

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 its 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.