty of the attending physician at the time of death: General Practitioners (GPs) attend in home and residential home settings, elderly care physicians attend in nursing home, and clinical specialists in hospitals. To be able to single out deaths in inpatient hospice facilities (who can be attended for by all three types of physicians) we specifically asked this information in the questionnaire, by asking whether the patient had stayed in hospice or palliative care unit, and if so, whether this was until death.

Care characteristics that were measured included whether palliation was the most important treatment aim at some point before death, whether additional health care professionals (palliative consultant or team, pain specialist, psychiatrist or psychologist, spiritual caregiver) were involved in patient care in the last month, whether the patient had been hospitalised one or more times in the last month of life, and whether the patient received opioids in the last 24 hours of life. End of life decisions that were asked about were (1) withholding/withdrawing potentially life-prolonging treatment (2) intensifying pain or symptom relief whilst taking into account the possible hastening of death (3) continuous deep sedation until death (4) whether the physician had administered, supplied, or prescribed drugs with the explicit intention of hastening death that then resulted in the patient's death on the explicit request of the patient. If the physician had

administered the drugs this was labelled as euthanasia, and if the patient had taken the drugs him or herself this was labelled as physician-assisted suicide. Finally it was asked whether the patient had completed a request for euthanasia or physician-assisted suicide, and, when death was not a result of euthanasia or physician assisted suicide, what the reason was for this.

Analysis

All cases were weighted to reflect the stratification procedure and to adjust for differences in the response rates in relation to age, sex, marital status, region of residence, and cause and place of death in order to reflect all deaths in 2010 in the Netherlands. For this study, sudden deaths and persons aged under eighteen at the time of death were excluded. 5448 deaths in total were included. The study population was classified into populations from hospice (including PCUs), home (including residential homes), nursing homes and hospital. Patient's demographic characteristics were assessed for heterogeneity using Pearson's chi-squared testing.

We controlled for age, sex, marital status and cause of death when testing differences between settings for care characteristics and end-of-life characteristics. For this we performed multinomial logistic regressions with setting as dependent variable.

Results

Place of Death

Of the people whose death was non-sudden, 10% died in an inpatient hospice facility, 39% at home (including residential homes), 24% in nursing homes and 28% in hospital (Figure 1).

Patient Characteristics

Age differed significantly between settings of care. 76% of patients in nursing homes were over 80 years of age, compared to between 43-49% in other settings. A similar discrepancy was reflected in the gender balance and marital status. Cancer was a majority cause of death in inpatient hospice facilities and homes (76% and 55% respectively), whereas nursing homes and hospitals showed a much broader range of causes of death. Hospitals had the highest rates of death from heart disease (25%), followed by home (16%) (table 1)

Care characteristics

Data on treatment aim at the end of life shows a large degree of variance between settings, from 71% of inpatient hospice patients having a palliative treatment aim of weeks or months, compared to 12% of those in hospital. Inpatient hospice facilities had the lowest proportion of patients with either no stated palliative treatment aim, or an aim of just hours at 5%. This was substantially different from other settings – homes and nursing homes had similar rates at between 18% - 20%, whilst the rate at hospitals was 66%. A relatively high proportion of inpatient hospice patients saw a palliative care

consultant or team in the final month of life, at 33% compared to between 2% - 14% in other settings. Patients in nursing homes had a comparatively high rate of use of psychiatrist/psychologist services and spiritual care, with rates of 14% and 23% respectively. A large number of inpatient hospice patients had spent time in hospital in the month preceding death – 48% – compared with 30% of patients from home and 16% from nursing homes. All differences in the care characteristics for different settings remained significant when controlling for patient characteristics. This was not the case for use of opioids in the final 24 hours of life. Opioids were given to the majority of patients in each setting, from 85% in inpatient hospice facilities to 73% at home. However settings differed in how long before death the prescription of opioids started. In inpatient hospice and home patients opioids were given more frequently over a week before death (50% and 55%) than in nursing homes (22%) and hospitals (9%) (table 2).

End-of-life decisions

Withdrawn or withheld treatments at the end of life occurred at a higher level in hospitals than other settings – 65% compared with between 31% - 55%. Intensification of treatments for pain and symptom management, taking into account the possibility that this could hasten the end of life, occurred between 53% - 61% across settings. The rate of deaths that occurred as a result of euthanasia or physician assisted suicide differed across settings. The highest number occurred at home (8%), whilst the lowest number occurred in nursing homes (0.2%). Palliative sedation occurred in up to a fifth of cases across settings, ranging from 9% of patients in nursing homes to 21% of hospital deaths. Differences between

settings were significant for all these decisions when controlling for patient characteristics. (figure 2)

Requests for euthanasia and physician-assisted suicide

In all settings most patients did not request for euthanasia or physician-assisted suicide. This being said there is a difference in the percentage of patients that request euthanasia or physician-assisted suicide in different settings. It is highest at home (15%) followed by hospice (10%), then, at more of a distance, in hospital (3%) and nursing homes (2%). The rate at which these requests result in euthanasia or physician-assisted suicide being performed also differs for settings. In the home setting about half of requests resulted in euthanasia or physician-assisted suicide, while this was the case in about one third of requests in hospice and hospital, and in about 1 out of 10 requests in nursing homes. (table 3)

The most-recorded reason for euthanasia requests not being granted in all settings other than nursing homes was that the patient died in the interim (45% - 68% of all requests not granted). The most stated reason in nursing homes was that due care criteria were not met (56%). Hospices, nursing homes and hospitals had similar rates of not carrying out requests due to such acts being against the policy of the institute (between 4% - 7%). In the home setting, this was reflected in rates of requests that were refused because of the attending physician being opposed (3%). The home setting saw a higher rate of patients withdrawing the request than other settings – 11% against 0% - 6%.

Discussion

The data shows that with 39% the highest proportion of non-sudden deaths occurred in the home setting (including residential homes). 10% of deaths occurred in inpatient hospice facilities, the first estimate for this setting as a distinct category in a death certificate study in the Netherlands.

There were notable differences in patient characteristics between settings, though differences in care characteristics and end-of-life decisions persisted after these differences had been controlled for. The existence and duration of a palliative treatment aim was a major difference between settings – with this aim being least frequent and long before death in hospitals. There were also differences in use of specialist caregivers within the palliative scope. Spiritual and psychological therapists were most widely accessed in inpatient hospices facilities and nursing homes. Morphine was widely used across all settings, though the point at which this was started varied significantly according to setting – with home and inpatient hospice facilities having the highest proportion of patients using for over a month before death. End-of-life decisions showed a wide degree of variance between settings, with treatments being withheld or withdrawn being more likely in hospital than in other settings. Only a small proportion of patients in any setting requested euthanasia or physician-assisted suicide. The home setting is where most requests were made (15%), and was also where the highest proportion of these requests were carried out.

Strengths and Limitations

The study population was identified using a representative sample from the Dutch death registry, which creates a strong and unbiased research base.

A large number of deaths were included in the study, giving the results statistical power. An intrinsic limitation of the data set is that data is derived from physicians, meaning that the data gathered is reliant upon their interpretation of the situation. Above that, data collection occurred retrospective which might have introduced recall bias.

Hospice as place of death

This data provides the first figure for the percentage of inpatient hospice facility deaths in the Netherlands based on a nationwide study. It is difficult to assess whether this indicates that hospice care at the end of life is becoming more widespread within the Dutch system, as a clear comparison cannot be drawn from previous data. The 5% of deaths that were attributed to the “elsewhere” category in the 2005 data from the similar questionnaire must be taken into account as this was before the “hospice” category was finalised, and so likely contained a number of deaths that would be categorised as such. During this period, the European Association of Palliative Care (EAPC) recorded that the number of dedicated palliative care beds rose from 716 in 2007 to 1226 in 2013^{12, 13}. Comparing the proportion of the population who die under hospice care internationally is difficult, due to differing definitions of hospice services and provision of different types of care. 44.6% in of patients in the USA in 2011 were recorded as having died whilst receiving hospice care¹⁴ – though the proportion of this population who died in an inpatient hospice was 26.1% of this proportion. England recorded 5.6% of deaths occurring in inpatient hospice settings in the same year, and Wales 2.7%¹⁵. Belgium recorded 9.8% of deaths as taking place in “inpatient palliative care units”¹⁶.

Differences in patient population between settings

One explanation for the differences found in end-of-life care and end-of-life decision-making can be found in the fundamentally different patient populations that are cared for in different settings. As was to be expected, we found differences in patient characteristics between settings and several of these patient characteristics have been found to be associated with end-of-life care or end-of-life decision-making. It has previously been found that older people less frequently request for euthanasia or physician-assisted suicide than younger people ¹¹. This resonates with our finding that such requests occur least often in nursing homes, the setting with the oldest patient population. Furthermore, it is known that care characteristics that indicate a palliative approach occur more frequently in cancer patients ¹⁷ as is echoed in our finding that the highest percentages of a palliative treatment aim of weeks or months and the relatively frequent involvement of palliative care consultants were found in inpatient hospice facilities and at home, where the percentages of cancer deaths are highest.

Differences in care delivery between settings

While we controlled for patient characteristics, including several that are known to be associated with end-of-life care provision and end-of life decision-making, significant differences still remained between settings.

Differences in the availability or culture of use of some services may be responsible for part of the differences found between settings. Fundamentally different levels of use of some services existed between settings— we found for instance a much higher level of use of spiritual and

psychological support services for patients in nursing homes and spiritual care use in inpatient hospice facilities. These are caregivers that are generally employed as standard practice in nursing homes, indicating an influence of availability. Yet these caregivers are generally also employed in hospital, which indicates an influence of culture of use. In both inpatient hospice facilities and at home these caregivers generally have to be called in, indicating an influence of culture of use. This might be a reflection of the extent to which there is a palliative care approach. Involving other caregivers reflects the multidisciplinary character of a palliative care approach. This seems to be limited at home, where the general practitioner is the attending physician – however, at home palliation as most important treatment aim for weeks or months before death occurred most frequently, which can also be a reflection of a palliative care approach. Use of morphine across settings was high, but large differences were seen in prescribing practices – with morphine being prescribed earlier in hospice and home. This may be indicative of recognition of limited life expectancy, but may also be influenced by a lack of confidence in end-of-life prescribing knowledge¹⁸. Interpretation of life-prolonging treatments that are withheld or withdrawn must be considered with the nature of the institution in mind – of the four settings, only hospitals usually operate with a curative aim, and so have facilities to offer potentially life-prolonging treatments.

End-of-life decisions and acts may be subject to being shaped by institutional policy and culture. Inpatient hospice facilities and hospitals had higher levels of not granting euthanasia or physician-assisted suicide requests due to organisational policy, whilst nursing homes had a high level of individual physicians being against carrying out such acts. Finally,

populations may be shaped at the stage of intake by institutional policies – patients who are in favour of euthanasia and consider this as a possibility might be less likely to engage with an institution that has guidelines that preclude this totally, thus shaping the outcome when end-of-life requests are recorded.

Conclusions

We found that there are substantial differences in end-of-life care and end-of-life decisions between settings, and that these differences are not only related to differences in patient populations, but also in differences in care delivery between settings potentially related to availability of services and culture. The study does not allow for definite conclusions on whether these differences in care delivery between settings are problematic, as we have no data on patient and caregiver satisfaction levels or needs. Thus it is not possible to judge whether the patients dying in each setting need fundamentally different types of palliative care or whether standardisation of care between settings would best serve patients. However, recognising the patient's transition into a phase in which palliation is increasingly important, and later the dying phase, is considered important for both patient and caregivers ¹⁹. In the Netherlands, this seems to be done most frequently in inpatient hospice facilities and home settings.

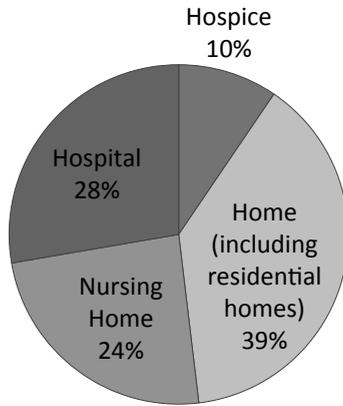


Figure 1: Place of death for patients whose death was expected (n=4881)

Table 1: Patient characteristics according to setting (weighted percentages)

	Hospice (n=567)	Home (n=2383)	Nursing Home (n=840)	Hospital (n=1091)	P value
<i>Age</i>					
17-64	17.9	21.0	3.0	17.5	
65-79	39.4	29.7	21.0	36.6	
80+	42.7	49.3	76.0	46.0	<.0001
<i>Sex</i>					
Male	44.9	49.1	33.8	54.1	<.0001
<i>Marital Status</i>					
Married	36.0	48.9	28.8	46.5	<.0001
<i>Cause of Death</i>					
Cancer	75.7	54.6	8.9	25.0	
Heart Disease	7.7	15.7	12.4	24.6	
Lung Disease	3.5	7.9	14.5	12.4	
Central Nervous System Disease (including stroke)	3.5	4.7	19.8	13.1	

Other / Unknown	9.6	17.0	44.4	24.7	<.0001
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Figures stated represent column %

*Table 2: Palliative and end-of-life care characteristics according to setting
(weighted percentages)*

	Hospice (n=567)	Home (n=2383)	Nursing Home (n=840)	Hospital (n=1091)	P value*
<i>How long before death was the treatment mainly aimed at palliative care?</i>					
Never	4.0	15.7	15.7	53.1	
Hours	1.2	2.3	4.5	12.6	
Days	23.7	19.8	22.5	22.2	
Weeks	46.9	32.0	14.2	4.7	
Months	24.3	30.1	43.1	7.4	<.001
<i>Which caregivers were involved in the final month of life?</i>					
Palliative care consultant/team	32.7	13.7	2.2	4.8	
Pain Specialist	4.4	4.1	1.0	4.1	
Psychiatrist/psychologist	6.4	1.9	13.6	3.9	

Spiritual Caregiver	28.3	7.2	23.1	5.1	<.001
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Was the patient admitted to hospital during the final month of life?

Yes	48.3	29.5	15.5	100	<.001
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Did the patient receive morphine or a morphine derivative within the final 24hours of life?

Yes	85.4	72.9	77.3	74.7	<.001
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*How long before death was administration started? ***

Within 24 hours	n=472	n=1788	n=629	n=796
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2-3 days	15.6	18.2	32.0	58.3	
4-7 days	19.6	13.9	30.7	24.3	
1 week – 1 month	14.9	12.6	15.8	8.1	
>1 month	28.2	24.5	13.5	6.4	
	21.8	30.8	8.0	2.8	0.001

*controlled for patient characteristics (age, sex, diagnosis, marital status) using multinomial regression analysis

** more than 5% of values missing (6.7%)

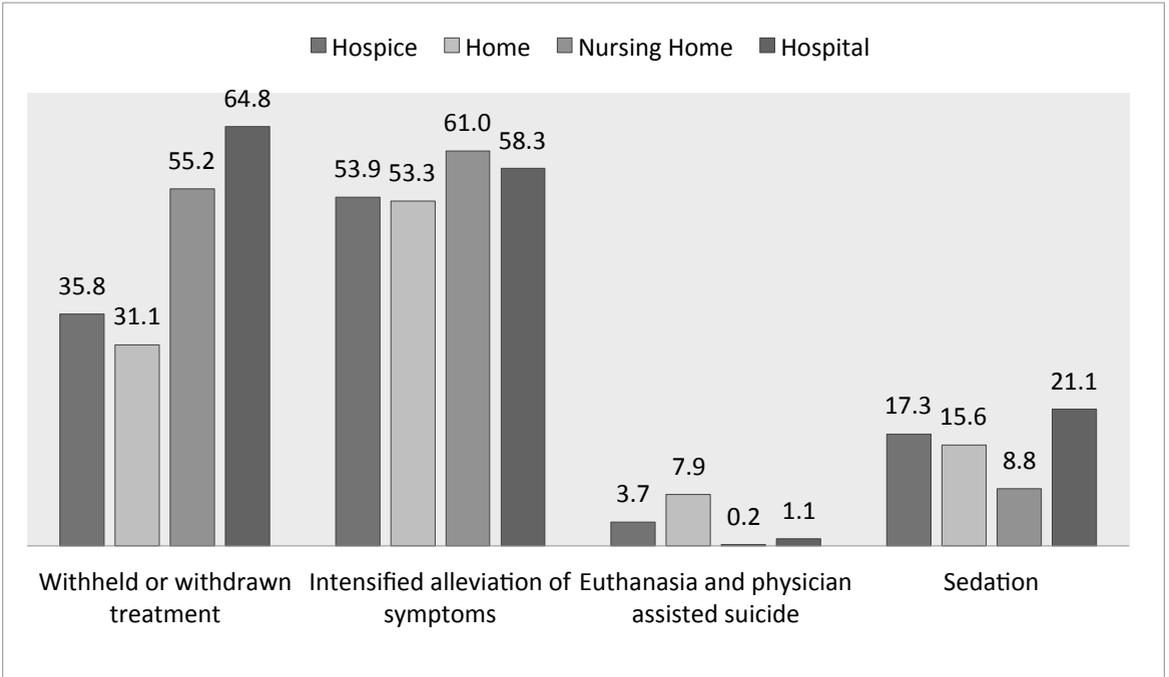


Figure 2: End-of-life decisions by setting (n=4881)*

*For all end-of-life decisions, differences between settings are significant (p<.0001), controlling for patient characteristics

Table 3: Euthanasia requests and actions

	Hospice (n=567)	Home (n=2383)	Nursing Home (n=840)	Hospital (n=1091)	P value*
<i>Did the patient ever express a wish for the end of life to be hastened?</i>					
No request	90.0	84.8	97.9	96.9	
Request that resulted in euthanasia or physician-assisted suicide	3.3	7.9	0.2	1.1	
Request that did not result in euthanasia or physician-assisted suicide	6.6	7.3	1.9	2.1	<.0001
<i>Reason for request not resulting in euthanasia/physician-assisted suicide**</i>					
Patient died in interim	48.5	44.7	12.0	67.9	
Due care criteria were not met	12.1	27.6	56.0	21.4	
Decision was against the policy of the institute	6.1	-	4.0	7.1	

Physician was opposed to the decision	9.1	3.3	12.0	-
Patient withdrew the request	6.1	10.5	-	3.6
Other	18.2	13.8	16.0	-

* controlled for patient characteristics (age, sex, diagnosis, marital status) using multinomial regression analysis

** not statistically tested due to small numbers in most settings

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Part Two

"But the ultimate problem of design concerns not how I design the world outside, but how I design myself—or, rather, how I deal with the way in which the world designs me"

Boris Groys

Chapter 5

Hospice care in the Netherlands: who applies and who is admitted to inpatient care?

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Abstract

Background: 10% of non-sudden deaths in the Netherlands occur in inpatient hospice facilities. To investigate differences between patients who are admitted to inpatient hospice or not following application, how diagnoses compare to the national population, characteristics of application, and associations with being admitted to inpatient hospice or not.

Methods: Data were gathered from a database representing over 25% of inpatient hospice facilities in the Netherlands. The study period spanned the years 2007 - 2012. Multivariate regression analyses were performed to study associations between demographic and application characteristics, and admittance.

Results: 10254 patients were included. 84.1% of patients applying for inpatient hospice care had cancer compared to 37.0% of deaths nationally. 52.4% of applicants resided in hospital at the time of admission. Most frequent reasons for application were the wish to die in an inpatient hospice facility (70.5%), needing intensive care or support (52.2%), relieving caregivers (41.4%) and needing pain/symptom control (39.9%). Living alone (OR 1.68, 95% CI 1.46 – 1.94), having cancer (OR 1.40, 95% CI 1.11 – 1.76), relieving caregivers (OR 1.18, 95% CI 1.01 – 1.38), needing pain/symptom control (OR 1.72, 95% CI 1.46 – 2.03) wanting hospice care until death (vs respite care) (OR 3.59, 95% CI 2.11 – 6.10), wanting to be admitted as soon as possible (OR 1.64, 95% CI 1.42 – 1.88), and being referred by a primary care professional (OR 1.36, 95% CI 1.17 – 1.59) were positively associated with being admitted. Wishing to die in an inpatient

hospice facility was negatively associated with being admitted (OR 0.85, 95% CI 0.72 – 1.00).

Conclusions: This study suggests that when applying for inpatient hospice care, patients who seem most urgently in need of hospice care are more frequently admitted. However, non-cancer patients seem to be an underrepresented population. Staff should consider application based on need for palliation, irrespective of diagnosis.

Introduction

End of life care exists in many forms in healthcare systems, from services fully integrated into acute healthcare settings to standalone units and peripatetic visiting teams. Hospice as a model of end-of-life care can take a number of different forms according to organisational strategies and the needs of patients. Inpatient hospice facilities in the Netherlands are organised into three main types, providing different types of caregiver support and integration with other models of care. The 2013 European Atlas of Palliative Care recorded 212 inpatient hospice facilities in the Netherlands, of which 55 were standalone hospice facilities, and 157 were palliative care units (PCUs) embedded in tertiary and non-tertiary care facilities, generally nursing homes ¹. Standalone hospice facilities are further divided into two types – inpatient ‘hospices’, which are staffed by nurses and physicians who are part of the institution and *bijna-thuis-huizen* (almost-home-homes) that have visiting nurses and physicians but the majority of care carried out by volunteers and families ².

Currently 10% of all non-sudden deaths in the Netherlands occur in inpatient hospice facilities ³. The number of inpatient hospice facilities is growing rapidly; from 86 inpatient hospice facilities that were recorded in the 2007 edition of the EAPC European Atlas of Palliative care ⁴, to 212 in the 2013 edition ¹. Hospice as an institution was originally developed for cancer patients ⁵ and use of inpatient hospice facilities today still reflects this bias. European data have shown an imbalance in inpatient hospice use for certain groups when compared with the national average, with cancer patients consistently being found to be more likely to receive specialist palliative care (including in inpatient hospice facilities) than other groups

such as patients with lung disease or heart failure ⁶. Demographic differences have also been found to have an influence, with the oldest-old being less likely to receive specialist care at the end of life ⁷. This unequal distribution of the use of inpatient hospice facilities may be related to different levels of need, but may also represent unequal levels of access ⁸.

This paper aims to investigate the differences between the populations who are admitted to inpatient hospice facilities or not following application, and how the spread of diagnoses compares to the national population at the end of life in terms of the characteristics of people who apply for care in inpatient hospice facilities. We will also investigate the characteristics of application in terms of what type of inpatient hospice facility is being applied for, where the patient is admitted from, the reason for application, the length of desired care, how urgent admission is, the person who referred to inpatient hospice care, when care in a hospice is sought and which patient and application characteristics are associated with being admitted to inpatient hospice facilities or not.

Methods

This study utilised a Dutch database of patients applying for inpatient hospice care between 2007 and 2012 registered for the Netherlands hospice – database managed by the comprehensive cancer center of the Netherlands (IKNL). Data were gathered from 64 institutions that provide inpatient hospice care. Not all institutions provided data for all years, but provided data for one or more years of this timespan. Given the 212 inpatient hospice facilities in the Netherlands in 2013 ¹, this means that

around a quarter of all inpatient hospice facilities are involved in providing data.

The original database contained 10502 cases. 248 records were removed, of which the majority were duplicate records. In addition, if a patient was recorded as having more than one admission, only the data from the final admission were used for analysis and other visits were removed from the database – this was the case for 21 patients, with number of visits varying between two and nine. In total 10254 cases were included for analysis.

Ethics

In accordance with Dutch law, this study was exempt from seeking approval from an ethical review board as there were no imposing actions or interventions involved. Data were de-identified, so that individual patients could not be recognised.

Instrument

Applications to inpatient hospice care in the Netherlands are not centrally regulated or coordinated, and are made directly to individual hospices. Any person, including the patient and their informal caregivers, can make an application for hospice care. According to insurance regulations, hospice care is for patients in the final three months of life ⁹. Healthcare professionals in participating institutions registered data using standardised electronic forms. The standardised form recorded demographic and application characteristics of patients before admittance, and

characteristics of care received if the patient was admitted to inpatient hospice care.

Demographic variables included for analysis were age, gender, whether the patient lived alone or not and their primary diagnosis. Application variables were the type of inpatient hospice facility applied to, where the patient resided at the time of application, the stated reason for application, whether the patient wanted care until death or respite care, the desired timing for admission and who referred the patient to inpatient hospice care.

Analysis

The study population was dichotomised into those who were admitted to inpatient hospice care, and those who applied but were not admitted. Differences between the two groups for demographic and application characteristics were assessed using chi-square testing.

To compare the spread of diagnoses for patients applying for inpatient hospice care with the main diagnosis of all people in the Netherlands who died non-suddenly, data on cause of death from a national death certificate study were used ¹⁰. Non-sudden deaths were classified as all deaths that were not the result of an accident or sudden acute medical condition such as a stroke or cardiovascular accident.

To study the association between demographic and application characteristics and admittance to inpatient hospice care, we performed uni- and multivariate logistic regression analyses with being admitted to hospice or not as dependent variable and demographic and application

characteristics as independent variables. Analyses were firstly performed univariately, and independent variables that were significant were then entered backwards stepwise in multivariate analyses.

Results

Demographic Patient Characteristics (table 1)

Neither age nor sex differed significantly between those admitted and not admitted to inpatient hospice facilities, with most patients in each group aged between 61-80 years, with a slightly larger female than male population. Patients who were admitted to inpatient hospice facilities statistically significantly more often lived alone than patients who were not admitted (53.4% and 51.2%). Though the highest proportion in either group were cancer patients, (84.1% of admitted patients and 80.6% of not-admitted patients), the difference between the two groups was statistically significant.

Comparison of diagnosis for hospice population and national population (figure 1)

The main diagnosis of those applying for inpatient hospice care differed greatly from the spread of causes of non-sudden deaths found nationally. In the studied inpatient hospice group, cancer formed by far the largest population at 84%, whereas nationally this accounted for 37% of deaths. The incidence of pulmonary disease as a cause of non-sudden death nationally is five times higher than in the inpatient hospice population, at 10% against 2%, and both heart and neurological diseases show an

incidence rate that is more than three times higher in the national population than the inpatient hospice population.

Application Characteristics (table 2)

About half of all applicants (52.4%) were staying in hospital at the time of admission. The most frequent reason for application was the wish to die in a hospice (70.5%), followed by needing intensive care or support (52.2%), relieving the caregivers (41.4%) and needing pain and symptom control (39.9%). Intensive care and support includes medical, psychological, spiritual and psychosocial aspects of care. About 9 out of 10 applicants wanted to stay in hospice until death (versus respite care) (96.2%), and about half of all applicants wanted this care as soon as possible (52.5%). A statement of a wish to die in hospice was recorded as a motivation for applying to hospice, whilst wanting hospice care until death was recorded as the intended time span of care.

There were widespread differences between those who were admitted and those not admitted when looking at application characteristics. A higher percentage of patients who were not admitted were already residing in hospital (57.4% against 51.2%). While there was no difference between the two groups in wishing to die in hospice as reason for application, all three other reasons occurred most often in the group that was admitted to inpatient hospice facilities. Over four-times as many patients admitted for respite were admitted into inpatient hospice facilities than not (4.4% against 1.5%). In the group admitted to inpatient hospice facilities, the percentage of patients wanting to be admitted as-soon-as-possible was higher than in the group that was not admitted (55.4% versus 42.2%). Finally, there were

differences between the two groups in terms of who had referred the patient to inpatient hospice facilities. The percentage of referrals by GPs was larger in the admitted group than in the not admitted group (32.3% versus 19.4%) and similarly, the percentage of referrals by patient or family were smaller amongst those admitted (9.6% versus 15.0%).

Associations affecting admittance (table 3)

In the multivariate regression analyses two demographic characteristics were positively associated with being admitted to inpatient hospice facilities: living alone (OR 1.68, 95% CI 1.46 – 1.94) and having cancer (OR 1.40, 95% CI 1.11 – 1.76). Apart from where the patient would be admitted from and needing intensive support as reason for application, all studied application characteristics remained significant in the analysis. Of different organisational models, PCUs embedded in nursing homes more often admitted patients to care than inpatient hospice facilities (OR 1.93, 95% CI 1.60 – 2.32). Of the reasons for application, wishing to die in hospice was negatively associated with being admitted to inpatient hospice facilities (OR 0.85, 95% CI 0.72 – 1.00), though this is not statistically significant. Relieving caregivers (OR 1.18, 95% CI 1.01 – 1.38) and needing pain and symptom control (OR 1.72, 95% CI 1.46 – 2.03) were positively associated with being admitted to inpatient hospice facilities. Finally, wanting care until death (versus respite care) (OR 3.59, 95% CI 2.11 – 6.10), wanting to be admitted as soon as possible (OR 1.64, 95% CI 1.42 – 1.88), and being referred by a professional working in primary care (OR 1.36, 95% CI 1.17 – 1.59) were positively associated with being admitted to inpatient hospice facilities.

Reason for non-admittance to hospice (figure 2)

The majority of patients who were not admitted after application were not admitted because they had died in between application and the opportunity for admittance (53%). A further 7% were too ill to transfer to another care setting, and 11% stated that the care was no longer wanted or needed. In total, 26% of patients were transferred to another care setting – be that another inpatient hospice facility, a nursing home, a care home or a hospital. Of these transfers, admission to another inpatient hospice facility was the most common at 21%.

Discussion

Summary

The data show that certain demographic characteristics differed significantly between patients who were admitted and who were not following application. Primary diagnosis as a characteristic differed between the population who applied for inpatient hospice care and the national records of non-sudden deaths, with more cancer patients applying for inpatient hospice care. Logistic regression showed that patients with a cancer diagnosis were more likely to be admitted to inpatient hospice care.

Application characteristics showed several significant differences between those who were admitted and not. Notably, in regards to where a patient resided at the time of admission, patients were admitted from home rather than hospital. This was reflected in who made the application, with an applicant from a primary care setting being positively associated with the

patient being admitted to inpatient hospice facilities. The reason for application was also significant, with a need for pain and symptom control being strongly associated with a patient's admittance to inpatient hospice care. Timing of care - both in terms of whether patients were seeking care until death or for respite, and how soon they wanted inpatient hospice care to commence – differed significantly between patients who were admitted and not, with admitted patients requesting more urgent care and care until death. The reason recorded for patients not being admitted was primarily because they had died between application and opportunity for admittance.

Strengths and Limitations

The study population was gathered from a database representing over 25% of inpatient hospice facilities operating in the Netherlands. A representative spread of different types of hospice was recruited for this database, largely from the South and South-East of the Netherlands. A large number of deaths were included in the study, giving the results statistical power. As data are a record of admission and stay characteristics and was recorded in a standardised manner, this forms a reliable set of data, as the information gathered is part of the patient's usual process of care.

An inherent limitation of the study is that these data only covers the professional perspective of care – thus allowing us to identify which patients enter inpatient hospice facilities and why patients might not be admitted, but it does not provide any information on admittance and non-admittance from the patient perspective and the ramifications of these decisions on an experiential level.

Applications

Hospice care was originally developed to care for the dying cancer population [5] and this is still reflected today. Results showed that a much higher proportion of patients who applied to hospice services had a primary diagnosis of cancer, when compared to the cause of death for all non-sudden deaths nationwide. This reflects what has been shown in previous international literature – a 2014 paper by Klinger et al.¹¹ found that ~90% of patients who died in hospice in Canada, England and Germany had a cancer diagnosis. Our study shows that, although cancer patients have a somewhat higher chance to be admitted than other patients after applying to inpatient hospice facilities, the main reason for the high percentage of cancer patients in inpatient hospice facilities lies in there being more applications for cancer patients than for other patients. The question is whether this is due to cancer patients more frequently needing hospice care. One argument against this is that previous studies have reported on the symptom burden experienced by patients with a number of non-malignant diagnoses, and have found that symptoms that may have benefitted from specialist palliative care (pain, breathlessness, social and psychological needs) were common across different patient groups^{12,13}. Ostgathe et al. found that non-cancer patients experience more symptoms than cancer patients¹⁴.

This suggests that the lack of utilization of specialist services by such patients is not due to a lack of need for services that provide holistic relief and concentration on quality of life. Field¹⁵ identified the differences in disease trajectories and defining patients as being “in the terminal stage” as key factors that affect patients with non-malignant conditions access to

specialist palliative care. While our results may suggest that non-cancer patients represent an under-represented group, it remains unclear which part of the difference in application for inpatient hospice care in cancer and non-cancer patients is due to under serving, and which part is due to different needs and further literature is needed to address this. The underrepresentation of non-cancer patients could also be a result of most people assuming that inpatient hospice facilities are primarily for patients with terminal cancer. Earlier it was found in the US that physicians were not good in identifying appropriate candidate diagnosis for hospice referral ⁸.

Admittances

Results showed that those admitted to inpatient hospice facilities had more often stated needs for intensive care and support, relief for caregivers and pain and symptom control than applicants that were not admitted. This is concurrent with the WHO definition of palliative care as focusing on “treatment of pain and other problems, physical, psychosocial and spiritual” ¹⁶. Looking at the application characteristics that increase the chance of being admitted, it seems that certain characteristics might be related to a higher need for inpatient hospice care: patients living alone, needing pain relief and wanting care as soon as possible and until death.

Little over half of the admittances followed a hospital admission – this may be an indicator that earlier intervention, resulting in more care needs, then precludes returning home for patients. That patients who applied from hospital were somewhat less frequently admitted to hospice is likely to be due to dying before admission. Finally, the result that the most frequent reason for not being admitted to inpatient hospice facilities is the death of

the patient suggests that it may have been beneficial to consider applying for hospice earlier on for at least part of this group.

Conclusions

This study suggests that when applying for hospice, patients who seem most urgently in need of hospice care are more frequently admitted, yet our study has several implications for the process of admitting patients to hospice. Firstly, our results suggest that non-cancer patients are an underrepresented group, especially because they are less often referred to hospice care. Previous studies have highlighted palliative needs of non-cancer patients being similar or more. It is possible that non-cancer patients are underrepresented in inpatient hospice facilities as they are more often cared for in nursing homes, and are unlikely to transfer to inpatient hospice facilities before death. Staff should consider application for non-cancer patients based on need for symptom control and palliation, rather than basing a decision on diagnosis. Secondly, the most frequent reason for not being admitted to inpatient hospice facilities is the death of the patient, suggesting that this group might have benefitted from considering applying to an inpatient hospice facility earlier on – at least in part. Also in this situation considering application based on the need for symptom control and palliation rather than on diagnosis could help. Finally, hospices themselves should recognize stated needs for care, and hospices, PCUs and bijna-thuis-huizen could work together regionally so that places can be found for applicants even if this is not in the original institution of choice.

Table 1: Demographic Characteristics of Hospice Applicants

	All applicants (n = 10254)		Admitted to inpatient hospice facility (n=7966)		Not admitted to inpatient hospice facility (n=2288)		P value
	n	%	n	%	n	%	
<i>Age</i>							
19-40	74	0.8	52	0.7	22	1.0	
41-60	1182	12.3	930	12.4	252	12.0	
61-80	4665	48.6	3678	49.0	987	47.0	
81+	3682	38.3	2845	37.9	837	39.9	.118
<i>Sex</i>							
Male	4791	46.7	3749	47.1	1042	45.6	.205
<i>Religion</i>							
Roman Catholic	3643	35.5	3504	44.0	139	6.1	
Protestant	1218	11.9	1163	14.6	55	2.4	
Muslim	36	0.4	31	0.4	5	0.2	
None	1216	11.9	1181	14.8	35	1.5	
Other	66	0.6	65	0.8	1	0.0	
Unknown to hospice	4075	39.7	2053	25.8	2022	88.7	.004
<i>Living situation</i>							
Alone	4257	53.1	3735	53.4	522	51.2	
With Partner	2803	35.0	2430	34.7	373	36.6	

In Institution	509	6.3	428	6.1	81	7.9	
With Children	435	5.4	393	5.6	42	4.1	
Other	15	0.2	14	0.2	1	0.1	.032
<i>Primary Diagnosis</i>							
Cancer	8345	83.3	6617	83.0	1728	80.6	
Heart Disease	659	6.6	503	6.3	156	7.3	
Pulmonary Disease	217	2.2	159	2.0	58	2.7	
Neurological	330	3.3	239	3.0	91	4.2	
Disease (inc. CVA)							
Other	466	4.7	354	4.5	112	5.2	<.001

Missing Values: Total n (*Admitted, Not Admitted*) Age 651 (*461, 190*), Living Situation 2235 (*966, 1269*), Primary Diagnosis 237 (*94, 143*)

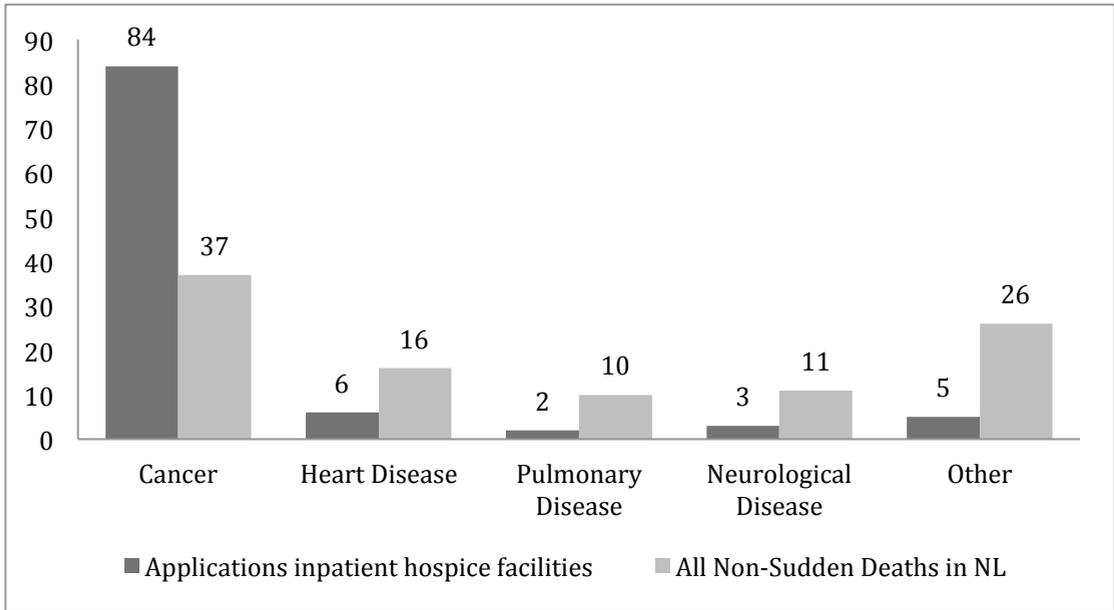


Figure 1: Main diagnosis of those applying for inpatient hospice facility and national figure of cause of death of all people who died unexpectedly and non-suddenly (van der Heide, 2012)

Table 2: Application Characteristics for inpatient hospice facility

	All applicants (n = 10254)		Admitted to inpatient hospice facility (n=7966)		Not admitted to inpatient hospice facility (n=2288)		P value
	n	%	n	%	n	%	
<i>Type of institution</i>							
Inpatient hospice	3512	34.3	2685	33.7	827	36.1	
PCU in/with Nursing Home	3322	32.4	2514	31.6	808	35.3	
Bijna Thuis Huis	3420	33.4	2767	34.7	653	28.6	<.001
<i>Patient applied from</i>							
Hospital	5210	52.4	4077	51.2	1133	57.4	
Home	3948	39.7	3237	40.6	711	36.0	
Nursing Home	296	3.0	252	3.2	44	2.2	
Care Home	287	2.9	231	2.9	56	2.8	
Inpatient hospice	56	0.6	47	0.6	9	0.5	

Other	142	1.5	121	1.5	21	1.1	<.001
<i>Reason for application*</i>							
Wish to die in hospice	6948	70.5	5571	70.0	1377	72.9	.111
Intensive care/support	5144	52.2	4331	54.4	813	43.1	<.001
Relief for caregivers	4081	41.4	3443	43.2	638	33.8	<.001
Pain and symptom control	3933	39.9	3413	42.9	520	27.5	<.001
<i>Time span of intended care</i>							
Until death	9534	96.2	7616	95.6	1918	98.5	
Respite	379	3.8	350	4.4	29	1.	<.001
<i>Desired timing</i>							
ASAP	5379	52.5	4413	55.4	966	42.2	
Within one month	4210	41.1	3352	44.6	658	28.8	
Just-in-case	665	6.5	1	0	664	29.0	<.001
<i>Who referred</i>							
GP	3021	29.5	2577	32.3	444	19.4	

Nurse (hospital)	3872	37.8	3034	38.1	838	36.0	
Patient or Family	1104	10.8	762	9.6	342	15.0	
Nursing home staff	947	9.2	805	10.1	142	6.2	
District nurse	466	4.5	419	5.3	47	2.1	
Care mediation service	154	1.5	151	1.9	3	0.1	
Other	690	6.7	218	2.7	472	20.6	<.001

*More than one answer possible

Missing Values: Total n (*Admitted, Not Admitted*) Admitted From 315 (1, 314),
Reason for Application 404 (4, 400), Timespan of Intended Care 341 (0, 341)

Table 3: Demographic and application characteristics associated with being admitted for care in inpatient hospice facility*

	Univariate		Multivariate	
	OR	95% CI	OR	95% CI
Demographic Characteristics				
<i>Age</i>				
<60 years	1.05	0.90-1.23		
61-68 years	1.10	0.98-1.21		
81+ years	1.00			
<i>Male (vs female)</i>	1.06	0.97-1.17		
<i>Living alone (vs not)</i>	1.73	1.54-1.95	1.68	1.46-1.94
<i>Main diagnosis</i>				
- Cancer	1.33	1.13-1.56	1.40	1.11-1.76
- Heart failure	1.15	0.90-1.47	1.27	0.89-1.80
- Lung disease	0.95	0.68-1.33	0.84	0.53-1.34
- Other	1.00		1.00	
Application Characteristics				
<i>Type of inpatient hospice facility</i>				
- Inpatient hospice	1.00		1.00	
- 'bijna-thuis-huis'	0.96	0.86-1.07	1.21	1.03-1.43
- PCU in nursing home	1.31	1.16-1.47	1.93	1.60-2.32
<i>Applied from</i>				
- Hospital	1.00			**
- Home	1.27	1.14-1.41		
- Other	1.39	1.14-1.70		
<i>Reasons for application</i>				
Wish to die in hospice (vs not)	0.87	0.77-0.97	0.85	0.72-1.00

Intensive care / support (vs not)	1.58	1.43-1.75	**	
Relief for caregivers (vs not)	1.49	1.34-1.66	1.18	1.01-1.38
Pain/symptom control (vs not)	1.97	1.77-2.20	1.72	1.46-2.03
Wanting care until death (vs respite)	3.04	2.07-4.45	3.59	2.11-6.10
<i>Desired timing admission</i>				
ASAP (vs rest)	1.70	1.55-1.87	1.64	1.42-1.88
<i>Applicant from primary care</i>				
(vs rest)	1.69	1.51-1.90	1.36	1.17-1.59

* univariate and backwards multivariate logistic regression; reference group not being admitted to hospice

**were entered but in the multivariate logistic regression, but did not remain in the analysis until the final step

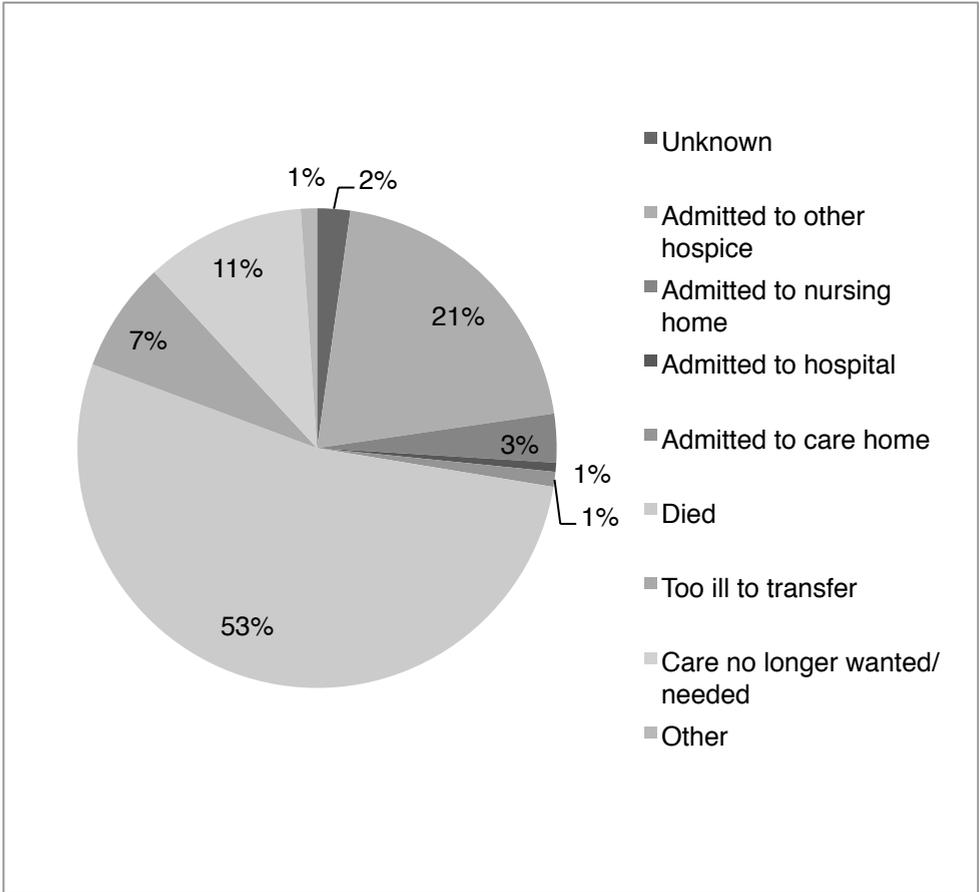


Figure 2: Reason for non-admittance to inpatient hospice facility

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Chapter 6

Does hospice care vary for patients admitted to the three types of inpatient hospice facility in the Netherlands?

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Abstract

Introduction: Three models of inpatient hospice care exist in the Netherlands, but admission is largely related to regional availability rather than need. We seek to investigate whether there are differences in patient and care characteristics between patients cared for in the three types of inpatient hospice facility in the Netherlands (hospice, 'bijna-thuis-huizen', palliative care unit (PCU)).

Methods: Data were gathered from a database on hospice admissions representing ~25% of Dutch inpatient hospice facilities from 2007 - 2012. Members of healthcare staff recorded data on standardised electronic forms.

Results: Patient characteristics were similar in all types of inpatient hospice facility. PCUs recorded the highest level of use of many ancillary caregivers. The proportion of patients who received no technical procedures was higher in 'bijna-thuis-huizen', (30.2% against 17.3%-19.4%). The majority of patients in each setting received no complementary therapies.

Conclusions: A large proportion of care is shaped by institutional characteristics leading to differences in care between similar patient groups.

Introduction

Specialist palliative care can be delivered across many settings. The modern hospice movement was catalysed by the construction of St Christopher's Hospice in London. St Christopher's was instrumental in creating a specific environment for the care of dying patients, consciously different from hospitals and other settings of care available at the time ¹.

Though palliative care has since developed away from a solely inpatient hospice facility model, inpatient hospice care does exist across the world. In the Netherlands, three types of inpatient hospice facility exist – standalone hospices, which are staffed by nurses and physicians specific to each facility, *bijna-thuis-huizen* (almost-home-homes) which have peripatetic nursing and medical staff, and the majority of care provided by families and volunteers, and Palliative Care Units (PCU) embedded in nursing homes, where the staff from the nursing home (including a physician specialized in nursing home care) attend to patients ².

The three types of inpatient hospice care operate under the proviso that their patients can no longer be cared for at home, and largely cater to the same groups of patients ³. Practically, where patients are admitted to is often related to regional availability - though ideally care given should not differ between different institutions for similar patient groups. It is known that organizational characteristics can influence care received by patients ⁴, therefore, in this paper we investigate whether there are differences between the sociodemographic and illness characteristics of patients admitted to the three types of inpatient hospice facility, and the differences

between the care received by patients who are admitted to each type of inpatient hospice facility.

Methods

The study population was taken from a database that represents ~25% of Dutch inpatient hospice facilities. Data were gathered on persons who applied for inpatient hospice care between the years of 2007 – 2012. Data were gathered from 64 inpatient hospice facilities.

The original data set contained 10502 applications to inpatient hospice care. 248 records were removed. The majority of these were duplicate records, but for patients who had more than one admission only the data from the final admission was used for analysis, and the other records were removed. This was the case for 21 patients who had between two and nine admissions each. In total, 10254 were included in the final analysis. For this study, we took only the applicants who were admitted to an inpatient hospice facility following application. The final number included for analysis was 7966.

Members of healthcare staff from participating institutions recorded data on standardised electronic forms. The form recorded demographic and application characteristics for all patients, and characteristics of care received for those admitted to inpatient hospice care.

Results

Demographic Characteristics (Table 1)

Patients were distributed almost evenly between the three settings - 2685 standalone hospice patients, 2514 bijna-thuis-huizen patients and 2767 PCU patients were included for analysis. Most patients in each setting were ages between 61-80 years, and around a third of patients in each setting are aged over 81. Sex did not differ significantly between settings.

Care Characteristics (Table 2)

The largest proportion of patients in each setting had a stay of between a week and a month. Close to a third of patients in each setting had a stay of up to one week, and around a fifth stayed for one to three months.

Nurses were involved in the care of the vast majority of patients in each setting – over 90% in all cases. Volunteers also had a high rate of involvement (between 77.7% - 94.1%). Healthcare assistants were involved least in bijna-thuis-huizen (64.5%) at the highest rate in PCUs (94.6%). Large discrepancies in involvement by setting existed in the involvement of elderly-care physicians (67.8% in standalone hospices, 7.5% in bijna-thuis-huizen and 92.4% in PCUs) and GPs (31.5%, 95.3% and 7.2%). PCUs showed the highest involvement of a number of professionals, including physiotherapists (38.7% against 18.7% of standalone hospices and 7.9% of bijna-thuis-huizen), ergotherapists (26.7% against 5.9% and 1.8%), dieticians (16.7% against 0.7% and 1.7%) and activity based therapists (16.2% against 0.7% and 1.7%). All other caregivers had an involvement of under 12% in each setting.

The most commonly used technical procedures were subcutaneous lines and catheters (35.5%-56.3% of patients in all settings). A similar proportion of patients in each setting received oxygen (19.2% - 26.7%). All other therapies were used in 5.2% or under of patients in each setting, and significant differences were only found in the use of IV lines and chemotherapy. The proportion of patients who received no technical procedures was highest in bijna-thuis-huizen, at 30.2% compared to 17.3%-19.4% of patients in standalone hospices and PCUs respectively.

The majority of patients in each setting received no complementary therapies. This was highest in PCUs at 79.6% and ranged from 60.6% in standalone hospices to 77.2% in bijna-thuis-huizen. Patients in standalone hospices received significantly higher levels of massage (27.1% against 14.5% in bijna-thuis-huizen and 9.4% in PCUs), aromatherapy (14.1% against 6.9% and 8.4%) and music therapy (13.6% against 5.4% and 4.3%). All other complementary therapies were received by less than 5% of patients in each setting.

Discussion

Strengths and Limitations

The study data were populated from a database representing one-fifth of inpatient hospice facilities across the Netherlands. The hospices selected provided a representative mix of models of hospice in the Netherlands, and were mostly recruited from the South and South-East of the country. The number of deaths included in gives statistical significance to the results. Data were recorded by means of a standardised form, incorporated into

usual patient care. This strengthens the reliability and representation of the database.

Though the data is comprehensive, and the population sizeable, the data gives no indication as to suitability of care procedures for individual patients^{5, 6}.

Models of Care

The data show significant differences between procedures of care – in terms of technical and complementary therapies, and caregivers involved – between the three types of inpatient hospice care available in the Netherlands. One possible explanation for this would be a difference in patient needs in each setting, however we didn't find differences in patient characteristics. A limited number of patient characteristics were measured for this study, which limits the amount of nuance available to assess differences in patient needs. Since we do know that regional availability has a marked affect on admittance to institutions³ it is unlikely that patient populations in each setting are admitted purely based on how their medical needs correlate with the institution. Thus, a more likely explanation of the differences in care found between settings is the effect of institutional culture and policy.

Differences in organisational expertise and availability of procedures and staff can affect the treatment received. PCUs are organisationally and spatially related to the nursing homes that they are linked to, and share services with. The higher rates of involvement of ergotherapists, physiotherapists and spiritual carers in PCUs is probably due to their

connection to nursing homes, where such professionals are already regularly employed or consulted.

The organisational philosophy of inpatient hospice care in the Netherlands is largely based on the English model spearheaded by Cicely Saunders ¹. The higher use of technical procedures in standalone hospices may indicate a top-down approach based on this more medicalised philosophy, rather than differing needs of the patient population - though this may also be ascribed in part to the facilities available in standalone hospices, or the presence of more specialised staff and thus availability for more complex procedures. The large differences also seen in use of complementary therapies are less likely to be related to patient needs or preferences, and may be a reflection of a specific culture of care that is institution wide as opposed to demand-driven.

Bijna-thuis-huizen were developed to provide care that reflects the home environment, and the lower use of many caregivers, technical procedures and complementary therapies reflects this. Very high levels of GP involvement for those cared for in bijna-thuis-huizen mirrors the structure of palliative homecare, but in a formalised setting. As patients are dependent on availability of beds in their home region, all models of inpatient hospice care should be able to provide a full spectrum of care based on actual needs of the patient rather than institutional culture ⁷.

Implications for Practise

Patient-centred care is the gold-standard for end-of-life care, but our results suggest that a large proportion of care is shaped by institutional characteristics rather than the needs of individual patients. Owing to the

fact that admittance to different types of inpatient hospice care is influenced by regional healthcare policy, institutions should be reflexive enough to provide care based on the symptoms and needs of patients regardless of what they were originally set up to cater for.

Table 1: Sociodemographic characteristics of patients admitted

	Standalone Hospice (n=2685)		Bijna Thuis Huizen (n=2514)		PCU (n=2767)		P value
<i>Age</i>	n	%	n	%	n	%	
19-40	19	0.8	13	0.6	20	0.8	
41-60	330	13.5	274	11.7	326	12.8	
61-70	482	19.7	437	18.7	437	17.2	
71-80	716	29.2	709	30.3	724	28.5	
81+	904	36.0	907	37.9	1034	39.8	.074
<i>Sex</i>							
Male	1286	47.9	1159	53.9	1463	52.9	.431
<i>Primary Diagnosis</i>							
Cancer	2279	85.4	2053	83.6	2285	83.2	
Heart Disease	147	5.5	179	7.3	177	6.4	
Pulmonary Disease	55	2.1	50	2.0	54	2.0	
Neurology (in. CVA)	72	2.7	69	2.8	98	3.6	
Other	116	4.3	106	4.3	132	4.8	.143

Missing Values: Total n (*Hospice, Bijna-Thuis-Huizen, PCU*) Age 461 (172, 118, 171), Primary Diagnosis 94 (16, 57, 21)

Table 2: Care characteristics of patients admitted

	Standalone Hospice (n=2685)		Bijna-Thuis-Huizen (n= 2514)		PCU (n=2767)		Total		P value
	n	%	n	%	n	%	n	%	
<i>Length of stay</i>									
Up to a week	870	32.4	864	34.4	921	33.3	2655	33.3	
A week to a month	1024	38.1	964	38.3	946	34.2	2934	36.8	
1 – 3 Months	581	21.6	495	19.7	607	22.0	1683	21.1	
3 – 6 Months	155	5.8	151	6.0	186	6.7	492	6.1	
Over 6 Months	55	2.0	40	1.6	105	3.8	200	2.5	<.001
<i>Caregivers involved</i>									
Nurse	2380	91.0	2453	97.6	2579	93.2	7412	93.0	<.001
Volunteer	2337	89.4	2365	94.1	2149	77.7	6851	86.0	<.001
Healthcare assistant	2043	78.1	1622	64.5	2617	94.6	6282	78.8	<.001
Elderly care physician	1772	67.8	188	7.5	2556	92.4	4516	56.6	<.001
Spiritual caregiver	1305	49.9	650	25.9	1695	61.3	3650	45.8	<.001
GP	823	31.5	2396	95.3	199	7.2	3418	42.9	<.001
Physiotherapist	490	18.7	198	7.9	1072	38.7	1760	22.0	<.001
Social worker	643	24.6	129	5.1	658	23.8	1430	17.9	<.001
Ergo-therapist	154	5.9	45	1.8	740	26.7	939	11.7	<.001
Dietician	17	0.7	43	1.7	462	16.7	522	6.5	<.001

Activity-based therapist	10	0.4	12	0.5	448	16.2	470	5.9	<.001
Carer care	312	11.9	42	1.7	42	1.5	396	4.9	<.001
Psychologist	41	1.6	35	1.4	193	7.0	269	3.3	<.001
Logopedist	21	0.8	14	0.6	81	2.9	116	1.4	<.001
Other	200	7.6	56	2.2	122	4.4	378	4.7	<.001
<i>Technical procedures involved</i>									
Subcutaneous line/pump Catheter (kidney or bladder)	1474	56.3	893	35.5	1471	53.4	3838	48.1	<.001
	1463	55.9	1123	44.7	1245	45.2	3831	48.0	<.001
Oxygen	570	21.8	482	19.2	737	26.7	1789	22.4	<.001
Stoma	137	5.2	123	4.9	131	4.8	391	4.9	.706
Tube feeding	88	3.4	75	3.0	120	4.4	283	3.5	.021
IV line	92	3.5	49	1.9	52	1.9	193	2.4	<.001
Stomach siphon	62	2.4	69	2.7	53	1.9	184	2.3	.140
Ascites puncture	34	1.3	30	1.2	33	1.2	97	1.2	.925
Tracheotomy	29	1.1	21	0.8	37	1.3	87	1.0	.213
Epidural/intrathecal pain relief	19	0.7	30	1.2	31	1.1	80	1.0	.192
Blood transfusion	19	0.7	5	0.2	21	0.8	45	0.5	.011
Chemotherapy	5	0.2	5	0.2	29	1.1	39	0.4	<.001
Artificial Respiration	5	0.2	1	-	9	0.3	15	0.1	.058

Other	44	1.7	30	1.2	31	1.1	105	1.3	.371
None	453	17.3	758	30.2	535	19.4	1746	21.9	<.001

*Complementary
care*

Massage	708	27.1	364	14.5	259	9.4	1331	16.7	<.001
Aromatherapy	370	14.1	173	6.9	231	8.4	774	9.7	<.001
Music therapy	355	13.6	135	5.4	120	4.3	759	9.5	<.001
Relaxation therapy	87	3.3	85	3.4	52	1.9	224	2.8	.001
Creative therapy	63	2.4	89	3.5	44	1.6	196	2.4	<.001
Multisensory therapy	6	0.2	8	0.3	4	0.1	18	0.2	.419
Other	12	0.4	38	1.4	4	0.1	54	0.6	<.001
None	1585	60.6	1939	77.2	2199	79.6	5723	71.8	<.001

Missing Values: Total n (*Hospice, Bijna-Thuis-Huizen, PCU*) Length of Stay 2 (0, 0,

2)

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Chapter 7

Does hospice care vary between patients with cancer, heart failure and lung disease?

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Abstract

Background: Inpatient hospice facilities still largely cater for those with cancer. If the underrepresentation of patients with other diseases is based more on access than on needs, it would be expected that these patients would not receive less/different? care than cancer patients when admitted to inpatient hospice care.

Objective: To compare care received by patients with cancer, heart failure and lung disease who are admitted to inpatient hospice care.

Design: A descriptive study using a database used in daily care.

Setting/participants: The database represents about 25% of inpatient hospice facilities in the Netherlands. All patients who were admitted to inpatient care with cancer (n=6617), heart failure (n=458) or lung disease (n=159) were included for analysis.

Measurements: Age, sex and type of inpatient hospice facility were controlled for when comparing care characteristics.

Results: In all three groups nurses (between 91.7% and 93.8%), volunteers (between 84.2% and 87.5%) and healthcare assistants (between 73.8% and 87.5%) were involved most frequently in patient care. The most commonly used technical procedures in all groups were subcutaneous lines (between 33.8% and 50.9%) and catheters (between 47.8% and 50.1%). A majority of patients in all three groups received no complementary therapies (between 72.1% and 81.5%). Controlling for sex, age, and type of

inpatient hospice facility showed no differences between the three groups for the majority of care characteristics.

Conclusions: Since patients with heart failure and lung disease do not receive less treatment when in inpatient hospice facilities, the underrepresentation of heart and lung disease patients in hospice is more likely access rather than needs based.

Introduction

Patients dying from non-malignant diseases often have high symptom burdens and other psychosocial needs that could benefit from palliative support towards the end of their lives, but are underrepresented in inpatient hospice care ^{1,2}. The relatively unpredictable and lengthy decline trajectories of non-malignant disease have been hypothesised to be a major reason for the underrepresentation of these groups in specialist palliative care ³. Whilst the terminal period of decline in cancer is often predictable in the deterioration of function for patients, this phase of many non-malignant diseases is characterised by a slow functional decline punctuated by a number of crises and recoveries ⁴.

Even with this hypothesis, it remains unknown whether the underrepresentation of diseases other than cancer is due to issues of need, or of access. If the underrepresentation of patients with other diseases is based more on access than on needs, it would be expected that these patients would not receive less care than cancer patients when admitted to inpatient hospice care. This paper therefore aims to investigate the sociodemographic characteristics of three groups of patients admitted to inpatient hospice care, and look at any differences present in sociodemographic characteristics and care received by cancer, heart failure and lung disease patients.

Methods

The study population was taken from a database that represents around 25% of inpatient hospice facilities in the Netherlands. Healthcare staff from participating institutions filled in electronic forms to record information. Data

were gathered on those who requested inpatient hospice care in the six years from 2007 – 2012 ,from 64 institutions. In the Netherlands there are three types of inpatient hospice facility: Palliative Care Units (PCUs) embedded in tertiary and non-tertiary care facilities such as nursing or care homes, and two distinct types of standalone hospices. These are *bijna-thuis-huizen* (almost home homes), which are staffed by healthcare assistants and volunteers and have visiting nursing and medical staff, and standalone hospices with a permanent staff of nurses and physicians.

The original database contained 10502 cases of persons who applied for inpatient hospice care. 248 records were removed, mainly due to duplication in records – though in 21 cases patients had more than one admission recorded. For these patients, only the last admission was included for analysis. For this study, we took only applicants who were admitted to inpatient care (n=7966), and then selected patients with cancer, heart failure or lung disease. The final number included for analysis was 7234.

Logistic regressions were performed to control for differences of age, sex and type of institution when comparing care characteristics between the three disease groups.

Results

Demographic characteristics (Table 1)

6617 cancer patients, 458 heart failure patients and 159 patients with lung disease were included for analysis. Most patients in each disease group were over the age of 61, however the spread differed significantly between

groups - 53.1% of cancer and 44.7% of lung disease patients were aged between 61-80 years, whereas in the heart failure group the majority of patients fell into the 81+ years age bracket at 75.7%. A similar number of patients in the cancer and lung disease groups were male (47.9% and 54.1% respectively), whilst this was lower in heart disease patients at 41.3%.

A high proportion of patients in each group lived alone – between 47.1% of lung disease and 57.6% of heart failure patients. Lung disease patients relatively more often came from institutional settings (14.3% against 4.5% of cancer patients and 11.2% of heart failure patients).

Care Characteristics (Table 2)

Stays of less than a week and between a week and a month showed significant differences according to disease after controlling for sex, age and type of institution. Heart failure and lung disease patients had the highest proportion of patients staying up to one week, at 42.5% and 35.2% respectively. For cancer patients, the highest proportion (38.0%) stayed in inpatient hospice facilities for between a week and a month.

In all three groups, nurses (between 91.7% and 93.8%), volunteers (between 84.2% and 87.5%) and healthcare assistants (between 73.8% and 87.5%) were involved most frequently in the care of patients. In over half of patients elderly care physicians (between 58.6% to 51.9%), and in just under half of patients GPs were involved in patient care (between 36.9% to 46.2%). Of non-medical caregivers, in all three groups spiritual caregivers were most frequently involved (between 42.9% to 51.6%),

followed at distance by physiotherapists (between 19.1% and 29.9%), social workers (between 17.6% and 24.2%) and ergotherapists (between 9.5% and 15.9%). All other caregivers were involved in less than ten percent of cases in all three groups. After controlling for age, sex and type of institution there were differences in involvement of four types of caregivers. Compared to cancer and heart failure patients, patients with lung disease more frequently received care from healthcare assistants, physiotherapists and social workers.

The most commonly used technical procedures in all groups were subcutaneous lines (between 33.8% of heart failure patients to 50.9% of cancer patients), catheters (between 47.8% to 50.1%) and oxygen (between 21.0% for cancer patients to 70.7 for lung disease patients). All other technical procedures were performed in five percent or less of all patient groups. After controlling for age, sex and type of institution, significant differences between disease groups remained for the use of three procedures. Subcutaneous lines were used more highly in cancer and lung disease patients than in heart failure patients. Oxygen was used much more frequently in lung disease patients than in patients with heart failure and cancer. Heart failure patients saw the lowest use of stomas at 0.4% against 2.5% of lung disease patients and 5.5% of cancer patients. The number of patients receiving no technical therapies also remained significant at 7.6% of lung disease patients, against 22.0% and 25.8% of cancer and heart failure patients respectively.

A large majority of patients in all three groups received no complementary therapies (between 72.1% to 81.5%). If complementary therapy was given, this most frequently was massage - between 8.9% of lung disease patients

and 17.3% of cancer patients. After controlling for age, sex and type of institution, only one therapy showed significant differences: lung disease patients more frequently received relaxation therapy than cancer and heart failure patients (5.1% versus 2.6% to 3.3%).

Discussion

Strengths and Limitations

The high number of patients included in the study population gives significance to the findings. Data were gathered by means of a standardised process, incorporated into the usual process of patient care and admission - a reliable and cross-verifiable means of data collection.

However, the study also has limitations - the data do not indicate any measure of suitability of care for the different patient groups, thus the results cannot be interpreted as providing a measure of such.

Access or need?

We found more similarities than differences between inpatient hospice care given to patients with cancer, heart failure, and lung disease. Differences found partly reflect a patient-level needs-based approach with, for example, oxygen being used at a much higher rate amongst lung disease patients than other groups. However, there are also differences in the use of some caregivers between the groups not clearly attributable to disease – such as the significantly higher involvement of social workers in the lung disease group.

Inpatient hospices facilities do still largely cater to those dying from cancer, however our data show that after admittance neither heart failure nor lung disease patients have a lower usage of care than those with malignant disease. A recent systematic review by Moens et al.⁴ found multiple common symptoms in end-of-life patients across disease groups. This suggests that, though care needs may vary for individuals with different diseases, the underrepresentation of patients with non-cancer diagnoses in inpatient hospice facilities is likely to be attributable to access to services rather than the need for care on an individual level. This may be related to prognosticating life expectancy - which is even more difficult with diagnoses other than cancer⁵.

Structural issues affecting the admittance of those with non-malignant diseases were highlighted by Skilbeck and Payne as early as 2005⁶, though their proposed model of structuring care based on patient problems has not been adopted across service delivery models. Documents such as the Supportive and Palliative Care Indicators Tool aim to identify patients, and use a combination of general signs of deteriorating health and disease-specific information to determine the potential palliative care population⁷.

Implications for Practise

Equity of access to care and caregivers should apply to all patients - further consideration should be taken to ensure that care is based on the needs of individuals, and not determined by life expectancy or diagnosis.

Table 1: Sociodemographic Characteristics of Patients Admitted

	Cancer		Heart Failure		Lung Disease		P value
	(n=6617)		(n=458)		(n=159)		
Age	n	%	n	%	n	%	
19-60	898	14.5	11	2.5	12	8.0	
61-80	3298	53.1	95	21.7	67	44.7	
81+	2015	32.4	331	75.7	71	47.3	<.001
Sex							
Male	3169	47.9	189	41.3	86	54.1	<.001
Living situation							
Alone	3098	51.6	247	57.6	66	47.1	
With Partner	2077	34.6	110	25.6	49	35.0	
In Institution	273	4.5	48	11.2	20	14.3	
With Children	346	5.8	11	2.6	3	2.1	
Other	214	3.6	13	3.0	2	1.4	<.001
Type of institution							
Hospice	2279	34.4	133	29.0	55	34.6	
Bijna Thuis Huis	2053	31.0	166	36.2	50	31.4	
PCU	2285	34.5	159	34.7	54	34.0	<.001

Missing Values: Total n (Cancer, Heart Failure, Lung Disease) Age 436 (406, 21, 9), Religion 1828 (1707, 82, 39), Living Situation 657 (609, 29, 19)

Table 2: Care Characteristics of Patients Admitted

	Cancer (n=6617)		Heart Failure (n= 458)		Lung Disease (n=159)		P value	Adjusted P value
	n	%	n	%	n	%		
<i>Length of stay</i>								
Up to a week	2076	31.4	193	42.1	56	35.2		<.001
A week to a month	2516	38.0	136	29.7	51	32.1		.003
1 – 3 Months	1450	21.9	89	19.4	35	22.0		.357
Over 3 Months	575	8.7	40	8.7	17	10.7	<.001	.733
<i>Caregivers involved</i>								
Nurse	6151	93.8	431	94.7	144	91.7	.251	.346
Volunteer	5738	87.5	383	84.2	136	86.6	<.001	.063
Healthcare assistant	5260	80.2	335	73.6	133	84.6	<.001	.006
Elderly care physician	3798	57.9	236	51.9	92	58.6	<.001	.237
Spiritual caregiver	3048	46.5	195	42.9	81	51.6	.067	.329
GP	2809	42.8	210	46.2	58	36.9	<.001	.029
Physiotherapist	1455	22.2	87	19.1	47	29.9	.004	.013
Social worker	1157	17.6	95	20.9	38	24.2	.006	.012
Ergotherapist	788	12.0	43	9.5	25	15.9	.035	.077
Dietician	422	6.7	24	5.3	13	8.3	.548	.244
Activity-based	401	6.1	19	4.2	11	7.0	.007	.255

therapist									
Carer support	342	5.2	29	4.2	6	3.8	.037	.745	
Psychologist	215	3.3	19	4.2	5	3.2	.785	.488	
Logopedist	85	1.3	3	0.7	3	1.9	<.001	.590	
Worker from CZ	38	0.6	2	0.4	1	0.6	.374	.979	
Other	271	4.2	14	3.0	10	6.3	.011	.185	

*Technical
procedures
involved*

Subcutaneous	3338	50.9	153	33.8	76	48.4	<.001	<.001
line/pump								
Catheter (kidney or								
bladder)	3134	47.8	227	50.1	75	47.8	<.001	.623
Oxygen	1374	21.0	161	35.5	111	70.7	<.001	<.001
Stoma	363	5.5	2	0.4	4	2.5	<.001	.001
Tube feeding	221	3.4	6	1.3	4	2.5	<.001	.464
IV line	171	2.6	4	0.9	2	1.3	.641	.191
Stomach siphon	171	2.6	0	-	1	0.6	.002	.423
Ascites puncture	89	1.4	2	0.4	0	-	.306	.451
Tracheotomy	75	1.1	1	0.2	0	-	.012	.455
Epidural/intrathecal								
pain relief	72	1.1	4	0.9	1	0.6	.957	.870
Blood transfusion	41	0.6	1	0.2	0	-	.985	.614
Chemotherapy	39	0.6	0	-	0	-	.950	1
Artificial	10	0.2	0	-	0	-	<.001	1
Respiration								

Other	82	1.2	4	0.8	6	3.8	<.001	.043
None	1441	22.0	117	25.8	12	7.6	<.001	<.001

Complementary

care

Massage	1132	17.3	69	15.2	14	8.9	<.001	.062
Aromatherapy	670	10.2	31	6.8	7	4.5	<.001	.054
Music therapy	505	7.7	33	7.3	8	5.1	.186	.596
Relaxation therapy	172	2.6	15	3.3	8	5.1	<.001	.028
Creative therapy	166	2.5	8	1.8	3	1.9	.010	.964
Snoezelen	13	0.2	0	-	0	-	<.001	1
Other	45	0.7	3	0.7	2	1.2	.999	.489
None	4731	72.1	343	75.4	128	81.5	.002	.079

Missing Values: Total n (*Cancer, Heart Failure, Lung Disease*) Length of Stay 2 (2, 0, 0)

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Chapter 8

General Discussion

Introduction

This thesis aimed to comprehensively explore, through a combination of qualitative and quantitative approaches, differences in palliative care between settings; firstly through comparing hospice to other common settings, and secondly by investigating differences between populations and types of inpatient hospice facility in the Dutch palliative care model.

Starting with a reflection on the relevance of comparative research on palliative care between different settings, this final chapter brings together the findings from the individual chapters, to synthesise and discuss what this study contributes in terms of understanding what hospices are, whom they care for, what their care consists of and how this compares to other settings. The chapter culminates in recommendations for policy, practice and research – both in terms of lessons for hospice, and lessons from hospice for other settings of care.

Reflection

This thesis is based on a comparative approach, aimed at describing and comparing end-of-life care in a diverse range of settings. Critics may argue that examining differences between end-of-life settings in terms of care philosophy, population, medications, procedures and processes adds little to the knowledge base if these differences simply reflect the diversity of aims and target populations of the particular settings. This thesis, however, demonstrates that a thorough understanding of *who* is cared for in different settings and *what* care they receive can help to inform policy and contribute recommendations for clinical practice. Conversely, an assumption of

difference without a thorough exploration of the dimensions only serves to perpetuate the status quo and propagates existing inequities further.

The comparability of patients between settings may also be questioned. The studies included in this thesis contain no information about patients' desire for palliative or more 'aggressive' care. Comparing basic patient personal and health characteristics between settings gives no indication of the predictability of individual patients' disease course – for example whether the cancer patients who die in inpatient hospice facilities are comparable to those who die in hospital. Throughout this thesis, however, steps have been taken to control for possible confounders, such as age and gender, which may affect the predictability of the disease course. It may also be argued that, regardless of the patient mix, in all settings where people meet the end of life holistic and appropriate palliative care should be available.

What are inpatient hospice facilities?

The development of inpatient hospice facilities as a specific setting for patients who are not seeking curative care has existed in a number of forms throughout history. The first inpatient hospice facilities were built on pilgrimage routes to provide care for travellers who were not expected to survive their journeys¹. Such institutions were common across Europe until the twentieth century, when Cicely Saunders began to make scientific advances in the treatment and care of the dying whilst working at St Joseph's Hospice in Hackney. Saunders' work in this area formed the basis of her philosophy for establishing St Christopher's Hospice in South East London. St Christopher's is widely considered to be the first modern

inpatient hospice facility, and was developed with a specific philosophy and set of aims for both its patients and staff ².

Chapter 2 explores the development of the physical environment of St Christopher's as it was being planned and built in the 1950s. Using data from the Cicely Saunders archive, five key themes were developed through iterative analysis of notes and documents that linked palliative care as a concept with the physical environment of St Christopher's. The overarching theme identified was *home/homelike* – within this major theme four sub-themes were also recognised: *community*, *consideration for others*, *link with the outside world* and *privacy*. Within *home/homelike* as an overarching theme the concept of an environment constructed to be like a home was posited as the opposite of the conventional hospital environment and was a key driver in the development of a unique physical environment for inpatient hospice facilities. This reference to inpatient hospice facilities representing a homelike situation for patients who don't have the option to stay at home is still a central aim of inpatient hospice care in many places ³.

All sub-themes can be seen as key aspects of the inpatient hospice philosophy, and had an influence on how the physical environment was constructed to reflect these themes. Space around the beds, for instance, and the ability to push beds to different locations was key both in maintaining patients' privacy and facilitating loved ones being involved in care. *Community* was the second theme identified from the archive data, and many notes focussed on the drive to redefine "normality" for inpatient hospice patients. This focus echoes Habermas' concept of the constructed lifeworld ⁴ – the extent to which an institution needs to provide a holistic structure for its patients or users to inhabit. In inpatient hospice care, this

was seen to be fundamentally different to acute hospital care, with the non-pursuit of curative care being key in the formation of a community of patients. The construction of a separate environment, specifically catering for terminally ill patients situates this often-maligned population as the social norm within the inpatient hospice environment. The conscious development of an environment for patients who are no longer seeking curative treatment echoes the social separation found in Foucauldian heterotopia ⁵ – spaces that exist to separate bodies and persons who deviate from the accepted social norms. This has important implications for the philosophical situation of end-of-life care as a distinct speciality – the continued separation of palliative care reflects the separation of patients who are not seeking cure.

The physical structure of environments of care has been a source of conscientious concern since at least the times of Florence Nightingale, who described “*the want of fresh air, or of light, or of warmth, or of quiet, or of cleanliness*” as a key concern in caring for the sick in 1859 ⁶. The development of the physical environment of inpatient hospice facilities, starting with St Christopher’s, was part of a conscious decision to move away from the hospital environment. As palliative care developed as a specific approach, a focus on the physical environment has always been at the forefront of the identity of inpatient hospice facilities, and over time these same principles have transferred to other long-term and terminal care environments.

Inpatient hospice care worldwide

Hospice as a specific form of organisational healthcare reflects key parts of Cicely Saunders' own end-of-life philosophy, including the psychosocial and spiritual element of total pain ⁷. Many types of inpatient hospice care have developed in today's multitude of healthcare systems. A study in 2009 recorded 10,000 international palliative care programmes – though these took many different forms ⁸. A 2006 survey recorded specialist palliative care available in 15% of countries worldwide ⁹. Such programmes do not always take the form of inpatient hospice services, but may integrate the palliative care philosophy into existing institutions or provide care outside of the boundaries of any specified institutional setting. The common point of these services is that they create a socially normalising lifeworld for the dying. In recognising that the particularistic characteristics of local cultural frameworks should be reflected in creating such a lifeworld, it is not surprising that a variety of kinds of inpatient hospice care have developed in which the physical space and social organisation of each institution changes.

Inpatient hospice facilities in the Netherlands

Inpatient hospice care in the Netherlands has evolved in a way unique to the country's healthcare structure and existing frameworks of medical specialism. The Netherlands has a strong emphasis on primary care, and GPs act as the contact point for this as well as overseeing end-of-life care in care homes and the home setting ^{10, 11}. Any person, including the patient and their informal caregivers, can make an application for inpatient hospice care. Applications to inpatient hospice care in the Netherlands are not

centrally regulated or coordinated, and are made directly to individual inpatient hospice facilities for care until death or respite ¹². Inpatient hospice care is split between three main types of institutional model:

Standalone hospices in the Netherlands provide a more formally medicalised option for end-of-life care. As well as providing a homelike environment they offer a number of technical interventions. They are largely based on the UK-developed inpatient hospice model, and have the facilities to provide certain technical treatments and procedures, alongside complementary therapies and access to specialist staff. Standalone hospices usually have a dedicated hospice physician and nurses on-site.

Bijna-thuis-huizen roughly translates as “almost-home-homes”, and is a model of care developed to reflect the home environment. They typically have a high level of GP involvement, as home palliative care would, but in a specific physical location. Bijna-thuis-huizen are very much care-focussed, can be very small and are generally staffed by volunteers and visited by district nurses.

Palliative care units are organisationally, and often physically, linked to nursing homes – with which they share facilities and access to specialist staff. PCUs are intended for those from outside the main nursing home, and patients are primarily cared for by elderly care physicians. As nursing homes more regularly use visiting staff such as physiotherapists and spiritual carers within usual care, links to these can be stronger for patients in PCUs than in other settings. A survey in 2012 recorded 256 palliative care services active across the Netherlands, with 62% of these being palliative care units (PCUs) in nursing homes ¹³.

Each of these models has a particular approach to space and environment, as determined by the environments that they coexist and interact with. Each of the three models emphasise a home-like environment of care for patients and their families, though this is strongest in bijna-thuis-huizen; standalone hospices and palliative care units in nursing homes focus on medical and therapeutic intervention more than other models.

Who is cared for in inpatient hospice facilities, and who is not?

A 2008 Europe-wide telephone survey found that 10% - 30% of the population would like to die in an inpatient hospice setting ¹⁴ - in the Netherlands this was 11% of respondents. From the Dutch death certificate study (**Chapter 4**) we know that of all non-sudden deaths in the Netherlands in, 10% died in an inpatient hospice setting. Almost half of these patients were aged 80 years or over, 36% were married and the majority (76%) had died of cancer.

Access to care in an inpatient hospice facility can vary widely across countries and health systems, but also within single systems by diagnosis and social factors ¹⁵. **Chapter 5** focussed on the differences between patients who applied for, and patients who were admitted to, inpatient hospice care in the Netherlands. This study utilised a Dutch database of patients applying for inpatient hospice care between 2007 and 2012 – this database was managed by the comprehensive cancer center of the Netherlands (IKNL). Data were gathered from 64 institutions that provide inpatient hospice care. Not all institutions provided data for all years, but each provided data for one or more years of this timespan. Given the 212 inpatient hospice facilities in the Netherlands in 2013, this means that

around a quarter of all inpatient hospice facilities are involved in providing data ¹³. Healthcare professionals in each institution recorded data concerning demographic, application and stay characteristics of those who applied.

Of all registered applicants between 2007 and 2012 (10254), 78% were admitted to inpatient hospice care. Several factors were found to be positively associated with admission: living alone, having cancer, relief for caregivers as a reason for application, pain and symptom control as a reason for application, wanting care until death (vs. respite care), wanting admission as soon as possible and referral by a GP. These factors seem to suggest that patients who are admitted to inpatient hospice care are those who are most urgently in need of hospice care. However for some factors, like having cancer, it is uncertain whether patients are more urgently in need of palliative care or whether there are other factors that play a role in the overrepresentation of this patient group.

Inpatient hospice care was originally developed for the dying cancer population, and this is a bias still reflected widely today. We found that a large majority of those applying for inpatient hospice care had a cancer diagnosis (84%) – though the percentage of deaths from cancer nationally is just 37%. In addition to this, patients with cancer had a significantly higher chance to be admitted to inpatient hospice care than other patients. As with our data from the Netherlands, worldwide literature reports a higher population of cancer patients than those with other diagnoses dying in the inpatient hospice setting – inpatient hospice facilities in England reporting that 17% of all cancer deaths occur in the inpatient hospice setting, in stark contrast to just 0.4% of non-cancer deaths ¹⁶. This figure is reflected

elsewhere in Europe, where non-cancer patients are consistently a minority of recipients of inpatient hospice care – 10% in the UK, Spain and France, 11% in Poland, 20% in the Netherlands and a high of 40% in Italy – despite cancer only accounting for ~25% of deaths across Europe ¹⁷.

A commonly cited reason for the underrepresentation of non-cancer patients in inpatient hospice facilities is the relative unpredictability of non-malignant diseases in the end stage ¹⁸. Two potential scenarios exist that address the under-representation of non-cancer patients in inpatient hospice care – that non-cancer patients are underrepresented by inpatient hospice facilities, or that non-cancer patients have less needs that can be addressed by inpatient hospice care. Previous studies have found symptom burdens in non-malignant disease that specialist palliative care addresses – such as breathlessness, pain and social isolation ¹⁹. This suggests that the first posited scenario is more likely to be true.

Chapter 5 shows that the most frequently recorded reasons for admission to hospice included the wish to die in hospice (71%), needing intensive care or support (52%), relieving caregivers (41%) and needing pain/symptom control (40%) – of these reasons, relieving caregivers (OR 1.18) and needing pain and symptom control (OR 1.72) were positively associated with being admitted. These are reasons that seem applicable across diagnoses, and care should be taken to ensure that referrals are made for patients from all disease groups based - on need rather than diagnosis or life expectancy to avoid non-cancer patients being underrepresented.

Specifically in the Netherlands, this underrepresentation may also be attributable to the health care system, as nursing homes provide care for many non-cancer patients at the end of life. As seen in **Chapter 4**, the majority of patients who die in inpatient hospice facilities have cancer but most patients who die in a nursing home have a central nervous system disease (including stroke) or lung disease. These conditions are characterized by a longer disease trajectory and a more unpredictable death¹⁸. It is likely that these patients were already admitted to the nursing home before their last months of life, and were then cared for in the nursing home until they died. The insurance criteria that stipulate inpatient hospice care as being for those in the final three months of life also facilitate the overrepresentation of cancer patients in inpatient hospice facilities, due to the relatively predictable period of decline in end-stage cancer¹⁹. Finally, applications to inpatient hospice facilities for care in non-malignant diseases may also be affected by the prevailing assumption that inpatient hospice facilities are only for cancer patients, and difficulties in referring non-cancer patients to inpatient hospice services²⁰.

What care do patients receive in inpatient hospice facilities?

In comparing care across different settings, it is important to first build a picture of the type of care that patients receive in specific institutions. Data from several chapters aid us in identifying processes and characteristics of care in the inpatient hospice setting. **Chapter 6** explored the differences in inpatient hospice care received according to the model of hospice in which care was provided. By looking at the stay characteristics of patients from all three models in total, we can glean information about care in hospices in general as an institutional model. Firstly, we looked at stay characteristics.

Our analysis showed that 70% of patients stay in an inpatient hospice facility for up to one month, with 21% staying for between one and three months and 9% for over three months. The shift in treatment aim to a palliative one is likely to coincide with admittance to an inpatient hospice facility – data from **Chapter 4** show that around two thirds of patients who died in an inpatient hospice facility had a palliative treatment aim as a priority for weeks or months before death.

There were a number of differences in staff involvement and the use of medical interventions following admittance to an inpatient hospice facility. Over three-quarters of patients who died in an inpatient hospice facility received care from nurses, volunteers and healthcare assistants, however far fewer received care from allied health professionals such as physiotherapists (22%), social workers (18%) and psychologists (3%). Many patients had technical procedures performed following admittance to inpatient hospice care, however around a fifth of patients received none. Of those who did receive technical procedures, the most common (48%) undertaken in an inpatient hospice facility were the insertion of a subcutaneous line or catheter. Furthermore, 22% of patients received oxygen and 5% had stomas fitted. Data from **Chapter 4** showed that 85% of patients in the Netherlands who died in an inpatient hospice facility received morphine in the final 24 hours of life. This figure is similar to the 88% of patients who received morphine in Italian inpatient hospice facilities in the final 24 hours of life (**Chapter 3**).

Complementary care was received by approximately one-third of patients, and this was most frequently delivered in the form of massage (17%), aromatherapy or music therapy (10%). These figures, alongside data from

Chapter 6 record a limited provision of complementary treatments in standalone hospices, which indicates that this model of inpatient hospice care appears to be more focussed on care than treatment. The data showed less multidisciplinary staff involved in the care of the dying than was anticipated by Cicely Saunders' original model of inpatient hospice care. This can be seen particularly in the low percentage of patients who received complementary care – a key tenet of Cicely Saunders' original model of care ².

Differences in care received between disease groups

Even within a single care model, care can vary across patients with different characteristics. **Chapter 7** explored process of care for patients with cancer, lung disease and heart failure – the three most common diseases in the Netherlands at the end of life – amongst patients who were admitted to inpatient hospice care. The study found more similarities than differences in care characteristics for each of the three groups. In terms of care characteristics, length of stay was variable between patient groups - especially in terms of the shortest and longest stays. The highest proportion of those with a stay of one week or less were heart failure patients (42%) compared to 31% of cancer patients and 35% of lung disease patients. Conversely, a higher proportion of lung disease patients stayed for over three months compared to other patients groups, at 11% compared to 9% of both cancer and heart disease patients.

There were also differences in care between the groups after admittance to inpatient hospice care. Heart failure patients had a generally lower involvement of different types of caregivers, including healthcare assistants

(74% vs. 80-84%), ergotherapists (10% vs. 12-16%), dieticians (5% vs. 7-8%) and activity based therapists (4% vs. 6-7%). In terms of technical procedures received, lung disease patients had a far higher usage rate of technical procedures than other groups, with only 8% receiving none following admittance, compared to 22% of cancer patients and 26% of heart failure patients. Some of these differences between groups reflect needs based differences – such as higher oxygen use amongst those with lung disease – however differences in specialist caregivers, for instance, did not have a directly disease-attributable reason. This might be attributed to differences in the recognition of palliative care needs, especially amongst non-cancer patients. Such differences may also be due to a lack of opportunities to involve other staff in care – either because of institutional culture differences between individual institutions, or length of stay where the patient is well enough to engage with other types of therapies.

Differences between types of inpatient hospice facilities

Chapter 6 explored the differences in treatment practices and philosophy found in the different models of inpatient hospice care in the Netherlands. In exploring differences in demographic and care characteristics for patients admitted to standalone hospices, *bijna-thuis-huizen* and palliative care units (PCUs), this study found similar patient characteristics across settings but different patterns of professional involvement and therapy use. In terms of basic stay characteristics, length of stay was distributed similarly between settings – roughly a third of patients stayed for a week or less, a third for one week to one month and a third for over a month.

We also investigated care received across the different models of care. Over 60% of patients in each setting received care from nurses, volunteers and care assistants. Of the three settings, PCUs consistently showed the highest level of involvement for a number of professionals including physiotherapists (39%), dieticians (17%) and activity-based therapists. GP involvement in care was the highest in bijna-thuis-huizen at 95% as they are central to this model of care provision – standalone hospices saw a 32% involvement, and PCUs 7%. Conversely, patients in PCUs had elderly care physicians involved in 92% of cases, primarily because this model of care is built around nursing homes, where such staff are resident. In contrast, elderly care physicians were involved in 68% of standalone hospice cases and 8% of care in bijna-thuis-huizen. Treatment received in each care setting varied, and there were differences in both the use of drug treatments and complementary therapies. The highest proportion of patients receiving no drug treatment therapies was found in bijna-thuis-huizen (30%), and the highest percentage of patients receiving no complementary therapies was found in PCUs (80%). Such differences may be due to both the availability of therapies and institutional cultural differences. Bijna-thuis-huizen are designed to provide a very homelike environment, with a deliberately low level of medical intervention – thus it would be outside of their core remit and ability to facilitate high-intervention care for patients.

Dying outside of inpatient hospice facilities

From its roots in the inpatient hospice setting, palliative care has developed to include almost all settings where healthcare is delivered. How palliative care is delivered in different settings is still the subject of much research.

Chapter 4 of this thesis investigated the differences between the dying process in different study settings across the Netherlands - using data from death certificates of people who had died in inpatient hospice facilities, homes, nursing homes and hospitals to assess the extent to which the palliative approach was used in the care of the dying patient. These data revealed large differences between care and the palliative approach between the different settings. The extent to which patients' care was considered primarily palliative was a significant difference. Of patients who died in hospital, 53% did not have a primarily palliative treatment aim before death, compared to 4-16% in other settings. The highest proportion of patients with a palliative treatment aim that had been in place for a number of months before death was found in nursing homes, at 43% compared to 7-30% in other settings.

Treatment patterns also varied significantly between settings, both in terms of care that patients received and caregivers involved. Specialist palliative care consultant or team access was highest - outside of inpatient hospice facilities - in the home setting at 13% compared to 5% in hospital and 2% in nursing homes. Different generalist carers also have varying involvement in end-of-life care – for example, elderly care physicians are trained to care for patients until the end of life. Thus, the skills and experience of patients' primary physician – which varies according to setting – may also have an influence on the need for other specialists. Structural variations in care provision may account for such differences, with palliative care teams being already embedded into the culture and practice of home-care systems for patients with chronic and terminal diseases. Pain specialists were accessed in 4% of cases in both home and hospital, and 1% of cases in

nursing homes, against 4% of cases in inpatient hospice facilities. Other institutions follow different ways of integrating specialists and outside teams into care, and this can be seen in different usage rates of professionals. Access to psychological/psychiatric care and spiritual care was highest in nursing homes, at 14% and 23% respectively – compared to between 2%-7% of other non-hospice settings. Drug use was similar across settings. Morphine use varied between 73% at home to 75% in hospital, compared to an 85% usage rate in inpatient hospice facilities. In both hospital and nursing homes, administration of morphine most frequently began in the final 24 hours before death whilst at home the highest proportion of patients receiving morphine had started the drug over one month before death, and in inpatient hospice facilities between a week and a month before death.

These findings echo those from **Chapter 3**. This study compared care in the final three days of life in hospitals and inpatient hospice facilities across Italy, and found a significantly higher usage of opioid drugs in inpatient hospice facilities than hospitals (88% compared to 67%). When drugs were classified as potentially appropriate or inappropriate according to expert opinion, hospitals consistently showed a higher usage of potentially inappropriate drugs in patients nearing the end of life, and a lower usage of potentially appropriate drugs such as opioids, haloperidol, midazolam and drugs for pulmonary secretions. 75% of patients in hospital received three or more potentially inappropriate drugs in the final three days of life compared to 43% in inpatient hospice facilities. The use of technical procedures was also investigated, with procedures being classified as being either therapeutic or diagnostic. All diagnostic procedures were used at higher rates in hospital than in inpatient hospice facilities, and of

therapeutic procedures only vesical catheterisation (60% vs. 55%), artificial hydration (24% vs. 15%) and bronchial aspiration (18% vs. 12%) were used at a higher rate in inpatient hospice facilities than hospital. When different patient characteristics were controlled for, it was shown that care setting had a unique contribution to the differences found in the use of drugs and procedures.

The type of differences found between care settings may be indicative of a fundamental difference in recognising the need for a palliative rather than curative approach, and enacting this efficiently within the institutional framework. As **Chapter 5** illustrated, admission to an inpatient hospice facility is not solely based on individual need or preference but may also be dependent on referral practices. Thus there is a real need for palliative care to be accessible across the full spectrum of care settings. Differences in institutional philosophy and culture can have a major effect on treatment provided and received by patients. Currently in the Netherlands 28% of the population who die non-suddenly die in the hospital setting, so it is of particular importance the end-of-life care provided in hospitals is scrutinised and that hospitals continue to be a key area for further research and innovation in palliative care. In the Netherlands, a major focus is the improvement of hospital care at the end of life through the use of specialist palliative care teams. There are already such initiatives in practice, and there are plans to further develop and expand such services. Insurance companies are a major backer of this type of initiative, and are also pushing for the further inclusion of consultant-lead teams in hospital palliative care.

The recognition of the dying phase and the cessation of curative treatment in hospital particularly can be fraught, and initiating a palliative treatment

aim can be a difficult process. The culture of hospitals can tend towards death being seen as a failure of medical interventions, and this can impact on the dying experience of the patient and their family as active treatment is continued and the holistic palliative care approach delayed. Abarshi et al.²¹ noted that across the Netherlands, up to 80% of patients in hospitals didn't have the dying phase recognised, and this can affect the dying experience for both the patient and their family^{22, 23}. Such delays in beginning primarily palliative treatment may also reflect the facilities available. Of all settings investigated, it is likely that only hospitals would have the necessary facilities to pursue continued diagnostic test and particular treatments so differences must be considered structurally as well as culturally.

Models of integrating palliative care

As inpatient hospice facilities and palliative care have developed, it has been recognised that the philosophy of palliative care can, and should, be applied across different institutions. The aging demographic of the European population makes the need for widely accessible palliative care ever more pertinent. As the population's age of dying increases, so does their likelihood of dying with chronic illnesses – both malignant and non-malignant. The range of care needed will vary widely according to individual patients, diagnoses and care needs, but must be holistic and accessible to all. In order to facilitate palliative care within disparate settings, many institutions use a range of specialist end-of-life care interventions to integrate the principles pioneered in inpatient hospice care into other environments and structures.

An increasingly common model of incorporating specialist palliative care outside of the inpatient hospice setting is by using a team of staff who are specialised in providing palliative care. This may be physician or nurse lead, and can incorporate any number of combinations of allied specialists. This is an integration model that is particularly used in general hospital wards. Specialist palliative care teams initially developed in part as a reaction to the poor experience of dying in hospital and a reported lack of access to staff with specialisation in palliative care ²⁴. Access to such teams can have marked benefits. Yang et al. found that patients and families in acute hospitals particularly valued the input of a specialist palliative care team for physical symptom control, psychological support and providing a consistent point of liaison ²⁵. There is also evidence that specialist palliative care teams can have a positive influence on hospital admissions, symptom control, prescribing practices and patient's access to multidisciplinary care ²⁶. Introducing targeted palliative care outside of the inpatient hospice setting need not involve specialist staff, and the training of generalists in palliative and end-of-life medicine is also an important consideration in expansions of palliative care provision. The Netherlands in particular has built its end-of-life policies around the belief that generalists should be specifically trained in providing palliative care, and should be supported in cases where further specialisation is necessary ^{27, 28}. Current policies point to an intention to make palliative care part of the curriculum for both GPs and nurses, and a nationwide network of specialists and specialist education is available through the Integraal Kankercentrum Nederland (IKNL).

Other measures brought in to facilitate specialist palliative care in non-specialist settings focus on structural issues to drive palliative care forwards. Outside of the Netherlands, a 2012 systematic review ²⁹ found few collaborative arrangements and structures between generalist and specialist staff caring for patients at the end of life. This lack of a clear structural arrangement could lead to gaps in service provision and ultimately negatively affect the patient and their family. To combat the possibility of such issues, frameworks such as the Gold Standards Framework ³⁰ in the UK and the PaTz ³¹ in the Netherlands aim to strengthen the knowledge of generalist practitioners in different settings within a unified framework, enabling them to provide effective primary palliative care within a supportive training network. Integrated care pathways and practice frameworks provide a means of enabling a palliative care focus within the generalist setting. A number of pathways exist, which provide prompts, checks and measures designed to echo the inpatient hospice care focus. This may include the inclusion of non-medical staff in care, and a review or cessation of certain drugs or procedures used ³². The use of integrated care pathways can allow the involvement of multidisciplinary carers without a formal specialist palliative care team needing to be in place. Care pathways have been noted to improve care coordination, allow the cessation of inappropriate routine care and promote a proactive approach to palliative care within the non-specialised setting ³³,

³⁴ .

Strengths and Limitations

Qualitative Archive Study

Data from an archive of Cicely Saunders' collected written and published materials at King's College London were analysed to explore the development of the philosophy of inpatient hospice care. The design and construction stage of St Christopher's hospice was focussed on in order to build a comprehensive study of the philosophy and motivations that underpinned the development of this model of care.

The foremost strength of this study was the depth of the qualitative data. To ensure sufficient contextual information to support and interpret data, the full range of archived material was initially assessed for inclusion by two researchers. The selection process was corroborated from initial inclusion through to data validity checking and theme generation. The breadth of data included in this study, and its situation within its relative historical context was a key strength.

The nature of the archived material also constitutes a key limitation of this study. The information represented was largely from a single viewpoint – that of Cicely Saunders – and included fairly little information from other sources who were involved in the construction and development of St Christopher's. Most crucially, very little qualitative information from patient and family perspectives was included.

The Liverpool Care Pathway Cluster Controlled Trial

Baseline data from a cluster-controlled trial of the Liverpool Care Pathway for the Dying Patient were used to compare care delivered in inpatient hospice facilities and in hospital across Italy. The study population was made up of patients in 16 general medical wards (n=145) and five inpatient hospice facilities (n=127). The data were taken when all patients were receiving standard non-specialist end-of-life care. This information was split into three different time points to give an indication of longitudinal usage and administration patterns for drugs and procedures. Demographic and stay characteristics were also recorded via the standardised form.

The main strengths of this paper come from the way in which the data were gathered. The standardised means of data collection is an efficient and reliable means of research. That the data collected already exists as part of patients' care continuum means that no extra burden is placed on patients and families at the end-of-life through the research process³⁵.

The lack of consensus on certain definitions constitutes a key limitation for this study. The dichotomisation of drugs into potentially appropriate or inappropriate for use at the end-of-life is based on a single survey of experts, and cannot be assumed to represent a wider consensus. Furthermore, the potential (in)appropriateness of all drugs and medications is dependent on the individual situation of any given patient. Similarly, the same caution in extrapolation must be applied to the definitions of therapeutic and diagnostic procedures – this study does not aim to infer any inherent validity, or lack thereof, to the use of drugs and procedures at the end-of-life.

The Dutch Death Certificates Study

The Dutch death certificate study was used to investigate care delivery across the four most common end-of-life settings in the Netherlands. Data from 2010 were collected via survey, and deaths were stratified based on cause of death and whether end-of-life decision-making was feasible before death. 5448 deaths were recorded. Palliative treatment aim, hospitalisation history and the involvement of healthcare staff in the final month of life were recorded, alongside end-of-life decision-making. Demographic characteristics and cause of death were extracted from the municipal death registry.

The study population was identified through a nationally representative sample of non-sudden deaths across the Netherlands. Deaths were then stratified to proportionally represent different types of death. This method of sampling and stratification gives a statistically powerful and unbiased research base.

A drawback of this study was that data were reliant on the input of physicians after the death of the patient. This can mean that data are subject to recall bias and interpretation of the situation surrounding a patient's death. Respondents providing socially desirable answers – especially surrounding their own care and response in the situation – may also influence the data provided³⁶.

IKNL hospice database

Part II focussed on the Dutch inpatient hospice setting, and utilised data from the comprehensive cancer center of the Netherlands (IKNL). This

database represents ~25% of inpatient hospice facilities in the Netherlands, and is populated by patients who applied for inpatient hospice care 2007 – 2012 (n=10,254). This data was firstly used as a whole to study the entire population of applicants, and was then split along diagnosis and care-model lines in order to further explore the dimensions of difference of care in the Netherlands for those interested in inpatient hospice care.

The study population was gathered from a database representing roughly a quarter of Dutch inpatient hospice facilities. This meant that a large number of application and care characteristics were included, giving the results statistical power and a degree of representativeness. The data for this study were gathered as part of the standard records for admission and care – limiting the intrusiveness of the data collection process on patients and their families, and providing a reliable means of comparison.

An inherent limitation of this data set is that only the professional perspective of care is recorded. This allows us to track the process of application and care, but doesn't record the patient perspective on admission and treatment and any ramifications of this on the experiential level. It is not possible to assess, for instance, the extent to which care provided is related to symptom burden.

Recommendations for policy, research and practice

That palliative care needs to be delivered across the range of healthcare settings is an issue that will only become more important as demographics change. Thus settings need to adapt and be aware of the needs of their patients – regardless of diagnosis or other extraneous characteristics. Needs should be understood as a term referring to all medical, spiritual and psychosocial needs of the dying patient and their family. This thesis has highlighted a number of issues and discrepancies between care provided in different settings. The physical environment of care can differ significantly between settings, leading to very different dying experiences for patients and their families. The need for the end-of-life care setting to fulfil the function of a home for the patient and their family has been recognised throughout the span of hospice literature, and has been a key part of the philosophy of inpatient hospice and specialist end-of-life care from its earliest developmental stages. Further qualitative research identifying physical environments of end-of-life care and their utilisation by dying patients and their caregivers should be undertaken to synchronise and systematise the ways in which these spaces are used and accessed by diverse patient groups.

The recognition of palliative care needs across patients with all diagnoses should be a key priority in future research and practice. A strategically led recognition of this phase would facilitate further research into enacting a suitable palliative approach across care settings. Currently, the differences highlighted between the use of particular drugs and procedures between settings suggests the need for a thorough expert consultation concerning what drugs and procedures may be appropriate or inappropriate at the end

of life. Further research aimed at formulating a coherent set of guidelines for drug and therapy use at the end of life should be undertaken. More in-depth surveying of expert practitioners and a thorough assessment of end-of-life medications would help to formulate a more clear idea of the use of drugs in the dying phase, and an indication of the appropriateness of different substances. Such a set of guidelines could be used in a similar way to quality indicators, whereby a low percentage of potentially inappropriate drugs and procedures at the end of life could indicate preferable palliative care. Further expert survey to reach an agreement on definitions of appropriate and inappropriate drugs and procedures at the end of life would also be key in providing a corroborative list of interventions for dying patients, and their potential suitability.

Lessons from inpatient hospice care

The advances in caring for the dying made through the inpatient hospice model of care have been instrumental in influencing and guiding palliative care. The concept of the inpatient hospice facility as a total institution that cares for patients not only medically but psychosocially and spiritually continues to be a guiding force in how palliative care is structured across diverse healthcare structures and models of delivery. The linchpin of inpatient hospice care – recognising the dying phase and treating patients holistically and accordingly – is a key lesson that should be enacted across care settings. Patients dying in all settings should have access to care that addresses their psychosocial and spiritual needs, as well as medical and means of integrating such care within all care settings should be a key priority to best serve the needs of a changing population.

Lessons for inpatient hospice care

Data from across Europe highlights the fact that inpatient hospice facilities still predominantly care for patients with cancer, despite well-documented palliative care needs of patients with other diseases. Clear guidelines ensuring that patients are admitted on the basis of symptom palliation and other care needs should be formulated to ensure that non-cancer patients are not systematically excluded from the inpatient hospice model of care. Similarly, care received in inpatient hospice facilities should be needs-based for all patients, regardless of diagnosis, and needs of different patient groups should be further researched to address the relative paucity of knowledge concerning the end-of-life needs of non-cancer populations.

Final Remarks

Overall, this thesis highlights how care received by comparable patients in different settings varies significantly. The current provision of care both in and outside of the inpatient hospice care setting means that some groups seem to be under-represented, though their care needs are often comparable to groups that are well provided for.

Lessons learnt from the development of inpatient hospice care should be seen as a transferrable approach to care, a philosophy used to guide palliative care regardless of the setting in which it is delivered – and this should include the timely recognition of palliative needs, a strategic consideration of drugs and procedures undertaken and an environment in which dying patients and their families can participate meaningfully.

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Summary

To build a comprehensive picture of the diversity of end of life care, it is important to investigate the differences between models of care. This thesis aims to explore variances in palliative care according to the setting that it is delivered in, concentrating specifically on the differences between inpatient hospice facilities and non-hospice settings. This topic is addressed in two parts; firstly comparing inpatient hospice facilities to other palliative care settings and secondly by concentrating on the Dutch inpatient setting and focussing on differences in care between models.

Part One

Chapter two utilises data from the Cicely Saunders Archive at Kings College London to explore the development phase of the inpatient hospice model of care. Data from meetings, notes and paraphernalia was collated to investigate the development of the philosophy of St Christopher's Hospice and the reflection of this in its physical space and social organisation. Five themes were identified using open coding. The predominant overarching theme was home/homelike, and next to this were "community", "consideration of others", "link with the outside world" and "privacy". These themes reflect the philosophy of St Christopher's in formulating a specific lifeworld for it's patients, and engaging with them on a domestic level in this new model of care.

Chapter three draws on baseline data from the cluster controlled trial of the Liverpool Care Pathway conducted in Italy. This study analyses how often potentially appropriate and inappropriate drugs and procedures are given in

both inpatient hospice facilities and general hospital wards. The longitudinal perspective is also explored, as drugs and procedures are analysed in light of whether they are started, stopped or maintained throughout the patient's final three days of life. The role of patient characteristics in care received is analysed also. Drugs were classified as potentially appropriate or inappropriate based on expert survey, and procedures were classified as being either diagnostic or therapeutic. 75% of patients in hospital were found to have received three or more potentially inappropriate drugs in the final three days of life, compared to 42.6% of patients in hospice. Diagnostic procedures in the final phase were carried out more often in hospital than in hospice. Multivariate logistic regressions showed that setting had a unique contribution to the differences found in use of drugs and procedures, after demographic differences had been controlled for.

Chapter four consists of an analysis of the characteristics of the end of life in four inpatient settings in the Netherlands – namely hospital, inpatient hospice facility, home and nursing home. The characteristics of the end of life care delivered are assessed, as well as the type of patient in each setting, their process of care and any stated end of life decision. Data was drawn from a 2010 nationwide survey of death certificate data across the Netherlands. Physicians filled in a questionnaire to provide data on end of life care and wishes. 10% of deaths were recorded to have happened in inpatient hospice facilities, 39% at home, 24% in nursing homes and 28% in hospital. 71% of inpatient hospice patients had a long-term palliative treatment aim, compared to 12% of those in hospital. Substantial differences in end of life care and decisions between settings were found, not only related to populations but to availability and institutional culture.

Part Two

Chapter five utilised the REPAL database; a set of data gathered from 25% of hospices across the Netherlands. An analysis of the differences between patients who applied and subsequently were or weren't admitted was undertaken. The spread of diagnoses and characteristics of patients who applied for care was then compared to the wider end-of-life population. 10254 patients were included for analysis. Of patients applying for hospice care, 84.1% had cancer compared to 37% in the national spread of deaths. 52.4% applicants resided in hospital at the time of application. The most frequent reasons for application were the wish to die in hospice (70.5%), needing intensive care or support (52.2%), relieving caregivers (41.4%) and needing pain or symptom control (39.9%). A number of factors, including wanting to be admitted as soon as possible (OR 1.64, 95%CI 1.42- 1.88) were positively associated with being admitted to hospice. The data suggests that patients who seem most urgently in need of hospice care are more frequently admitted. However, non-cancer patients appear to be an underrepresented population.

Chapter six also drew from the REPAL data set. This study investigated differences in sociodemographic and disease characteristics for patients who are admitted to inpatient care in the Netherlands. The data was split according to the model of hospice that the patient was admitted to, and care received in each setting was recorded and compared. Patient characteristics were shown to be similar across settings. Differing levels of caregiver involvement were shown, with PCUs consistently reporting higher levels of involvement of ancillary caregivers. The proportion of patients who

received no technical procedures was highest in bijna-thuis-huizen. Care seemed to be shaped by institutional characteristics and availability, leading to differences in care received by similar patient groups.

Chapter seven utilised the same database in order to make a comparison between patients with the three most common diseases at the end of life, who were admitted to an inpatient hospice facility for care. Care characteristics for patients with cancer, heart failure and lung disease were explored, as well as sociodemographic data. In all three disease groups, nurses, volunteers and healthcare assistants were most frequently involved in patient care. The most commonly used technical procedures were subcutaneous lines and catheters. Over 70% of patients in all groups received no complementary therapies. Controlling for age, sex and model of hospice showed no differences between the three groups for the majority of care characteristics. As patients with heart and lung disease were not shown to receive less treatment when admitted to a hospice facility as an inpatient, the underrepresentation of these patients may be access rather than needs based.

General Discussion

Chapter eight begins with a reflection on the comparative approach used throughout this thesis, and the strengths and limitations of this approach. The definition of “inpatient hospice facility” is then explored in further depth, both in terms of its original genesis and how this idea is now manifested worldwide – with a specific focus on the Netherlands. Palliative care in the Netherlands is delivered through three main models – inpatient hospice facilities, bijna thuis huizen and palliative care units. Inpatient hospice are

staffed by nurses and physicians who are part of the institution, *bijna-thuis-huizen* (almost-home-homes) have visiting nurses and physicians but the majority of care carried out by volunteers and families whilst palliative care units are specialised spaces within already existing tertiary care facilities. The differences between patients who are cared for in inpatient hospice facilities, and those who are not are assessed. The type of care provided in inpatient hospice facilities is then explored, with a particular focus on types of inpatient hospice facility and differences between disease groups. This is then compared to how patients die outside of the inpatient hospice setting. Models of integrating palliative care into non-inpatient hospice facilities are then explored.

The strengths and limitations of the different chapters of this thesis are then gone into in depth, according to their data source. The breadth of data and its historical situation was a key strength for the qualitative paper, though the lack of patient and family perspectives constituted a limitation of the paper. For the Liverpool Care Pathway Cluster Controlled Trial, the standardisation of data collection and the fact that this formed an already existent part of the patients' care continuum meant that the data were strong and reliable, however the lack of consensus on the definitions of key terms is a limitation for this study – especially in the definition of potentially [in]appropriate drugs and procedures. The statistical power and strength of the death certificate study was highlighted, however this data was reliant on the input of physicians following the death of a patient, which may be influenced by wanting to provide socially desirable answers – especially regarding their own involvement with a patient. The IKNL database studies drew on the strength of a large and representative database with statistical

power. This data is also drawn from the standard continuum of care, minimising intrusiveness and bias. However, only the professional perspective on care is recorded which limits the conclusions that can be drawn on the experience of differing care processes.

Finally, recommendations for policy and practice are explored, with a particular focus on both lessons learnt from hospices, and lessons for inpatient hospice facilities. The differences in care received by comparable patients across settings provide the key message of this thesis; namely that lessons learnt throughout the development of palliative care (both inside and outside of inpatient hospice facilities) should be seen as an approach to care, and should include a number of key features including the timely recognition of palliative care needs, a strategic consideration of drugs and procedures and an environment within which both dying patients and their families can inhabit and participate meaningfully.

Part Three

"In all our decadence people die"

Crass

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About the Author

Emily West was born in Chester, United Kingdom on June 13th 1988. After completing school she moved to London to undertake a BSc (hons) in Social Anthropology from Brunel University. During this time, she also lived and worked in a hospice in central Romania, researching illness and care setting perception amongst patients. In 2008, she started working for the Wellcome Trust in a public engagement role, which she continued until moving to Italy in 2011 to start work as a researcher on the EURO IMPACT FP7 Project. During this time, Emily completed her PhD thesis and undertook a number of graduate courses on research skills and palliative care coordinated by academic and non-academic EURO IMPACT partners. Emily moved from Italy, to London and on to Amsterdam during her EURO IMPACT tenure, where she still resides. Since completing her work with EURO IMPACT she has undertaken a Brocher Fellowship in Switzerland, founded a successful art collaborative focussed on death in the digital realm and worked in public policy research with the Hogeschool van Amsterdam.

Publications

West, E, Gysels M **Ethical issues in dementia research – A review of current evidence** (forthcoming – 2016)

Gysels, M, West, E **Participation in research on dementia – methodological issues** (forthcoming – 2016)

West, E, Pasman, HRW, Galesloot, C, Lokker, ME, Onwuteaka-Philipsen, B **Does hospice care vary for patients admitted to the three types of hospice in the Netherlands?** (under review – 2016)

West, E, Pasman, HRW, Galesloot, C, Buiting, H, Onwuteaka-Philipsen, B **Does hospice care vary between patients with cancer, heart failure and lung disease?** (under review – 2016)

West, E, Pasman, HRW, van der Heide, A, Onwuteaka-Philipsen, B **Characteristics of the end of life in four settings in the Netherlands: care and decisions** (under review – 2016)

West, E, Onwuteaka-Philipsen, B, Philipsen, H, Higginson, IJ, Pasman, HRW **Keep all thee ‘til the end: reclaiming the lifeworld for patients in the hospice setting** (under review – 2016)

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