Care and Quality of Life in the Dying Phase

The contribution of the Liverpool Care Pathway for the Dying Patient

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ERASMUS UNIVERSITEIT ROTTERDAM

Care and Quality of Life in the Dying Phase

The contribution of the Liverpool Care Pathway for the Dying Patient

Zorg en kwaliteit van leven in de stervensfase

De bijdrage van het Zorgpad Stervensfase

Proefschrift

ter verkrijging van de graad van doctor aan de
Erasmus Universiteit Rotterdam
op gezag van de rector magnificus

Prof.dr. S.W.J. Lamberts

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Overgrootopa

Toen mijn overgrootopa met mijn overgrootoma verhuisde naar een bejaardenwoning, maakte mijn vader een tekening voor hem. Hij tekende het uitzicht dat zijn opa had vanuit zijn stoel aan de eettafel in het oude huis, om hem het gevoel te geven dat hij het uitzicht meenam. In het nieuwe huis heeft mijn overgrootopa de tekening toen weer boven de eettafel gehangen. Mijn overgrootopa is op 84 jarige leeftijd rustig in zijn slaap overleden.

Contents

1
General Introduction

1.1.Background

The western population is ageing.[1] Life expectancy increases, to which the medical capability to prolong life, and the decrease in the frequency of unexpected and sudden death contribute substantially. As a result, chronic diseases, such as cancer, cerebrovascular disease, and dementia become more common. Growing numbers of people will die from chronic diseases, demanding care for specific symptoms in the dying phase.[1 2]

During the 60ties of the previous century, experience was developed with caring for patients who died from cancer in hospices in the UK. In these hospices the care was aimed at managing the patient's total pain, often caused not only by physical suffering, but also by psychosocial and spiritual problems.[3] This hospice care practice became integrated in hospitals, nursing homes and in home care services in Europe. Besides, each type of care setting started to build up skills and knowledge needed to provide good end-of-life care to their specific patient populations. Since 2002, the World Health Organization uses the following definition of palliative care: '…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 of and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual'.[1]

Patients' views on a good death

Several studies investigated what constitutes a good death and high-quality end-of-life care according to terminally ill patients and their relatives.[4-12] Next to physical comfort, many patients consider a sense of completion, and preparation to death important for a good death.[9 10] They attach much value to their dignity, and to the affirmation of their whole person.[9 12] They often prefer to have a say in decisions about their treatment, about how they spend their time, and about the dying process.[7 12] According to many of them, inappropriate prolongation of dying should be avoided.[8] The strengthening of relationships and relieving of the burden of the family caregivers are important for patients and relatives.[8 11] High-quality end-of-life care should address these needs and expectations by providing adequate symptom control, clear information about the treatment and the prognosis, and emotional support to patients and their families before and after the death of the patient.[4 6 11] It is often also suggested that enabling people to die at their place of preference contributes to their quality of dying, and patients often prefer to die at home.[5] One

study showed that relatives were quite satisfied with the provision of medical and nursing care for patients who died in either an institution or at home, and the frequency of physical symptoms was similar in both settings.[13] However, relatively little is known about the differences in end-of-life care between patients dying at home and patients dying in other healthcare settings.

Shortcomings in end-of-life care

Various problems have been shown to be insufficiently addressed by end-of-life care.[14-28] Physical symptoms like pain, fatigue, shortness of breath and delirium were present in 32-80% of the dying patients, and it is suggested that these symptoms could be avoided at least in some cases.[22 24 28] Other frequently mentioned problems are insufficient communication about the prognosis and treatment options[18 23 25 27], and insufficient emotional and psychosocial care.[14 15 20 21 24 26] Further, anxiety and depression need to be better treated in patients and relatives.

Liverpool Care Pathway for the Dying Patient

In the United Kingdom, the Liverpool Care Pathway for the Dying Patient (LCP) has been developed to translate the hospice care practice into other healthcare settings.[29 30] The LCP is based on the principle of the 'Integrated care pathway', a care method that aims to facilitate distinct care through integrated multidisciplinary cooperation.[31] The LCP aims to better structure the delivery of care in the dying phase and to ensure that patients and their families receive good symptom control, psychosocial support and bereavement care.[30 32] It lists a number of care goals that clearly describe various aspects of patient comfort, that form the starting-point for continuous monitoring of the patient's comfort and for the necessary care actions until the death of the patient (see also the Appendix in this thesis).[30] The document is structured into three discrete sections:

1 Initial assessment - completed when the multidisciplinary team makes the decision that the patient has entered the dying phase. This section deals with anticipatory prescription of important medications, discontinuation of inappropriate interventions, spiritual / religious assessment and appropriate information giving and communication with patients, relatives and other agencies.
2 Ongoing assessment - 4 and 12 hourly assessment of important indices of comfort for dying patients and their families including symptom control and

maintaining the ongoing physical, psychological and spiritual / religious comfort of patients and relatives.

3 Care after death - assessment of important practical issues and appropriate support for relatives after the death of the patient.[33]

The LCP can be used for all patients for whom professional caregivers establish that the dying phase has started. At the start of the dying phase the LCP replaces the usual nursing and medical records. Care goals are documented as either 'achieved' 'not achieved', or, where appropriate, 'not applicable'. Where 'not achieved' is documented notes are made concerning the cause or reason, detailing the course of action taken. In 2004, the British Government launched a funding for four years to support the LCP as one of three 'End of Life Initiatives' that deliver high quality care to dying patients and their families in the UK.[33 34]

Implementation project in the Netherlands

During the 90ties the growing interest in palliative care led to the development of various palliative care facilities in the Netherlands, as well as the stimulation of education and research in palliative care.[33 35 36] One of the effects concerned the evaluation of the relevance and use of the LCP in the Dutch health care system. The document was translated into Dutch following EORTC guidelines and subsequently implemented into three palliative care units in the Rotterdam region. The majority of the staff in these units felt that the LCP structured patient care, supported problem anticipation, promoted proactive management of care, and facilitated multidisciplinary communication.[33] However, the extent to which the LCP improves the care and the quality of life for dying patients had , neither in the UK nor in the Netherlands been thoroughly investigated.

Research questions

The study that is described in this thesis aimed to answer the following research questions:

What is the effect of LCP use on:

1. the quality of life of patients in the last three days of life?
2. the content of care for patients in the last three days of life?
3. the communication in the last three days of life and the level of bereavement of relatives?

1.2 Methodology of the study

We applied a pre- and post intervention study in which data were collected after the death of patients.

Research design

The randomized clinical trail (RCT) is known as the most appropriate method to study the effect of an intervention. However, practical problems in the field of palliative care often limit the appropriate application of RCTs. At first, it is typically not known if and when a patient is going to die. Secondly, the potential risk of information leakage concerning the LCP within settings precluded an RCT. Therefore, we applied a pre- and post-intervention design, comparing patient and care characteristics before and after implementation of the LCP. A control group was formed under comparable circumstances as the intervention group, be it during a different period of time. This design probably enabled sufficient control for factors other than the factor we were primarily interested in. In our analysis, we used the intention-to-treat principle, meaning that we included all deceased patients, no matter if the LCP had actually been applied to them or not.

Proxy respondents

For each deceased patient we asked a nurse, a physician and a bereaved relative to fill in a questionnaire. In former retrospective studies, bereaved relatives of the patient and professional caregivers, like nurses and physicians, have acted as proxy respondents. The reliability of proxy assessments for various aspects of end-of-life care and quality of life are well described.[37-45] We investigated mainly those aspects that have shown sufficient agreement between patients and proxy respondents: namely those aspects that are relatively objective: physical symptoms, such as vomiting and dyspnoea, evaluation of care, service use, and awareness of the diagnosis.[37 44 45] We also investigated some subjective aspects, such as psychological symptoms, like anxiety and depression, and spirituality. It is known from the literature that in comparison with patients, nurses and relatives tend to overestimate the severity of symptoms, whereas physicians tend to underestimate them.[39] We asked both nurses and relatives to assess the severity of symptoms, so that we could study both perspectives.

Questionnaires to measure care and quality of life at the end of life

At the start of our study, few validated questionnaires were available for the retrospective assessment of care and quality of life in the dying phase. Many of the questionnaires were developed either to be filled in by terminally ill patients themselves, or concerned questions that were not applicable to dying patients. We developed questionnaires to be filled in by relatives, nurses and physicians, after the death of the patient. We based part of the questionnaires upon existing questionnaires such as, the EORTC QLQ-C30, the Views Of Informal Carers Evaluation of Services questionnaire (VOICES), the Palliative Outcome Scale (POS), and the Leiden Detachment Scale (LDS).[40 43 46-48] Additional questions were developed based upon insights that we gained from former research concerning medical care and decision making in the last phase of life.[13]

Participants

We aimed to investigate dying in various healthcare settings. Therefore we included different types of healthcare settings. Each participating healthcare setting had a special interest in end-of-life care, which partly explained their interest in participating in the study. All settings were located in the southwest of The Netherlands.

Informed consent

When a patient died, in principle, his or her medical records became eligible for investigation. Each patient was given the opportunity to express objections against the use of his or her records. Since we could not know who was going to die and who was not, we informed all inpatients at the participating departments about the study. The relatives of the patients who died were asked informed consent, prior to filling in the questionnaire. The Medical Ethical Research Committee of the Erasmus MC approved of the study.

1.3 Outline of this thesis

Chapter 2 concerns the pilot study that preceded the main study described in this thesis. The pilot study was an audit in which the use and the applicability of the LCP in the Netherlands were tried out. The achievement of care goals was compared between cancer patients who died at the palliative care unit of a Dutch cancer hospital and a comparable group of cancer patients who died in the hospice in the UK

where the LCP was developed. Chapter 3 subsequently describes the most important differences in the baseline assessment of the main study between the hospital, nursing home and home care setting. We compared the symptom burden, the application of medical and nursing interventions, and some aspects of the communication between patients, family and professional caregivers between the settings. Chapter 4 addresses research question 1 and 2. It describes the effect of the LCP on the documented care during the dying phase, the symptom burden for dying patients, and several aspects of communication in the last three days of life within each setting. Chapter 5 concerns the effect of recognition of the dying phase on the application of medical interventions in the dying phase, and is related to research question 2. Then, Chapter 6 elaborates further on research question 2 with describing the effect of the LCP on medical decisions and medication during the last three days of life. Chapter 7 finally concerns research question 3: the effect of using the LCP on communication, end-of-life care, and levels of bereavement in relatives. Chapter 8 concludes this thesis with a general discussion.

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2

Audit of The Liverpool Care Pathway for the Dying Patient in a Dutch Cancer Hospital

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Abstract

The Liverpool Care Pathway for the Dying Patient (LCP) provides care goals to ensure that dying patients and their family receive the best possible comfort care. The LCP has been developed and used in the Marie Curie Hospice, Liverpool for the past seven years. A translated version of the LCP was introduced at the Erasmus MC medical oncology department in Rotterdam in November 2001. We performed an audit of its use in the Netherlands by assessing the degree to which care goals were achieved in 40 patients. The results were compared with those in 40 cancer patients in Liverpool, who were matched for gender and age. All patients studied died between October 2001 and July 2003. The care goals at the start of the dying phase were achieved for on average 34 Rotterdam patients and 30 Liverpool patients. During the last 24 hours preceding death, symptoms could be controlled without additional actions for on average 28 Liverpool patients and 30 Rotterdam patients. Care goals after death were achieved for on average 29 Liverpool patients and 30 Rotterdam patients. We conclude that the LCP is applicable in a Dutch tertiary hospital setting and that it provides useful insights in the delivery of care for the dying.

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2.1 Introduction

In recent years, effective and appropriate care for dying patients has become a priority in health care delivery. Control of pain and other symptoms, and support for psychological, social and spiritual problems are of paramount importance in the last phase of life.[1] However, professional caregivers often feel uncomfortable when they have to care for dying patients. In the United Kingdom, the Liverpool Care Pathway for the Dying Patient (LCP) has been developed to translate the model of hospice care into the hospital sector, where care in general is less primarily focused on ensuring the comfort of dying patients.[2] The LCP is based on the principle of the 'Integrated care pathway', a care method that aims to facilitate distinct care through integrated multidisciplinary cooperation.[3] The LCP aims to better structure the delivery of care in the dying phase and to ensure that the patient and his or her family are provided with the best care possible.[4,5]

The LCP can be used for all patients for whom professional caregivers establish that the dying phase has started. At the start of the dying phase the LCP replaces the usual nursing and medical records. It lists a number of care goals that clearly describe various aspects of patient comfort, and that form the starting-point for continuous monitoring and potential adjustment of care until the death of the patient.[4,6] Care goals are documented as either 'achieved' 'not achieved' (i.e. variance) or, where appropriate, 'not applicable'. Where not achieved is documented notes are made concerning the cause or reason, detailing the course of action taken. The LCP is cited as an example of good practice in end of life care in Key Recommendation 14 of the NICE Guidance on Supportive and Palliative Care (National Institute of Clinical Excellence, 2004) and is currently being disseminated nationally as part of the End of Life Care Initiative to improve care for dying patients in the UK.[7]

In 2001, a translated and slightly adapted version of the LCP was introduced at the palliative care unit (PCU) of the department of medical oncology at the Erasmus MC - Daniel den Hoed cancer center in Rotterdam, the Netherlands.[8-11] This PCU admits cancer patients with multidimensional problems needing a multidisciplinary approach for diagnosis and treatment. The aim is to discharge them back home, but a substantial proportion of the patients (27% at first admission) die at the PCU.[10] We performed an audit to assess the experiences with the LCP in this new setting outside the UK, and compared the results with a comparable group of cancer patients in Liverpool.

2.2 Methods

We studied the extent to which care goals were achieved for patients who died at the PCU in Rotterdam between October 2001 to January 2003. The results were compared with those for patients who died in the Marie Curie hospice Liverpool between April 2002 and July 2003. In Rotterdam, the LCP was used for 50 patients, which was 50% of all patients who died during the study period. In Liverpool, the LCP was used for 250 patients, which was 85% of all patients who died at the hospice during the study period. Our analysis is based upon data from 40 cancer patients in each setting who could be matched by age and gender. All 80 patients were 18 years or older when they died. As this was an anonymous retrospective audit, advanced consent was impossible to achieve.

For all care goals at the start of the dying phase and all after death care goals (sections one and three of the LCP), the number of patients for whom a care goal was achieved was calculated for each setting, For the ongoing assessment section, we looked at 6 common symptoms: pain, agitation, respiratory tract secretions, nausea and vomiting, mouth care, and micturition. We calculated the total number of four hourly observations made in the last 24 hours prior to death in each setting. We then calculated the proportion of observations for which care goals were documented as having been achieved. Further, we determined the proportion of patients for whom a care goal had been achieved during all applicable episodes in the last 24 hours prior to death.

The data were analyzed descriptively and are displayed in tabular format.

2.3 Results

The mean age at death of the patients who were included was 61 years; 50% were men and 50% were women (see Table 2.1). The LCP had been used for more than 48 hours for 42% of the patients in Liverpool, but for only 27% of all patients in Rotterdam. The median duration of LCP use, however, was comparable: 29 hours in Liverpool (range, 3- 213 hours) and 28 hours in Rotterdam (range, 2- 218 hours).

Table 2.1: Patient characteristics.

	Liverpool N = 40		**Rotterdam** N = 40	
Gender (male)	20 (50%)			
Age in years (mean, min., max.)	61 (40 - 76)			
Primary tumour site:				
Breast	7	(18%)	7	(18%)
Digestive organs and hepatobiliary organs	7	(18%)	6	(15%)
Respiratory system	9	(22%)	6	(15%)
Genital organs or urinary tract	6	(15%)	4	(10%)
Haematological cancer	2	(5%)	-	-
Other	9	(22%)	17	(42%)
Hours of LCP use (median, min., max.)	29 (3, 213)		28 (2, 218)	
0-24 hours	19	(48%)	18	(46%)
25 – 48 hours	4	(10%)	11	(27%)
> 48 hours	17	(42%)	11	(27%)

From each of the three sections of the LCP Table 2.2 shows several care goals. At the initial assessment, nine out of 14 care goals were achieved for over 80% of the patients, both in Liverpool and Rotterdam. Care goals were rarely documented as not having been achieved. The number of missing assessments was relatively large for the Liverpool patients (range, 3- 48%). In contrast, the assessment of ongoing care goals during the last 24 hours before death was almost complete in Liverpool.

Table 2.2: Achievement of selected care goals in Liverpool and Rotterdam

Care goal Goals at the start of the dying phase[1]		**Liverpool** n (%) N = 40	**Rotterdam** n (%) N = 40
Writing up of subcutaneous medication as required	Achieved	35 (87)	38 (95)
	Not achieved	-	2 (5)
	Missing	5 (13)	-
Discontinuation of inappropriate interventions	Achieved	34 (85)	40 (100)
	Missing	6 (15)	-
Assessment of the patient's awareness that he/she was dying	Achieved	15 (37)	24 (60)
	Not achieved	2 (5)	2 (5)
	Patient was comatosed	10 (25)	14 (35)
	Missing	13 (33)	-

Conituation Tabel 2.2

Care goal		**Liverpool** n (%) N = 40	**Rotterdam** n (%) N = 40
Goals at the start of the dying phase[1]			
Assessment of the family's awareness that the patient was dying	Achieved	35 (87)	40 (100)
	Missing	5 (13)	-
Assessment of religious or spiritual needs with patient or carer	Achieved	34 (84)	31 (78)
	Not achieved	1 (3)	7 (17)
	Missing	5 (13)	2 (5)
Goals of ongoing care during the last 24 hours prior to death[2]		N = 189	N = 188
Patient is pain free	Achieved	155 (82)	161 (86)
	Not achieved	26 (14)	15 (8)
	Missing	8 (4)	12 (6)
Patient is not agitated	Achieved	141 (74)	156 (83)
	Not achieved	41 (22)	22 (12)
	Missing	7 (4)	10 (5)
Excessive secretions are not a problem	Achieved	158 (84)	163 (87)
	Not achieved	25 (13)	15 (8)
	Missing	6 (3)	10 (5)
Goals after death[1]		N = 40	N = 40
Informing the GP of the patients' death	Achieved	24 (60)	18 (45)
	Not achieved	5 (12)	15 (38)
	Missing	11 (28)	7 (17)
Carrying out or discussing all other procedures following death	Achieved	13 (32)	31 (77)
	Not achieved	-	3 (8)
	Not applicable	24 (60)	4 (10)
	Missing	3 (8)	2 (5)
Informing the family or other of procedures	Achieved	34 (85)	30 (75)
	Not achieved	1 (3)	1 (3)
	Missing	5 (12)	9 (22)
Completion of the bereavement referral form	Achieved	33 (82)	28 (70)
	Not achieved	1 (3)	3 (7)
	Not applicable	-	1 (3)
	Missing	6 (15)	8 (20)

1 The denominator for percentages concerning goals at the start of the dying phase and goals after death is the total number of patients in each setting.
2 The denominator for percentages concerning goals of ongoing care is the total number of 4-hour episodes during the patients' last 24 hours for which the LCP was used.

The number of episodes for which documentation was missing was less than 5% in all cases. For on average 87% of the episodes, care goals were documented as having been achieved in Liverpool. In Rotterdam, the percentage of missed assessments for ongoing care goals during the last 24 hours before death was less than 10% in all cases. Symptom control was achieved without additional

interventions for on average 88% of the episodes. In 33% of all patients in Liverpool, no interventions were needed to achieve the goal 'patient is not agitated' in the last 24 hours prior to death (see Table 2.3).

Table 2.3: Proportion of patients in whom symptoms were controlled without additional actions during 0-24 hours prior to death.

Care goal	Liverpool n / N (%)	Rotterdam n / N (%)
Patient is not agitated	13 / 39[1] (33)	18 / 39[1] (46)
Patient is pain free	22 / 39 (56)	28 / 39 (72)
Excessive secretions are not a problem	22 / 39 (56)	29 / 39 (74)
Patient does not feel nauseous or vomits	37 / 39 (95)	38 / 39 (97)
Mouth is moist and clean	37 / 39 (95)	32 / 37[2] (86)
Patient is comfortable: no micturition difficulties	35 / 39 (90)	36 / 39 (92)

1 One patient in both settings died before the first assessment of symptom control.
2 Three patients in Rotterdam died before the first assessment of mouth care.

This percentage was 56% for the goals 'patient is pain free' and 'secretions are not a problem'. Nausea, mouth problems and micturition rarely required interventions. The problems that most often required additional interventions in Rotterdam were also agitation, pain and bothersome secretions, although the percentages of patients in whom these problems were controlled without additional actions were somewhat higher as compared to Liverpool (46, 72, and 74% respectively).

Table 2.2 also lists the extent to which a selection of care goals after death was achieved. Not all care goals were applicable in all cases, but if they were, most care goals were achieved for over 80% of all patients in Liverpool and for over 70% of all patients in Rotterdam. This does not hold for informing the general practitioner about the patient's death, which had been done for only 60% of the Liverpool patients and 45% of the Rotterdam patients. Procedures following death had been adequately followed for only 32% of the patients in Liverpool. To most Liverpool patients, this goal had been not applicable. In those for whom this goal was applicable (n=16), the goal was achieved for 81% of patients. The proportion of missing data was higher in this section of the LCP than in sections one and two.

2.4 Discussion

In this study, most care goals for dying patients were achieved in the majority of cases in a hospice setting in the United Kingdom and a tertiary hospital setting in the Netherlands. Our finding that the median number of days during which the LCP was used was similar in both settings suggests that there were no major differences between both settings in the stage at which the onset of the dying phase was acknowledged, although in Liverpool the LCP had been used for more than 48 hours

more often than in Rotterdam. In addition, the LCP was used for around 85% of all patients who died during the research period at the hospice in Liverpool, but for only 50% of all patients who died at the PCU in Rotterdam. It is likely that a relatively large proportion of the patients in Rotterdam died unexpectedly, which may be due to the fact that the primary goal of admission to the PCU is for symptom control and not for the delivery of care in the dying phase. Also, in the early stages of implementation, the diagnosis of impending death and thus the timely instigation of the pathway can be particularly challenging for teams.

The number of missing assessments was generally larger for Liverpool patients in section one and larger for Rotterdam patients in section three. Absence of documentation about whether or not care goals were achieved may reflect a certain level of routine in working with the LCP, resulting in lack of documentation when a goal has not yet been achieved and action is needed. The reverse, that is, documentation of only those care goals for which an action is needed, may also play a role. The relatively low proportion of missing data in section one of the LCP in the Rotterdam sample may be due to the fact that in Rotterdam the data were collected shortly after its introduction, when there is necessarily an emphasis on appropriate recording. For Liverpool, the data represent the process of documentation three years after the end of the pilot phase. The results do however highlight the need for ongoing education to ensure that the document is completed optimally.

At the start of the dying phase, several care goals were achieved for the large majority of patients. This especially holds for medical aspects of care and for communication with the family about the patient's condition. However, some other care goals were achieved for less than three quarters of the patients. The patients' insight in their own condition could in a substantial number of cases in both settings not be assessed because patients were already unconscious.

Symptom control has in many studies been identified as a key element in care for the dying, both by patients, family and professional caregivers.[1, 9, 12, 13] The LCP includes the most common symptoms and aims to assess their presence at least every four hours. Although control of most symptoms during the last 24 hours was achieved for the majority of patients without additional actions in both settings, interventions were required for a substantial minority. Action was especially commonly needed for pain, agitation and respiratory tract secretions. This need for action should definitely not be seen as indicative of shortcomings in care. The need for actions merely reflect the alertness of caregivers to patients' signs and symptoms

and suggests that care is really patient-oriented. It also underlines the necessity for prescribing medication as required, which is formulated as a goal at initial assessment in the LCP.

The differences between Liverpool and Rotterdam in the degree to which procedures following death were documented as 'not applicable' are possibly due to differences in the interpretation of how to document these care goals. The number of missing assessments is relatively high in both settings for care goals after the patient has died. Care for the dying is typically regarded as including care after death and care for bereaved family and using the LCP appropriately after the death of the patient should contribute to the quality and comprehensiveness of such after death care.

2.5 Conclusion

In summary, our findings concerning the use of the LCP and the extent to which its care goals were achieved in a tertiary hospital setting in the Netherlands were to a great extent comparable to those in the original hospice setting in the UK. Elsewhere we have described the experiences of the Dutch caregivers who used the LCP in its pilot phase: they reported that the LCP contributes to the fine-tuning and quality of care for the dying.[9] The translation process has also been shown to be successful.[11] We conclude that the LCP is applicable in a tertiary hospital setting outside the UK and that it provides useful insights in the delivery of care for the dying. Ongoing education seems a necessary requirement for the LCP to maintain its function as a tool to facilitate the evaluation of care.

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3

The last three days of life in three different care settings in the Netherlands

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Abstract

Little is known about the characteristics of dying in different care settings, such as the hospital, the nursing home or the home care setting. We measured the burden of symptoms, medical and nursing interventions, and aspects of communication during the last three days of life within each of these settings. We included 239 of 321 patients (74%) who died in one of these settings in the southwest of the Netherlands, between November 2003 and February 2005. After the patient's death a nurse filled in a questionnaire. Pain and shortness of breath were more severe in hospital patients as compared to nursing home and home care patients, whereas incontinence was less severe in hospital patients. Several medical interventions, such as a syringe driver, vena punctures or lab tests, radiology or ECG, antibiotics, and drainage of body fluids were more often applied during the last three days of life to hospital patients than to nursing home and home care patients. This also holds for measurement of body temperature and blood pressure. In the hospital setting the patient and the family were more often informed about the imminence of death of the patient than elsewhere. The general practitioner and other professional caregivers were less often informed about the imminence of death of hospital patients than of other patients. We conclude that pain and shortness of breath were more severe among hospital patients, whereas incontinence was more severe among nursing home and home care patients. Hospital patients relatively often receive medical interventions and standard controls during the last three days of life. In hospital, communication about impending death seems to take place more often shortly before death.

3.1 Introduction

Most people prefer to die at home.[1] In many western countries however, a major proportion of the population dies in hospital.[2] In the USA, England and Wales, Germany, Switzerland and France, more than half of all deaths occur in hospital.[2] In the Netherlands, a relatively small percentage of about 35% of all deaths occur in hospital; about 23% of all deaths occur in nursing homes and people relatively often (42%) die at home.[3] This holds even stronger for patients who die from cancer: 65% of cancer deaths occur at home, whereas only a quarter occurs in hospital.[4] The place of death has been shown to be related to several factors: people are more likely to die at home when competent informal caregivers are available and when professional health care services can be provided at home.[5-7] An increase in the complexity and intensity of patients' care needs is associated with admittance to a nursing home or hospital. The chance of dying in hospital further increases with the availability of nearby hospital beds.[8]

WHO Europe propagates optimisation of palliative care within both the institutional setting and at home.[9] Nevertheless, substantial proportions of patients dying in hospitals or nursing homes were shown to have received poor symptom control and insufficient emotional support.[10-15] The SUPPORT study among bereaved relatives in the USA also concluded that many patients dying in hospitals have unmet needs concerning symptom relief and psychosocial care.[11, 16]. It is often suggested that enabling people to die at their place of preference, that is, at home, may contribute to their quality of dying. However, relatively little is known about the care for patients dying at home and about differences in care between settings. Therefore, we aimed to investigate care for dying patients in the hospital setting, the nursing home setting, and the home care setting. In the Netherlands, patients at home receive care from their general practitioner and, if needed, from home care nurses who may visit patients once or several times a day. Nursing home residents typically have chronic conditions for which access to constant care, 24 hours a day, is needed. The nursing home physician and nurses provide nursing home care. In hospital, patients receive care from medical specialists and hospital nurses. Patients are typically admitted to a hospital for specialized, mostly short-term care that cannot be given elsewhere.

Our study encompasses the characteristics of care and quality of life during the last three days of life within these three care settings in the Netherlands. We looked at the symptom burden, the application of medical and nursing interventions, and at

some aspects of the communication between patients, family and professional caregivers.

3.2 Patients and methods

Patients

We did an observational study. A number of health care institutions in the southwest region of the Netherlands that were known to be interested in end-of-life care participated. They represented the three types of end-of-life care settings: the hospital setting, the nursing home setting and the home care setting. The hospital setting included a medical oncology department in a general hospital, and two medical oncology departments as well as a department for pulmonary diseases and a gynecology department in a university hospital. The typical aim of admitting patients to these departments is to provide specialized care for complex problems and to discharge them back home afterwards. Death is relatively rare at most of these departments (2 patients per month or less) except for the department of medial oncology of the general hospital, where on average 5 patients die each month. The nursing home setting included a general department and a palliative care department in one nursing home, a complete nursing home that also has a palliative care department, and a residential care organization providing nursing care to people who live in a residential home. The average number of deaths at each nursing home department is one to two per month. The home care setting was represented by a home care organization that provides nursing care at home in a region of eight villages and by the residential care organization, that also provides nursing care to people living at home. In both home care organizations, the average monthly number of dying patients is one.

All patients receiving care from either of the participating departments between November 2003 and February 2005 were informed of the study through an information letter. Patients of 18 years or older who died in this period were eligible for the study. Patients who had expressed objections against the use of their medical or nursing record were not included. Patients who could not be informed of the study, mostly because of their weak health status, were not included. Patients who expressed objections against the use of their medical or nursing record after their death were not included either. The Medical Ethical Research Committee of the Erasmus MC approved the study.

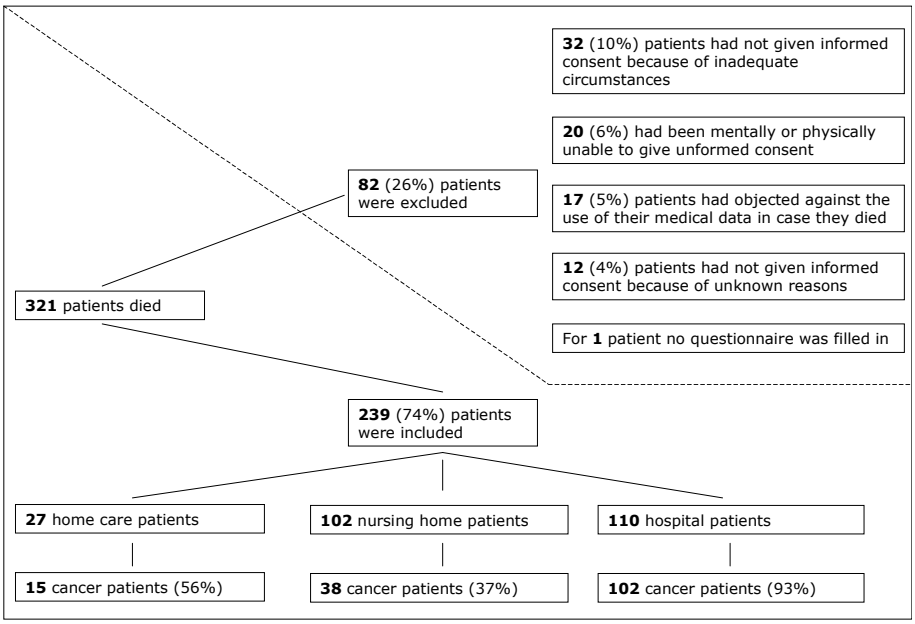
Data collection

General information about the patient, like gender, age and diagnosis, was obtained from the medical and nursing records, as well as information about whether or not the dying phase had been recognized by the caregivers and about communication with other caregivers. Further, within one week after the patient's death a nurse who had been closely involved in caring for the patient in the last three days of life filled in a questionnaire about the patient's symptoms and the care that had been provided to the patient and the relatives during the last three days of life. The questions about dyspnoea, pain, constipation, nausea or vomiting, and diarrhea, originated from the EORTC QLQ-C30 questionnaire. We considered this questionnaire a valid instrument for measuring the patients' symptom burden by others than patients themselves, because the agreement between patients and observers has been shown to be moderate to good (Intra class correlation = 0.42 to 0.79) [43]. Questions about agitation, fear, confusion, incontinence, and troublesome mucus production were added, because these symptoms are common in the last phase of life. Prior to its use in our study, the validity of the questionnaire was evaluated in face-to-face interviews with four nurses.

Analysis

Scores on EORTC QLQ-C30 items were linearly transformed to a 0-100 scale. A higher score on this 0-100 scale reflects more severe symptoms. We compared the symptom burden, the extent to which medical and nursing interventions were applied, and some aspects of communication, between the three types of settings. We distinguished cancer and non-cancer patients, because of the fact that the hospital setting included mainly oncology departments. The degree to which differences in patient characteristics could explain differences in symptom burden, interventions and communication between settings was analyzed in multivariate linear regression analysis.

Figure 3.1: Inclusion of patients into the study.



3.3 Results

Between November 2003 and February 2005, 321 patients died while receiving care from one of the participating institutions. Thirty-eight patients died at home, 128 patients died in a nursing home, and 155 patients died in hospital. We included 27 home care patients (71%), 102 nursing home patients (80%), and 110 hospital patients (71%) in our study. In total we included 239 patients (74%) in our study (see Figure 3.1). Eighty-two deceased patients could not be included. Thirty-two patients (10%) were not able to give informed consent, e.g. because there had been no good moment for the nurse to hand over the information letter to the patient. Twenty patients (6%) had been mentally or physically unable to give informed consent. Seventeen patients (5%) had objected against the use of their medical data in case they died; for 12 patients (4%) information about the reason why no informed consent was obtained is missing. Further, one case was missed because we did not receive a questionnaire back. In total, 153 nurses filled in 239 questionnaires: most nurses filled in one or two questionnaires, but 11 nurses filled in three or more questionnaires.

Of all included patients, 110 patients (46%) had died in hospital, 102 patients (43%) in a nursing home, and 27 patients (11%) at home (Table 3.1). Of all hospital patients 93% had cancer. This holds for 56% of the home care patients and 37% of the nursing home patients. Further, patients dying in the hospital setting were relatively young. For the majority of the patients within each setting caregivers had been aware that the dying phase had started. Further details are presented in Table 3.1.

Table 3.1: Patient characteristics.

		Patients with a cancer disease			**Patients with a non-cancer disease**		
		Home Care (N=15)	Nursing Home (N=38)	Hospital (N=102)	Home Care (N=12)	Nursing Home (N=64)	Hospital (N=8)
		N (%)					
Age	18 - 75 years	9 (60)	18 (49)	75 (74)	1 (10)	8 (13)	4 (57)
	76 years or older	6 (40)	19 (51)	26 (26)	9 (90)	53 (87)	3 (43)
Gender	Male	6 (40)	21 (55)	50 (49)	3 (25)	28 (44)	6 (75)
	Female	9 (60)	17 (45)	52 (51)	9 (75)	36 (56)	2 (25)
Nurse had been involved in care for the patient	Longer than 6 months	6 (40)	2 (4)	6 (6)	9 (75)	34 (54)	1 (13)
	1-6 months	5 (33)	12 (32)	4 (4)	2 (17)	12 (19)	-
	1-4 weeks	4 (27)	12 (32)	36 (36)	1 (8)	9 (14)	4 (50)
	Less than one week	-	12 (32)	55 (54)	-	8 (13)	3 (38)
Dying phase had been recognized	Yes	11 (73)	27 (73)	78 (77)	6 (50)	52 (83)	5 (63)
	Else	4 (27)	10 (27)	23 (23)	6 (50)	11 (17)	3 (37)
		N = 8	N = 26	N = 77	N = 6	N = 46	N = 5
Estimated duration time of the dying phase	0-24 hours	3 (38)	17 (65)	35 (46)	3 (50)	26 (57)	4 (80)
	more than one day	5 (62)	9 (35)	42 (54)	3 (50)	20 (43)	1 (20)

Table 3.2 presents the average EORTC symptom scores as reported by nurses for the last three days of life of the patients. Within each setting, fatigue, lack of appetite, shortness of breath, pain, and concentration difficulties had the highest mean scores. In the hospital setting patients had mean scores higher than 50 for pain and shortness of breath, whereas in the nursing home as well as in the home care setting patients had mean scores higher than 40 for incontinence. Of the psychological symptoms, worry had the highest mean score, except in the nursing home setting. Agitation and tenseness had moderate mean scores within each setting.

Table 3.2: Symptoms during the last three days of life.

	Patients with a cancer disease			**Patients with a non-cancer disease**		
	Home Care (N = 15)	Nursing Home (N = 38)	Hospital (N = 102)	Home Care (N = 12)	Nursing Home (N = 64)	Hospital (N = 8)
Physical symptoms	EORTC-QLQ-C30 mean score (standard deviation)					
Fatigue	73 (19)	70 (23)	74 (22)	77 (24)	68 (27)	61 (22)
Lack of appetite	76 (34)	68 (37)	67 (31)	69 (31)	77 (32)	42 (30)
Shortness of breath	48 (36)	41 (31)	58 (34)	65 (46)	41 (32)	92 (15)
Pain	44 (33)	38 (36)	55 (34)	44 (33)	41 (34)	58 (30)
Concentration difficulties	50 (36)	50 (33)	49 (31)	58 (38)	57 (40)	54 (35)
Incontinence	49 (28)	41 (33)	24 (33)	61 (28)	71 (33)	29 (38)
Difficulties with remembering things	38 (43)	33 (37)	31 (34)	52 (41)	48 (39)	25 (24)
Sleeping difficulties	31 (43)	23 (25)	34 (33)	39 (42)	15 (28)	42 (43)
Constipation	14 (23)	12 (24)	27 (35)	33 (38)	9 (22)	13 (17)
Nausea or vomiting	24 (27)	20 (26)	18 (25)	19 (32)	12 (22)	2 (6)
Diarrhea	10 (20)	13 (25)	11 (22)	15 (23)	14 (30)	4 (12)
Psychological symptoms						
Worry	52 (28)	23 (25)	49 (31)	48 (43)	25 (27)	71 (33)
Agitation	36 (36)	39 (36)	42 (36)	53 (39)	30 (35)	46 (43)
Tenseness	38 (34)	39 (36)	40 (35)	36 (38)	33 (37)	63 (38)
Feeling depressed	31 (32)	30 (29)	30 (32)	31 (39)	20 (27)	46 (35)
Feeling irritable	21 (40)	14 (24)	18 (30)	8 (29)	6 (14)	33 (36)

Table 3.3 shows the percentages of patients in the different settings who underwent medical or nursing interventions during the last three days of life. Medication as required was prescribed for most cancer patients and, although to a lesser extent, also to most non-cancer patients within each setting. Medical interventions, like setting up of a syringe driver, vena punctures or lab tests, radiology or ECG, antibiotics, and drainage of body fluids were most often applied to hospital patients. Within each setting the majority of the patients was showered or washed daily. Standard controls, like body temperature measurement, and blood pressure measurement were mainly applied to hospital patients. Other nursing interventions, like wound care, and a routine turning regime were mainly applied to patients in the nursing home and home care setting.

Table 3.3: Medical and nursing interventions during the last three days of life.

	Patients with a cancer disease			**Patients with a non-cancer disease**		
	Home Care (N = 15)	Nursing Home (N = 38)	Hospital (N = 102)	Home Care (N = 12)	Nursing Home (N = 64)	Hospital (N = 8)
Medical interventions	N (%)					
Medication as required was written up	10 (67)	26 (79)	65 (66)	5 (46)	42 (72)	4 (50)
Syringe driver set up	2 (13)	8 (24)	62 (62)	1 (9)	9 (16)	1 (13)
Vena puncture or lab tests	-	1 (3)	42 (42)	2 (18)	1 (2)	8 (100)
Radiology or ECG	-	-	30 (30)	-	-	4 (50)
Antibiotics	1 (7)	1 (3)	24 (24)	-	4 (7)	4 (50)
Drainage of body fluids	1 (7)	-	20 (20)	1 (9)	1 (2)	1 (13)
Nursing interventions						
Daily shower or wash	13 (87)	24 (73)	75 (76)	9 (82)	54 (92)	7 (88)
Body temperature measurement	4 (27)	1 (3)	61 (67)	3 (27)	21 (36)	8 (100)
Routine turning regime	6 (40)	15 (46)	24 (24)	4 (36)	38 (64)	2 (25)
Blood pressure measurement	1 (7)	2 (6)	58 (59)	2 (18)	17 (29)	8 (100)
Wound care	3 (20)	10 (30)	14 (14)	3 (27)	17 (29)	1 (13)
Removal of respiratory tract secretions	-	1 (3)	11 (11)	-	3 (5)	2 (25)

Table 3.4 lists some aspects of communication. In the hospital setting, more patients were explicitly informed about the imminence of death. In the majority of the cases within each setting the family was informed about the imminence of death of the patient. Compared to the nursing home and the hospital setting family of home care patients were less often informed about the imminent death of the patient. General practitioners and other professional caregivers were less often informed about the imminence of death of hospital patients than of nursing home or home care patients.

Table 3.4: Communication between caregivers, the patient and the family.

		Patients with a cancer disease			Patients with a non-cancer disease		
		Home Care (N = 15)	Nursing Home (N = 38)	Hospital (N = 102)	Home Care (N = 12)	Nursing Home (N = 64)	Hospital (N = 8)
		N (%)					
During the dying phase the patient has been told that he or she was dying		8 (53)	13 (43)	73 (76)	4 (36)	24 (43)	2 (25)
During the dying phase the family has been told that the patient was dying		10 (67)	25 (83)	90 (92)	7 (64)	50 (88)	4 (57)
General practitioner and or other care givers were informed about the imminent death of the patient	• General practitioner	12 (80)	10 (31)	17 (19)	8 (73)	17 (32)	-
	• Other caregivers	8 (53)	15 (47)	26 (30)	4 (36)	28 (53)	-
	• No professional care givers informed	1 (7)	11 (34)	51 (59)	3 (27)	12 (23)	8 (100)

3.4 Discussion

In our study, we compared characteristics of dying in the hospital setting, the nursing home setting and the home care setting. There were some differences in patient characteristics between the settings in our study. Nursing home and home care patients were older and more often died from non-cancer diseases as compared to hospital patients. These differences are typical for the general populations of patients dying in these settings.[4] but they are even more pronounced due to the fact that our study comprised several oncology departments in hospitals.

Pain and shortness of breath were more severe among hospital patients, whereas incontinence was more severe among nursing home and home care patients. Fatigue, lack of appetite, shortness of breath, pain, concentration difficulties, incontinence, worry, agitation and tenseness have been found as being typical for the last three days of life in our study. These symptoms have been found as being typical for the last weeks of life in other studies too.[18, 19] Six percent of the patients who died during the study period could not be included in the study because they were physically or mentally unable to give informed consent. This may have led to a selection of patients with on average fewer symptoms than the total population of deceased patients.

Several medical and nursing interventions were most often applied in the hospital setting. The palliative care approach assumes that treatments that are exclusively

aimed at prolonging the patient's life, and interventions aimed at assessing the patient's health condition, such as blood pressure and body temperature measurements, become minor to efforts that give patients the opportunity to invest their energy in saying goodbye to loved ones and other issues to complete life. However, caregivers may be reluctant to refrain from routine interventions in dying patients, especially when the dying phase has not been recognized. In the hospital setting, for example, standard controls were continued in a substantial minority of the patients. Caregivers may find it difficult to shift from a curative approach to a palliative approach.[20] Our finding that some hospital patients were informed about the imminence of their death and received antibiotics in the same period suggests that the transition from 'cure' to 'care' occurs often very shortly before death. Earlier awareness of a patient's impending death, may, especially in the hospital setting, facilitate a shift from the focus of care from prolonging life to accepting death.

In several studies, both patients and family have been shown to consider clear information about what to expect during the dying phase as very important.[21, 22] We found that in the hospital setting, patients and family were indeed relatively often informed of the imminent death of the patient in the last three days of life. This might be related to several factors. First, in the nursing home and at home end-of-life care may already have been discussed at an earlier stage. Second, our hospital setting included mostly cancer patients. Most cancer patients keep a high function level until shortly before death.[23] Not only may cancer patients remain able to communicate until shortly before death. Their decline in the terminal stage may also necessitate explicit communication about the imminence of death. Third, hospital care is in general aimed at temporarily treatment, to send patients home as soon as their health condition allows. In the last phase of life family of cancer patients have usually not given their farewells to the patient.[24] As a result, dying typically represents an unexpected course of events in hospital that possibly induces relatively clear communication about the imminence of death and its consequences for the decision making about medical and nursing care.

When interpreting the results we have to be aware of some limitations of this study, which are mostly typically associated with end-of-life research. To start with, all data were collected after the death of the patient. Obviously, the exact time of death of the patient could not be foreseen in most cases. Our data therefore do not warrant direct conclusions about the quality of care for dying patients in different settings. They are primarily aimed at enabling evaluation of the different practices. Further,

the majority of the nurses (81%) filled in the questionnaire within 7 days after death of the patient. We assume that within such a short time span the nurses, who had been closely involved with care for the patient during the last three days of life, were able to recall most care details, but it can not be precluded that the degree of involvement and recall bias is different between the settings.

We conclude that in the hospital setting patients have more pain and shortness of breath, whereas in the nursing home setting and at home patients have more severe incontinence. Medical and nursing interventions are in general more often continued during the last three days of life in the hospital than in the nursing home or home care setting. Communication about the imminence of death is more explicit during the last three days of life in the hospital than in the other settings.

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4

The effect of the Liverpool care pathway for the dying: a multi centre study

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Abstract

We studied the effect of the Liverpool care pathway (LCP) on the documentation of care, symptom burden, and communication in three health care settings. Between November 2003 and February 2005 (baseline period), the care was provided as usual. Between February 2005 and February 2006 (intervention period), the LCP was used for all patients for whom the dying phase had started. After death of the patient a nurse and a relative filled in a questionnaire. In the baseline period, 219 nurses and 130 relatives filled in a questionnaire for 220 deceased patients. In the intervention period, 253 nurses and 139 relatives filled in a questionnaire for 255 deceased patients. The LCP was used for 197 of them. In the intervention period, the documentation of care was significantly more comprehensive as compared to the baseline period, whereas the average total symptom burden was significantly lower in the intervention period. LCP use contributes to the quality of documentation and symptom control.

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4.1 Introduction

Palliative care in the dying phase aims to support the quality of life of dying patients and their family. During the past decades our understanding about what good terminal care may imply has increased.[1-5] In the UK the Liverpool Care Pathway for the dying patient (LCP) was developed to transfer the care practice from the hospice setting to the hospital setting.[6] The LCP is a standardized registration method to monitor the care and its results. It takes into account physical, psychosocial as well as spiritual aspects. Nowadays, the LCP is broadly applied in various types of care settings in the UK, where it has been shown to structure care and to facilitate audit.[7] However, the extent to which the LCP improves the care and the quality of life for dying patients has not yet been thoroughly investigated.

In 2001, the LCP was translated into Dutch and tested in three specialized palliative care units.[8] The majority of the staff felt that the LCP structured patient care, supported problem anticipation, promoted proactive management of patient comfort, and facilitated multidisciplinary communication. In the current study, we investigated the effects of using the LCP within the hospital, nursing home and home care setting. We assessed the degree to which care is documented during the dying phase, the symptom burden for dying patients, and several aspects of communication in the last three days of life.

4.2 Patients and methods

Patients

The hospital setting in our study was represented by an oncology department in a general hospital and three oncology departments in a university hospital. The nursing home setting included a general department and a palliative care department in one nursing home, and a complete nursing home that also has a palliative care department. The home care setting was represented by a home care organization that provides nursing care at home in a region of eight villages, and by the residential care organization, that also provides nursing care to about 60 people who live independently. All patients receiving care from either of these institutions between November 2003 and February 2006 were informed of the study. Patients of 18 years or older who died in this period were eligible for the study. Patients who had expressed objections against the use of their medical or nursing record were not included. About two months after the death of the patient, the relative who had been 'contact person' for the patient received a letter from the institution that had

provided terminal care, asking him or her for consent to be approached by the research team to fill in a written questionnaire. In case the relative did not respond, a reminder was sent after two and six weeks, respectively. Only relatives who gave their consent were mailed a questionnaire. The Medical Ethical Research Committee of the Erasmus MC approved the study.

Design

We compared the level of documentation, the symptom burden and several aspects of communication before and after the introduction of the LCP. A pre- and post-intervention design was considered preferable to a randomized clinical trial, because of the unfeasibility of simultaneously applying different care methods and because of practical and ethical problems related to randomizing dying patients. During the baseline period (November 2003 – February 2005), in all settings the care was provided as usual. The LCP was introduced at the start of the intervention period and subsequently used for all patients for whom the medical team agreed that the dying phase had started. The implementation of the LCP was in each institution supported by the Comprehensive Cancer Centre Rotterdam, which is experienced in supervising and supporting quality improvement initiatives in cancer care. The intervention period lasted from February 2005 to February 2006. According to the 'intention to treat principle', all patients in the intervention period were included in our analysis, whether or not with LCP care.

Data collection

Within each institution, one member of the care team, mostly a nurse, was key person for the study. For each participating patient, he or she collected information from the medical and nursing records or from the LCP, about the patient's gender, age and diagnosis, and about whether or not the caregivers had been aware of the start of the dying phase. Within one week after the death of an eligible patient, a nurse who had been closely involved with caring for the patient during the last three days of life filled in a questionnaire. Relatives received a questionnaire three months after the death of the patient. Nurses and relatives were asked to assess the symptom burden, and some characteristics of the communication between the patient, professional caregivers, and family during the last three days of life. The questions about dyspnoea, pain, constipation, nausea or vomiting, and diarrhea originated from the EORTC QLQ-C30 questionnaire. We considered this questionnaire

a valid instrument for measuring the patients' symptom burden by others than patients themselves, because the agreement between patients and observers has been shown to be moderate to good (Intra class correlation = 0.42 to 0.79).[43] Questions about agitation, fear, confusion, incontinence, and troublesome mucus production were added, because these symptoms are common in the last phase of life and are explicitly addressed in the LCP.[22 58-60] Questions about communication were based upon items from the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire. The VOICES is an instrument specifically developed for proxies to evaluate the care and services received by patients and their relatives in the last months of the patient's life.[40] Prior to their use in our study, all questionnaires were evaluated in face-to-face interviews with six physicians, six nurses, and five relatives, and subsequently refined where needed.

Analysis and statistics

Documentation could be categorized as either 'yes', 'no', 'unclear', 'not applicable', or 'standard'. 'Standard' was used for care that was not documented because it was carried out as a routine in the dying phase. One of the nursing homes, for example, applied standard procedures to organize the care after death for each patient, which were not documented for each patient separately. Therefore in the analysis, the categories 'yes' and 'standard' were combined. Differences in the documentation of care during the dying phase between the baseline period and the intervention period were analyzed for those patients for whom the caregivers had been aware of the start of the dying phase. For nine aspects of care, the proportion of patients for whom the care was documented was compared between the baseline and the intervention period, using Chi-square tests. The mean number of documented aspects per patient was also calculated, using Student's t-tests. Scores on EORTC QLQ-C30 items were linearly transformed from the 1-4 scale to a 0-100 scale. A higher score on this 0-100 scale reflects a higher symptom burden. Besides, for each patient the total symptom burden was calculated by adding up the scores of nurses and relatives, respectively, on dyspnoea, pain, agitation, incontinence, fear, confusion, troublesome mucus production, constipation, nausea or vomiting, and diarrhea. This resulted in a total symptom score with a possible range of 0 to 1000. Differences between assessments in the baseline period and the intervention period were statistically tested, using Chi-square tests, Student's t-tests and Mann-Whitney U tests where appropriate.

4.3 Results

During the *baseline period*, 283 patients died within one of the participating care settings, of whom 220 (78%) could be included in the study. Patients who could not be informed about the study (51 patients), mainly because of their weak health status, were not included. Patients who expressed objections against the use of their medical or nursing record after their death were not included either (12 patients). Nurses filled in questionnaires for 219 patients. For 130 patients (59%), a relative was willing to fill in a questionnaire. Patient characteristics were comparable between patients for whom a relative had filled in a questionnaire and patients for whom the relatives had not filled in a questionnaire. During the *intervention period*, 292 patients died within one of the participating care settings, of whom 255 (87%) could be included in the study. Thirty patients could not be informed of the study and 7 patients had objected to the use of their medical data. One patient could not be included because of missing data. For 253 patients a nurse filled in a questionnaire, and a relative did so for 139 patients (55%). Age and gender were comparable between patients for whom a relative had filled in a questionnaire and patients for whom the relatives had not filled in a questionnaire. The proportion of patients with a cancer diagnosis was higher in the group of patients for whom a relative had filled in a questionnaire. The LCP was used for 197 of the 255 patients (77%) in the intervention period. The median duration of use of the LCP was 63 hours (min. 5 hours, max. 14.5 days) in home care and 35 hours (min. 1 hour, max. 35 days) in the nursing home, whereas in the hospital setting the median duration of use of the LCP was 16 hours (min. 1 hour, max. 3.7 days).

Patient characteristics were comparable between both periods (Table 4.1). The mean age at death was 74 years in the baseline period and 75 years in the intervention period. Hundred-and-five baseline patients (48%) and 106 intervention patients (42%) were male. The majority of patients had cancer.

Table 4.1: Patient characteristics in the baseline period and the intervention period.

		Baseline period N = 219 Mean (SD)	**Intervention period** N = 253 Mean (SD)	p-value[1]
Age (years)		74 (15)	75 (15)	0.91
		N (%)	N (%)	p-value[2]
Age category	18 – 75 years of age	102 (48)	118 (47)	0.88
	76 – and over	110 (52)	131 (53)	
Gender	Male	105 (48)	106 (42)	0.23
	Female	114 (52)	147 (58)	
Diagnosis	Cancer	141 (65)	155 (62)	0.50
	Non-cancer	75 (35)	94 (38)	
Care setting	Primary care	27 (12)	48 (19)	0.27
	Nursing home	102 (47)	114 (45)	
	Hospital	90 (41)	91 (36)	

1 Student's t-test
2 Chi-square test

Table 4.2 shows the degree to which, after recognition of the dying phase, nine aspects of care were documented in writing. In the baseline period, the average number of aspects of care that was documented was 5.6, whereas it was 7.1 in the intervention period, ($p < 0.001$). Eight aspects of care were significantly more often documented in the intervention period as compared to the baseline period ($p < 0.05$).

Table 4.2: Documentation of care for patients for whom the caregivers had been aware of the start of the dying phase.

Aspect of care	**Baseline period** N = 167[1]			**Intervention period** N = 192[1]			p-value[3]
	Documentation in writing						
	Yes[2]	No/ missing	Not Applicable	Yes[2]	No/ missing	Not Applicable	
	(%)						
Assessment of current medication	72	26	2	83	15	2	0.031
Prescription of medication as required	74	26	1	76	24	1	0.92
Discussion about resuscitation	57	41	2	79	20	1	<0.001
Recognition of dying by patient	38	59	3	71	26	3	<0.001
Recognition of dying by relatives	80	20	-	96	4	-	<0.001
Assessment of religious or spiritual needs	55	45	1	72	25	3	<0.001
Contact with GP Practice about patient's death	55	38	7	68	31	1	0.001
Discussion of procedure following death	81	17	2	90	8	3	0.033
Provision of bereavement leaflet	47	51	2	73	26	1	0.000

1 Number of patients for whom the caregivers had been aware of the start of the dying phase.
2 Including cases in which this aspect of care was regarded as standard care.
3 Chi-square test

According to nurses as well as relatives, the burden of most symptoms was lower in the intervention period as compared to the baseline period (Table 4.3). The total symptom burden was significantly lower in the intervention period as compared to the baseline period, for both the nurses' scores, for which the average was 325 in the baseline period and 287 in the intervention period (p = 0.008), and the relatives' scores, for which the averages were 427 and 372, respectively (p = 0.016). The differences were statistically significant for the nurses' scores on pain and (nearly) significant for the relatives' scores on agitation, fear, and troublesome mucus production.

Table 4.3: Symptom burden in the baseline period and the intervention period.

		Baseline period		**Intervention period**		
		N = 219		N = 253		
Symptom	Respondent	N[1]	Mean (SD)	N[1]	Mean (SD)	p-value[2]
Dyspnoea	Nurse	213	49 (35)	243	44 (35)	0.15
	Relative	121	63 (35)	124	56 (36)	0.14
Pain	Nurse	216	47 (34)	246	41 (32)	0.043
	Relative	124	60 (35)	131	57 (35)	0.46
Agitation	Nurse	215	40 (37)	246	39 (35)	0.80
	Relative	121	58 (35)	130	49 (35)	0.054
Incontinence	Nurse	213	45 (38)	242	39 (35)	0.12
	Relative	120	45 (42)	127	44 (41)	0.94
Fear	Nurse	210	37 (35)	233	34 (34)	0.30
	Relative	120	46 (38)	127	36 (33)	0.031
Confusion	Nurse	202	33 (34)	241	29 (35)	0.27
	Relative	120	43 (39)	129	40 (38)	0.51
Troublesome mucus	Nurse	214	30 (34)	244	28 (33)	0.65
	Relative	120	46 (41)	128	33 (37)	0.007
Constipation	Nurse	208	18 (29)	235	17 (28)	0.90
	Relative	111	32 (34)	122	30 (35)	0.65
Nausea or vomiting	Nurse	214	16 (25)	241	14 (25)	0.31
	Relative	121	29 (35)	129	25 (31)	0.32
Diarrhea	Nurse	208	12 (25)	236	9 (22)	0.14
	Relative	114	24 (33)	128	21 (32)	0.58
Total	Nurse	178	325 (141)	216	287 (142)	0.008
	Relative	98	427 (170)	108	372 (151)	0.016

1 Number of patients for whom nurse or relative answered the item.
2 T-test

The relatives' appreciation of aspects of communication, such as communication about the care for the patient, or the imminent death of the patient, was comparable between the baseline and the intervention period, (Table 4.4). In cases where the relative had evaluated the patient's disease and death with a caregiver, this evaluation had been significantly more often helpful in the intervention period than in the baseline period.

Table 4.4: Communication about the patient's imminent death, according to relatives.

	Baseline period N = 130[1] N (%)	**Intervention period** N = 139[1] N (%)	p-value[2]
Relative had been aware that the patient was going to die within a few days			
– Yes	88 (68)	89 (64)	
– More or less	20 (15)	28 (20)	
– No	22 (17)	22 (16)	0.65
Amount of information relative received about care for patient			
– Too much	1 (1)	3 (2)	
– Enough	113 (87)	121 (88)	
– Too less	15 (11)	14 (10)	0.50
Information was understandable for relative			
– Yes	107 (85)	123 (93)	
– More or less	16 (13)	7 (5)	
– No	3 (2)	3 (2)	0.060
Caregiver had told relative that patient would probably die within a few days			
– Yes	84 (65)	91 (66)	
– No	46 (35)	47 (34)	0.73
Relative was informed about where to find further support			
– Yes	43 (52)	57 (64)	
– No	40 (48)	32 (36)	0.11
Relative feels that patients' personal and religious beliefs were adequately taken into consideration			
- Yes	99 (80)	112 (83)	
- More or less	18 (14)	14 (10)	
- No	7 (6)	10 (7)	0.68
Relative evaluated patients' disease and death with caregiver			
– Yes	82 (66)	91 (66)	
– No	43 (34)	46 (34)	0.88
This evaluation was helpful			
– Yes	56 (69)	77 (85)	
– A bit	23 (28)	14 (15)	
– No	2 (3)	-	0.014
Relative did not evaluate patient's disease and death with caregiver, but would have liked to			
– Yes	7 (17)	11 (24)	
– Maybe	18 (45)	17 (37)	
– No	15 (38)	18 (39)	0.82
Relative would have liked other help or support from caregivers			
– Yes	17 (14)	21 (15)	
– No	109 (86)	117 (85)	0.69

1 Number of patients for whom questionnaires were sent back by relatives.
2 Mann-Whitney U test.

4.4 Discussion

One of the most important aims of the LCP is to facilitate comprehensive documentation of symptoms, problems and care during the dying process. High quality documentation not only contributes to structuring care and to the proactive and multidisciplinary management of patient comfort ([7,8]), but it can also provide practice examples for education and further professionalization of the care for dying patients. Our study shows that after introduction of the LCP the degree to which care during the dying phase was documented in writing increased. This holds for the hospital setting, the nursing home setting, as well as the home care setting. In a previous study, the number of missing assessments was larger for a setting that was used to working with the LCP for several years as compared to a setting that had recently started working with the LCP.[15] Apparently, there is a need for ongoing education to ensure that the document is used comprehensively.

Obviously, increased documentation does not necessarily mean better care. However, our study shows that after introduction of the LCP the symptom burden for patients decreased. Symptom control has often been characterized as one of the key concerns in terminal care.[4, 16-18] This decrease in symptom burden was seen in both the assessments of the nurses and the relatives. Nurses may have been inclined to give more positive ratings in the intervention period, because our study was not blinded, which could result in an overestimation of the effects of the LCP. On the other hand, nurses might also have been more alert about symptoms in the intervention period because symptoms are listed in the LCP, which might have resulted in an underestimation of the effects of the LCP. The relatives were only involved during either the baseline or the intervention period and thus they were not aware of changes in care methods. Our finding that relatives rated the patients' symptom burden more positively during the intervention period therefore suggests that using the LCP actually contributes to a small but significant decrease of the symptom burden for dying patients. Communication between the dying patient, his or her family, and professional caregivers is also regarded as a crucial aspect of care for the dying.[19] The appreciation by relatives of several communication issues was not significantly different in the intervention period as compared to the baseline period. It should be recognized that the institutions that participated in our study were specifically interested in providing high quality palliative care to dying patients, which suggests that their communicative skills may have been of a good quality at baseline. Further, measuring satisfaction with care has been shown to be a complex

issue. Sinding et al. have described that complaining about care after the death of the patient may seem pointless or gratuitous to bereaved relatives, and that articulating negative experiences may only upset them.[20]

The improvements in documentation and symptom burden that we saw in the intervention period as compared to the baseline period were modest but evident. This may be seen as a remarkable result of using a care pathway that mainly introduces a structured registration method, and not a new intervention or therapy.[6] However, other studies in which clinical pathways were applied to dying hospital patients, also showed improved care outcomes, such as better symptom management, fewer interventions, and better documentation of care.[21, 22]

The median duration of use of the LCP was longest at home, and shortest in the hospital setting. This may be related to the fact that home care is often specifically started for patients who enter the terminal phase of their disease. Hospital care is often started to cure disease or treat symptoms, typically with the aim of enabling patients to go home again when possible. It cannot be precluded that the recognition of the dying phase is sometimes delayed in the hospital setting, because of this emphasis on cure, treatment, and short stay. Care benefits might have been more pronounced with earlier recognition of the dying phase and longer duration of LCP use in the hospital setting.

Strengths and limitations

Although the LCP had been disseminated nationally as part of the End of Life Care Initiative to improve care for dying patients in the UK [7], its possible benefits for patients has not been evaluated scientifically so far. Whereas a randomised clinical trial was impossible because of practical and ethical considerations, we used a pre- and post intervention design. The advantage of this design is that settings were their own control. However, within such a design, it cannot be precluded that differences between the baseline and the intervention period are caused by other changes than the intervention that is studied. However, we think that it is not likely that important changes other than our intervention occurred at any of the study sites, because the intervention period directly followed the pre-intervention period. Further the gender, age, and diagnosis of patients were similar in both periods.

The study questionnaires addressed symptoms and care during the last three days of life. However, the LCP was used for a shorter period of time for many patients: in the

hospital setting, the median duration time of use of the LCP was only 16 hours. Therefore, the LCP effect could have been diluted, especially in the hospital setting. Another limitation is our dependence on proxies for the assessment of symptoms of the patient during the last three days of life. However, proxy measurements have been shown to be relatively valid for such rather objective variables.[9, 14, 23]

Conclusion

In conclusion, the LCP contributes to the quality of documentation and symptom management. We therefore consider LCP use beneficial for the care for dying patients and their family.

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5

Does recognition of the dying phase have an impact on the use of medical interventions?

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Abstract

During the dying phase, patients often undergo interventions not aimed at promoting their comfort. We investigated how recognition of the dying phase affected the application of interventions. We included 489 of 613 patients (80%) who died either in a hospital, nursing home, or primary care setting between November 2003 and February 2006. After the death of patients, nurses filled in questionnaires and patient records were searched for information about therapeutic and diagnostic interventions that were applied during the dying phase. The dying phase was considered to have been recognized when the patient's record contained any written documentation concerning the start of the dying phase. Caregivers recognized the dying phase of 380 patients (78%). The number of patients receiving diagnostic interventions was significantly lower when the dying phase was recognized (39%), as compared to when it was not (57%) ($p = 0.00$). Significantly more patients with a recognized dying phase were routinely turned (46%) and had a syringe driver set up (36%), as compared to patients without a recognized dying phase (25% and 12% respectively) (for both $p = 0.00$). Significantly fewer patients with a recognized dying phase underwent lab tests (15%), radiology or ECG (12%), blood pressure measurements (21%), and body temperature measurements (26%), as compared to patients without a recognized dying phase (39%, 22%, 48%, and 50% respectively) (for each $p < 0.05$). We conclude that although recognition of the dying phase can reduce the number of undesirable interventions, for some interventions this is more difficult than for others.

5.1 Introduction

Dying patients often undergo invasive tests or receive treatments aimed at prolonging life, such as chemotherapy, in their last phase of life. This has especially been shown for cancer patients dying in hospitals.[1,2] Such interventions can have burdensome side effects, while their therapeutic or palliative effects are often small.[3-5] For dying patients, the necessity of interventions that are primarily aimed at curing disease or lengthening life, or interventions that aim to monitor the patient's health condition, seems doubtful. Instead, their care should predominantly encompass interventions that aim to promote the patients' comfort. During the past years, many initiatives have been undertaken to improve patient focused care for the dying. In the UK, the Liverpool Care Pathway for the dying patient (LCP) was developed.[6] It aims at recognizing the start of dying phase as the moment to discontinue interventions that are not primarily aimed at the dying patient's comfort.

About a third of all deaths in the Netherlands and other western societies occur unexpectedly, often due to ischaemic heart disease, cerebrovascular disease, or accidents.[7,8] Another major cause of death, namely cancer, often has a more or less predictable dying phase.[8,9] Patients of old age, with already low cognitive or physical functioning, often die more or less expectedly too.[9] It is unclear to what extent recognition of the dying phase affects the application of interventions in such patients. It has been shown that a resuscitation attempt was least likely when death was most expected.[10] However, another study showed that patients who had a comfort care plan because of expected death, still received life prolonging treatment.[1]

We wondered whether recognition of the dying phase could have an impact on medical interventions during the dying phase. Therefore we compared the application of interventions between patients for whom the caregivers recognized the dying phase and patients for whom the caregivers did not recognize the dying phase. We distinguished interventions with a therapeutic or a diagnostic focus. Besides, we investigated the possible influence of patient characteristics, care setting, and LCP use on the application of these interventions.

5.2 Patients and methods

Patients

A university hospital (three oncology departments, a department for pulmonary diseases and a gynecology department), a general hospital (a department of medical

oncology), a complete nursing home (five general departments and one palliative care department), another nursing home (a general department and a palliative care department), a residential care organization (which provides nursing care to about 60 people who live independently), and a home care organization (which provides home care in a region of eight villages) in the southwest of The Netherlands participated in the study. Between November 2003 and February 2006, all patients older than 18 years of age, who received inpatient care of the participating department, were informed of the study. Patients who died during this period were eligible for the study. Patients who had expressed objections against the use of their medical or nursing record were not included. The Medical Ethical Research Committee of the Erasmus MC approved of the study.

Design

We collected our data in the context of an intervention study. This study investigated the effect of using the Liverpool Care Pathway for the dying patient (LCP) on the care and quality of life during the last three days of life.[61 76] Data collection took place between November 2003 and February 2006. Halfway during this period the LCP was introduced, and subsequently used for each patient of whom the multidisciplinary team agreed that the dying phase had started.

Data collection

Within each institution, one member of the care team, most often a nurse, coordinated the project. This coordinator looked through the patient's records to assess written documentation about the start of the dying phase. Further, documentation was searched of interventions that were discontinued. Gender, age, and diagnosis of the patient were also based upon the patient's records. Further, within a week after the death of the patient, a nurse who had been caring for the patient filled in a questionnaire about applied interventions during the last three days of life.

Analysis and statistics

The dying phase was considered to have been recognized when the patient's record contained any written documentation concerning the start of the dying phase. We analyzed a number of therapeutic interventions (routine turning regime to prevent pressure ulcers, antibiotics, chemotherapy, radiotherapy, syringe driver set up for

continuous supply of for example pain medication, drainage of body fluids, removal of respiratory tract secretions, and wound care) and diagnostic interventions (vena punctures or lab tests, radiology or ECG, blood pressure measurement, and body temperature measurement). We regarded an intervention as being applied during the dying phase if it was applied during the last three days of life, and if no documentation was found about its subsequent discontinuation. We tested the significance of differences between groups using Chi-square tests. We also tested whether the application of interventions was associated with the age and gender of the patient, the diagnosis, the care setting, and use of the LCP, applying multivariate logistic regression analysis.

5.3 Results

During the study period, in total 613 patients died within one of the participating care settings. Ninety-four patients who could not be informed about the study, mainly because of their weak health status, were not included. Twenty-four patients who expressed objections against the use of their medical or nursing record after their death were not included either. Six patients could not be included in the analyses because of missing data. Nurses filled in questionnaires for 489 patients. For 380 patients (78%), the patient's records included documentation of the start of the dying phase. For the other 109 patients no evidence of recognition of the dying phase was found (22%). In both groups patients were on average 74 years old and somewhat over half of the patients in both groups had a cancer diagnosis (Table 5.1). In the group of patients with a recognized dying phase, 42% was male, which was a significantly lower percentage than the 55% males in the group of patients without a recognized dying phase ($p = 0.02$). The percentages of patients who died in either a hospital, nursing home or home care setting were comparable between both groups. The duration of the dying phase varied considerably. Of all patients for whom the dying phase was recognized, 50% died within 24 hours after such recognition. The LCP had been used for 170 of the 380 patients with a recognized dying phase (45%).

Table 5.1: patient characteristics

	Total	**Patients with a recognized dying phase**	**Patients without a recognized dying phase**	p-value[1]
	N = 489 N (%)	N = 380 (78%) N (%)	N = 109 (22%) N (%)	
Gender				
Male	221 (45)	161 (42)	60 (55)	
Female	268 (55)	219 (58)	49 (45)	0.02
Diagnosis				
Cancer	308 (64)	246 (66)	62 (58)	
Other	174 (36)	129 (34)	45 (42)	0.15
Care setting during the dying phase				
Primary care	77 (16)	53 (14)	24 (22)	
Nursing home	214 (44)	173 (46)	41 (38)	
Hospital	198 (40)	154 (40)	44 (40)	0.10
Liverpool Care Pathway was used	170 (35)	170 (45)	-	-
	Mean (SD)	Mean (SD)	Mean (SD)	
Age (in years)	74 (15)	74 (15)	74 (13)	0.91[2]
Duration of the dying phase (in hours)	-	(n = 349) 27 (27)	-	-

1 Chi-square test.
2 ANOVA.

Table 5.2 shows data about the application of therapeutic and diagnostic interventions. Of all patients with a recognized dying phase, 89% received any therapeutic intervention as compared to 88% of the patients without a recognized dying phase. Differences were found for routine turning and the set up of a syringe driver: significantly more patients with a recognized dying phase were routinely turned (46%) and had a syringe driver set up (36%) as compared to patients without a recognized dying phase (25%, and 12% respectively) (for both p = 0.00). Diagnostic interventions were applied to significantly fewer patients with a recognized dying phase (39%) as compared to patients without a recognized dying phase (57%) (p = 0.00). Especially vena punctures or lab tests, radiology or ECG, and the measurement of blood pressure and body temperature were less often applied to patients with a recognized dying phase. Patients of whom the dying phase was recognized 24 hours or less before their death had less often a syringe driver set up as compared to patients of whom the dying phase was recognized more than 24 hours before death, but vena punctures or lab tests, or other diagnostic interventions were more often applied to them.

Table 5.2: interventions during the dying phase

	Total	**Patients with a recognized dying phase**	**Patients without a recognized dying phase**	p-value[1]
	N = 489	N = 380	N = 109	
Therapeutic interventions		N (%)	N (%)	
Antibiotics	52 (11)	39 (11)	13 (13)	0.55
Chemotherapy	5 (1)	3 (1)	2 (2)	0.32
Radiotherapy	16 (3)	15 (4)	1 (1)	0.13
Routine turning regime	190 (41)	164 (46)	26 (25)	0.00
Syringe driver set up	142 (31)	130 (36)	12 (12)	0.00
Drainage of body fluids	34 (7)	24 (7)	10 (10)	0.25
Wound care	104 (23)	82 (23)	22 (22)	0.89
Removal of respiratory tract secretions	30 (7)	26 (7)	4 (4)	0.26
Other therapeutic interventions, such as blood transfusion or daily washing	332 (71)	251 (69)	81 (79)	0.05
Total number of patients with any therapeutic intervention (n = 466)[2]	414 (89)	325 (89)	89 (88)	0.79
Diagnostic interventions				
Vena punctures or lab tests	93 (21)	54 (15)	39 (39)	0.00
Radiology or ECG	66 (15)	44 (12)	22 (22)	0.02
Blood pressure measurement	114 (27)	68 (21)	46 (48)	0.00
Body temperature measurement	132 (31)	84 (26)	48 (50)	0.00
Other diagnostic interventions, such as function tests	48 (10)	35 (10)	13 (12)	0.47
Total number of patients with any diagnostic intervention (n = 460)[2]	198 (43)	141 (39)	57 (57)	0.00

1 Chi-square test.
2 Totals did not concern the patients of whom one or more of the assessments were missing.

After adjustment for age, gender, diagnosis, care setting, and use of the LCP, recognition of the dying phase still significantly decreased the chance on diagnostic tests, whereas it increased the chance on set up of a syringe driver, and a routine turning regime (Table 5.3). Diagnosis and care setting were also related to the application of diagnostic interventions. Patients who died in hospital underwent significantly more diagnostic interventions as compared to patients who died elsewhere. Cancer patients underwent significantly less diagnostic interventions as compared to patients with other terminal diseases. Further, a syringe driver was significantly more often set up for patients who had cancer or who were staying in hospital.

Table 5.3: Predictors of the therapeutic and diagnostic interventions during the dying phase.

	Dying phase was recognized	**Diagnosis**	**Care setting**		**LCP**
	Yes/no OR (CI)	Cancer/non-cancer OR (CI)	Home / hospital OR (CI)	Nursing home / hospital OR (CI)	Intervention/ baseline OR (CI)
Therapeutic interventions					
Antibiotics	0.86 (0.42-1.78)	0.48 (0.17-1.35)	0.09[2](0.02-0.37)	0.07[2](0.021-0.20)	0.90 (0.49-1.68)
Chemotherapy	0.16 (0.02-1.57)	1506 (0.00-∞)	0.00 (0.00-∞)	0.00 (0.00-∞)	0.20 (0.02-2.27)
Radiotherapy	4.98 (0.63-39.5)	678 (0.00-∞)	0.00 (0.00-∞)	0.00 (0.00-∞)	0.85 (0.30-2.42)
Routine turning regime	2.38[2](1.41-4.01)	0.79 (0.46-1.34)	0.66 (0.33-1.33)	1.65[1](0.96-2.81)	1.18 (0.78-1.77)
Syringe driver set up	5.96[2](2.92-12.2)	2.58[2](1.26-5.30)	0.11[2](0.04-0.28)	0.20[2](0.11-0.37)	0.61[2](0.37-0.98)
Drainage of body fluids	0.60 (0.27-1.35)	1.54 (0.47-5.03)	0.66 (0.20-2.19)	0.36[1](0.12-1.08)	0.47[1](0.22-1.00)
Wound care	0.02 (0.58-1.80)	1.07 (0.60-1.91)	3.51[2](1.65-7.48)	3.23[2](1.69-6.19)	1.00 (0.63-1.58)
Removal of respiratory tract secretions	2.26 (0.74-6.85)	0.48 (0.15-1.57)	0.14[1](0.02-1.23)	0.35[1](0.11-1.08)	0.78 (0.36-1.69)
Diagnostic interventions					
Vena punctures or lab tests	0.22[2](0.12-0.42)	0.11[11](0.03-0.41)	0.03[2](0.01-0.12)	0.01[2](0.00-0.06)	1.26 (0.72-2.22)
Radiology or ECG	0.45[2](0.23-0.97)	0.12[2](0.02-0.60)	0.02[2](0.00-0.13)	0.00 (0.00-∞)	0.90 (0.48-1.68)
Blood pressure measurement	0.23[2](0.13-0.41)	0.32[2](0.15-0.71)	0.04[2](0.01-0.12)	0.11[2](0.05-0.25)	0.88 (0.54-1.45)
Body temperature measurement	0.36[2](0.21-0.61)	0.37[2](0.19-0.73)	0.10[2](0.04-0.25)	0.17[2](0.08-0.33)	0.86 (0.55-1.37)

[1]p<0.10
[2]p<0.05
OR = odds ratio
CI = confidence interval

5.4 Discussion

We studied the effect of recognition of the dying phase on the application of therapeutic and diagnostic interventions in patients with a terminal disease who died either in hospital or elsewhere. Patients with a recognized dying phase received significantly less diagnostic interventions as compared to patients in whom the dying phase was not recognized. The effect of recognizing the dying phase on the number of therapeutic interventions was les obvious.

Therapeutic interventions were applied to the majority of the dying patients in our study. In contrast to the other therapeutic interventions, routine turning and set up of a syringe driver were applied significantly more to patients with a recognized dying phase as compared to patients without a recognized dying phase. The syringe

driver provides an appreciated alternative for oral medication.[13] In the LCP, special attention is paid to the set up of a syringe driver within four hours of the doctor's order. The benefit of routine turning for dying patients seems less obvious. Hospices have been reported to no longer routinely turn dying patients in order to promote their comfort.[14,15] Alternatives for routine turning are special mattresses to prevent pressure ulcers, or medication for pain. Possibly, caregivers in our study were less familiar with alternative interventions to prevent suffering from pressure ulcers in dying patients. In one of the nursing homes a special intervention program was started during the study period to prevent pressure ulcers. As a result, caregivers in this nursing home may have felt hesitant to discontinue the routine turning regime for dying patients. Since we did not assess the frequency with which patients were turned, we do not know to what extent routine-turning regimes actually affected the comfort of the patients.

The percentages of patients who received antibiotics (11%) or chemotherapy (1%), were rather low as compared to what other studies found. Studies in different inpatient settings found that 41 to 64% of patients received antibiotics until the last days before dying.[1,3,16] In hospital 16% of the cancer patients received chemotherapy within two weeks before death.[17] A study among cancer patients who died outside an institution, found that 9% received chemotherapy in the last month of life.[18] The low percentages in our study may be due to the fact that our study only concerns the last three days of life, whereas other studies often addressed a longer period before death. Recognition of the dying phase did not affect the application of chemotherapy and most other therapeutic interventions. Possibly, the need for such interventions was already assessed prior to the recognition of dying phase for many patients in our study, because they were known to be close to death.

Although recognition of the dying phase decreased the application of diagnostic interventions, 39% of the patients with a recognized dying phase, mainly hospital patients, received one or more diagnostic interventions during the dying phase. There may be several factors to explain this. Measurement of blood pressure and body temperature may be something to hold on to in a further 'uncontrollable' situation. It may give the patient and the relatives the impression to be 'well guarded' by the caregivers, whereas it gives the caregivers the opportunity to show commitment with the patient and with the family. Another plausible explanation could be that the caregivers just persisted in their daily routine of doing standard tests, without realizing that they were no longer really necessary. A third reason may

be that caregivers are hesitant to quit routine controls for patients of whom the course of the disease is still rather unpredictable. Especially in the hospital, where care is primarily aimed at cure, the transition to end-of-life care may be difficult to make.

Cancer patients received less diagnostic interventions as compared to non-cancer patients, which may be related to the fact that terminal cancer often follows a more predictable course than other terminal diseases.[9] Further, cancer patients had more often a syringe driver set up as compared to non-cancer patients. As an instrument for continuous administration of drugs, a syringe driver is often used to provide medication against pain, that has been shown to be a more severe problem for patients dying from cancer during the last week of life as compared to patients with other terminal diseases.[19] Another study amongst Dutch physicians revealed that terminal sedation mostly concerned cancer patients, suggesting that the increased number of syringe driver set ups among cancer patients may in some cases serve to provide sedatives.[20]

Strengths and limitations

Our study sample is not representative for the Dutch population with respect to several characteristics. We included relatively many cancer patients (64%), as compared to the percentage of cancer deaths (27%) in the Dutch population.[21, 22] Further, in our study the mean age of death was relatively low (74 years), as compared to 79 years in the Dutch population.[23] Finally, our study sample included a relatively high proportion of patients dying in nursing homes (44%) and a relatively small proportion of patients dying at home (16%), since the population proportions are 23% and 42%, respectively.[24] The proportion of patients dying in the hospital was similar to the national rate (35%). Our proportion of male deaths (45%) is also comparable with the 48% of male deaths in the Dutch population.[21,22]

Further it should be realized that the discontinuation of interventions was assessed based on what was written in the patient files. We cannot preclude the possibility that more interventions were discontinued during the dying phase than those documented. The effect of recognition of the dying phase might thus have been more pronounced in reality.

We conclude that recognition of the dying phase by the caregiver, and formulating an explicit policy to apply only interventions aimed at improving the comfort of the patient lead to the application of less diagnostic interventions. Although recognition

of the dying phase can reduce the number of undesirable interventions, for some interventions this is more difficult than for others.

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6

Medical care and decision-making for dying cancer patients in three clinical settings and the impact of the LCP

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Abstract

Differences in the general focus of care between hospitals, nursing homes and home may affect the adequacy of end-of-life decision-making for the dying. We studied end-of-life decision-making practices for cancer patients who died in either of these settings, and assessed the impact of the Liverpool Care Pathway for the Dying Patient (LCP), a template for care in the dying phase. Physicians and relatives of 311 deceased cancer patients filled in questionnaires. The LCP was introduced halfway the study period. During the last three months of life, patients who died in hospital more often than patients in both other settings received anti-cancer therapy and medication to relieve symptoms. During the last three days of life, patients who died in the hospital or nursing home received more medication as compared to patients who died at home. The LCP had no clear impact on the use of medication during the last days of life, except that the extent to which physicians thought that medication might have hastened death was reduced after introduction of the LCP. Relatives of patients who died in the hospital tended to be least positive about the patient's and their own participation in the decision-making. We conclude that cancer patients who die in the hospital are more intensively treated during the last phase of life than cancer patients who die elsewhere. The LCP has a limited impact on medical treatment during the dying phase. Communication about medical decision-making tends to be better in the nursing home and at home.

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6.1 Introduction

The goals of medical care need to be adjusted when death approaches. In the dying phase, the patient's comfort is key to all decisions about care and treatment.[1] Such decisions may involve the use of interventions aimed at symptom control and the forgoing of burdensome or futile interventions. Symptom control and emotional support have been shown to be suboptimal for substantial proportions of patients dying in the hospital, the nursing home or at home.[2-8]. The SUPPORT study among bereaved relatives in the USA concluded that many patients dying in hospitals have unmet needs concerning symptom relief and psychosocial care.[2,3]

In the WHO definition of palliative care, both prolonging of life and hastening of death are stated not to be among the goals of care for the dying.[1] However, studies in several countries have shown that efforts to enhance the patient's comfort not rarely result in the (possible) hastening of death.[9,10] Such hastening of death is often an unintended effect of decisions to forgo potentially life-prolonging but burdensome treatment, or to use highly dosed medication to relieve severe pain or other symptoms. In some cases, hastening of death is an appreciated or even explicitly intended effect, because of the severe suffering of the patient without any prospect of relief.

Decisions about medical care have to be made in all settings where patients die. The characteristics of each setting may have a significant impact on such decision-making. Hospital care is primarily aimed at curing disease and prolonging life; death is usually an unforeseen outcome of hospital admittance. Patients are typically admitted to a hospital for specialized, mostly short-term care that cannot be given elsewhere. In the hospital, patients receive care from clinical specialists and hospital nurses. In the Netherlands, chronic patients who need constant care is often provided in a nursing home. Death is often the expected final outcome of long-term admittance to a nursing home. The nursing home physician and nurses provide nursing home care. Patients who are dying at home in the Netherlands usually receive care from their general practitioner, with whom they often have a long-standing relationship, and, if needed, from home care nurses who may visit patients once or several times a day.

The Liverpool Care Pathway for the Dying Patient (LCP) has been developed to improve care for the dying in all settings. The LCP is aimed at structuring care in the last days of life and at facilitating audit by standardizing the monitoring of care.[12, 13] It takes into account physical, psychosocial and spiritual aspects and has been

shown to improve patients' symptom burden and to contribute to the communication with patients and their family.[14] One of the goals of care in the LCP concerns the decision-making about which treatments are appropriate during the dying phase.[15] The use of medication is assessed and non-essentials are discontinued. Essential oral drugs are converted to the subcutaneous route and a syringe driver is commended if appropriate. PRN ('as required') subcutaneous medication is written up for symptoms that may occur during the dying phase, such as pain and agitation. Medical and nursing interventions that are considered inappropriate, such as blood tests, intravenous fluids or a routine turning regime, are stopped.

We investigated the characteristics of end-of-life decision-making during the last three months and the last three days of life of cancer patients and assessed the impact of the LCP, in the three main settings for death and dying in the Netherlands, that is, the hospital, the nursing home, and at home.

6.2 Patients and methods

Patients

Patients were recruited for our study in a university hospital (three medical oncology departments, a department for pulmonary diseases and a gynecology department), a general hospital (department of medical oncology), all departments in one nursing home (five general departments and one palliative care department), two departments in another nursing home (a general department and a palliative care department), a residential care organization that provides nursing care to about 60 people who live independently, and a home care organization that provides home care in a region of eight villages, in the southwest of the Netherlands. The study comprised two consecutive periods: a baseline period, during which we assessed usual practices, and an intervention period, during which all departments used the LCP for patients who were recognized to be in the dying phase. All patients older than 18 years of age, who received inpatient care of the participating department, or outpatient care in case of the home care organization, were informed of the study. Patients who died during the study period were eligible for the study. Patients who had expressed objections against the use of their medical or nursing record were not included. The Medical Ethical Research Committee of the Erasmus MC approved the study.

Data collection

Data were collected between November 2003 and February 2006. Within a week after the death of the patient, the patient's physician filled in a questionnaire about medical decisions and interventions during the last three months of life of the patient, and about medication during the last three days of life. About two months after the death of the patient, the relative who had been 'contact person' for the patient received a letter from the institution that had provided care in the last phase prior to death, asking him or her for consent to be approached by the research team to fill in a written questionnaire. In case the relative did not respond, a reminder was sent after two weeks and after three months, respectively. Only relatives who gave their consent were mailed a questionnaire. Relatives were asked to assess the patient's symptom levels in the last three days of life and their own experiences with medical decision-making in the last three months of life. Questions about pain, dyspnea, nausea or vomiting, feeling depressed, and being worried originated from the EORTC QLQ-C30 questionnaire. The agreement between scores of patients and observers has been shown to be moderate to good for this questionnaire (intra class correlation = 0.42 to 0.79).[16] Questions were added about incontinence, agitation, anxiety and confusion, because these symptoms are common in the last phase of life.[17-21]

Analysis and statistics

Only patients who died of cancer were included in the analyses for this paper. Symptom scores 2 to 4 were recorded into 1 (symptom was present) and score 1 was recoded into 0 (symptom was not present). The statistical significance of differences between settings in end-of-life decision-making during the last three months of life and the relatives' evaluation was tested using Chi-square tests and ANOVA tests, where appropriate. Differences in medical care during the last three days of life and the contribution of the LCP were analyzed using the intention-to-treat principle, that is, all patients who died during the intervention period were included regardless of whether or not the LCP had been used. We used logistic regression models that controlled for the effect of setting and age.

6.3 Results

Response and patient characteristics

During the study period, 613 patients died within the participating care settings. Eighty-one patients who could not be informed about the study, mainly because of their weak health status, were not included. Nineteen patients who expressed objections against the use of their medical or nursing record after their death were not included either. Of the remaining 513 patients, 311 had cancer. Physicians' data could be used in 299 (96%) of all included cases, and relatives were willing to participate in 184 cases (59%). Of all included patients, 192 died in the hospital, 83 in the nursing home, and 36 at home. Patients dying in the hospital were younger than patients dying in the nursing home or at home (Table 6.1). The most common types of cancer were in all settings gastrointestinal cancer, lung cancer and breast cancer; hematological malignancies were relatively common in patients who died at home. The most frequently reported physical symptoms during the last three days of life were in all settings pain and dyspnea. Incontinence was more common among nursing home patients and patients who died at home, as compared to hospital patients. The majority of patients in all settings were also reported to have had psychological symptoms, such as feeling depressed and anxiety. Patients who died at home had less often than patients in both other settings suffered from being worried or feelings of anxiety. Hospital patients had less often than other patients been confused. About half of all patients had been included during the LCP period: the LCP had actually been used during this period for 63 hospital patients, 40 nursing home patients, and 17 patients who died at home (not in table).

Table 6.1. Characteristics of cancer patients dying in three different clinical settings

	Hospital patients	**Nursing home patients**	**Home care patients**	P value[1]
	N=192	N=83	N=36	
		Mean (standard deviation)		
Age (years)	64 (14)	74 (12)	75 (13)	<0.001[2]
		Percentage		
Sex				0.46
• Male	47	53	42	
• Female	53	47	58	
Type of cancer				0.19
• Gastrointestinal	26	29	33	
• Lung	15	14	19	
• Breast	13	10	11	
• Urogenital	16	18	8	
• Hematological	11	6	22	
• Other	15	21	3	
• Unknown	5	2	3	
Symptoms during the last three days of life[3]				
• Dyspnea	89	88	75	0.18
• Being worried	89	84	65	0.01
• Pain	88	82	83	0.62
• Agitation	84	82	83	0.96
• Feeling depressed	79	88	70	0.19
• Anxiety	79	76	40	<0.001
• Confusion	49	76	60	0.01
• Incontinence	38	81	68	<0.001
• Nausea/vomiting	36	38	42	0.87
Study period				
• Baseline period	53	46	42	0.31
• LCP period	47	54	58	

1 Chi-square test.
2 ANOVA test.
3 Based upon relatives' questionnaire

Cancer treatment during the last three months of life

Cancer treatment had extended to the last three months of life for a substantial number of patients, especially patients who died in the hospital: physicians reported that 40% of all hospital patients had received chemotherapy during the last three months of life, whereas this percentage was 26% for patients who died at home and 16% for nursing home patients (Table 6.2). Radiotherapy had also most frequently been used for hospital patients. In about a quarter of all patients in all settings it was decided to discontinue cancer therapy. These decisions were usually made at the request or with the consent of the patient. They were mostly due to the poor and deteriorating condition of the patient. In the large majority of patients, discontinuation of therapy was estimated to probably have shortened life by less than one week. Decisions not to initiate a cancer therapy were somewhat less

common than decisions to discontinue cancer therapy. The involvement of patients in such decisions, the underlying motives and the estimated impact were largely comparable to those of decisions to discontinue cancer treatment.

Table 6.2. Cancer treatment during the last three months of life (physicians' questionnaire)[1]

	Hospital patients N=190	**Nursing home** N=80 (%)	**Home care patients** N=28	P value[2]
Cancer treatment during the last 3 months of life	58	36	39	<0.001
• Chemotherapy[3]	40	16	26	<0.001
• Radiotherapy	26	10	15	<0.001
• Surgery	9	19	7	0.04
A cancer therapy was discontinued	29	23	18	0.29
• Medical reasons for discontinuing cancer therapy:				
• Poor condition patient	89	89	100	0.73
• Occurrence of side effects	13	22	20	0.62
Decision to discontinue cancer therapy was made after explicit request/consent of the patient	85	82	80	0.95
Discontinuing cancer therapy probably shortened the patient's life less than a week	90	83	80	0.62
A cancer therapy was not started	22	14	14	0.29
Reasons for not starting cancer therapy:				
• Poor condition patient	90	70	100	0.18
• Risk of side effects	78	80	50	0.45
• Wish patient	3	40	25	<0.001
Decision not to start cancer therapy was made after explicit request/consent of the patient	65	90	75	0.30
Not starting cancer therapy probably shortened the patient's life less than a week	85	50	100	0.03

1. Data on cancer treatment during the last three months of life were missing for two hospital patients, three nursing home patients and eight home care patients.
2. Chi square test.
3. Including hormone therapy.

Relatives' evaluation of medical decision-making

Somewhat over half of all relatives reported that the patient had discussed wishes concerning medical treatment at the end of life, with either the physician, nursing staff or relatives (Table 6.3). About a quarter of all patients were reported to have appreciated further discussions with their physician about their treatment preferences, such as their wish to abstain from life-prolonging treatments, their desire for sufficient symptom control, or the possibility of euthanasia or sedation. Few patients had laid down their wishes in a written living will. Nursing home patients had more often (29%) than patients who died at home (17%) or hospital

patients (7%) refused a medical treatment. Relatives of patients who died in the hospital somewhat more often than relatives of nursing home patients and patients who died at home felt that the patient's wishes had not fully been granted (43%, 33% and 25%, respectively) and they most often said that a decision had been made with which the patient had disagreed (13%, 7% and 0%, respectively). Relatives of hospital patients were also slightly less positive about their own involvement in the decision-making: 18% thought that they had been insufficiently involved, as compared to 12% of relatives of nursing home patients and 0% of the relatives of patients who died at home. Further, 21% of the relatives of hospital patients and less than 5% of the other relatives said that a decision had been made with which they had disagreed.

Table 6.3. Relatives' evaluation of medical decision-making at the end of life (relatives' questionnaire)

	Hospital patients N=107	**Nursing home** N=51 (%)	**Home care patients** N=26	P value[1]
Role patient				
The patient discussed his/her wishes in relation to medical treatment in the dying phase with:	64	69	54	0.44
• Physician(s)	48	55	44	
• Nurse(s)	13	16	16	
• Relative(s) / friend(s)	58	51	48	
The patient would have liked to discuss his/her wishes in relation to medical treatment in the dying phase	31	29	23	0.65
Wishes that patient would have liked to be discussed:				
• No life-prolonging treatments	28	7	20	
• Euthanasia/ sedation	31	38	20	
• No euthanasia	0	7	20	
• Other	24	38	20	
The patient had made up a written living will	13	14	15	0.96
Wishes that were included in living will:				
• No life-prolonging treatments	23	43	50	
• Symptom control	8	14	50	
• Euthanasia/ sedation	39	43	0	
• Other	31	29	50	
The patient refused a medical treatment	7	29	17	0.001

1. Chi square test.

Continuation Table 6.3

Role patient	**Hospital patients** N=107	**Nursing home** N=51 (%)	**Home care patients** N=26	P value[1]
Treatments that were refused				
• Surgery	14	33	0	
• Radiotherapy	43	27	0	
• Chemotherapy	29	40	25	
• Other	14	20	75	
Wishes that were discussed were granted:				0.17
• Yes	57	67	75	
• More or less	22	30	8	
• No	21	3	17	
A decision was made with which the patient disagreed	13	7	0	0.10
Role relative				
Relative was informed about the patient's situation:				0.22
• Too much	3	0	0	
• Adequately	81	90	96	
• Too little	16	10	4	
Relative was involved in decision-making for:				0.17
• All decisions	76	74	96	
• Some decisions	14	18	4	
• None of the decisions	10	8	0	
Relative thought that he/she was involved:				0.06
• Sufficiently	82	88	100	
• Insufficiently	18	12	0	
A decision was made with which the relative disagreed	21	2	4	0.002

1. Chi square test.

Medication during the last three days of life

Data on the use of medication during the last three days of life are presented in Table 6.4, as well as differences between the settings, the study periods, and two age groups. Patients who died in the hospital had on average received 5.7 types of drugs, whereas the mean was 5.6 for nursing home patients and 3.1 for patients who died at home. The most common type of drug in all settings was pain medication, especially opioids. Other common types were sedatives and antipsychotics. Virtually all types of medication were least common among patients who died at home, except antipsychotics. Antibiotics and anticoagulants were most often used for hospital patients. Psychoactive drugs, such as antipsychotics and antidepressives seem to be most common in the nursing home. The LCP had no significant impact on the use of drugs during the last three days of life in most cases.

Table 6.4. Medication during the last three days of life (physicians' questionnaire)[1]

	Hospital patients	Nursing home patients	Home care patients	Baseline period	LCP period	Age < 70 years	Age ≥70 years
	Mean (standard deviation)						
Total number of drugs	5.7 (3.0)	5.6 (2.6)	3.1 (2.0)	5.8 (3.2)	5.0 (2.5)	5.4 (2.9)	5.5 (3.0)
	Percentage Odds ratio (95% confidence interval)[2]						
Pain medication	91	94	79	94	87	93	87
	(ref.)	2.1 (0.7-6.2)	0.4 (0.2-1.3)	(ref.)	0.4 (0.2-0.9)	(ref.)	0.4 (0.2-1.0)
Opioids	89	89	75	91	84	90	85
	(ref.)	1.2 (0.5-2.8)	0.4 (0.2-1.1)	(ref.)	0.5 (0.2-1.0)	(ref.)	0.6 (0.3-1.2)
Sedatives	46	59	39	51	46	49	47
	(ref.)	1.8 (1.0-3.2)	0.8 (0.4-1.9)	(ref.)	0.8 (0.5-1.3)	(ref.)	0.8 (0.5-1.3)
Gastrointestinal medication	34	35	11	33	31	28	37
	(ref.)	0.9 (0.5-1.7)	0.2 (0.06-0.7)	(ref.)	0.9 (0.6-1.5)	(ref.)	1.6 (0.9-2.7)
Corticosteroids	34	23	4	30	25	32	22
	(ref.)	0.7 (0.4-1.3)	0.08 (0.01-0.6)	(ref.)	0.8 (0.5-1.3)	(ref.)	0.7 (0.4-1.2)
Cardiovascular medication	33	33	11	33	28	28	34
	(ref.)	0.9 (0.5-1.7)	0.2 (0.07-0.8)	(ref.)	0.8 (0.5-1.3)	(ref.)	1.5 (0.9-2.5)
Antibiotics	31	14	7	23	26	24	25
	(ref.)	0.3 (0.1-0.6)	0.1 (0.03-0.6)	(ref.)	1.3 (0.7-2.3)	(ref.)	1.5 (0.8-2.7)
Antiemetics	26	31	7	32	20	26	26
	(ref.)	1.4 (0.8-2.6)	0.2 (0.05-1.0)	(ref.)	0.5 (0.3-0.9)	(ref.)	0.9 (0.5-1.6)
Anticoagulants	24	6	7	21	13	16	18
	(ref.)	0.2 (0.07-0.5)	0.2 (0.05-1.0)	(ref.)	0.6 (0.3-1.2)	(ref.)	1.6 (0.8-3.0)
Antipsychotics	20	40	25	26	26	21	32
	(ref.)	2.5 (1.4-4.6)	1.3 (0.5-3.2)	(ref.)	0.9 (0.5-1.6)	(ref.)	1.4 (0.8-2.5)
Antidiabetic medication	7	5	4	5	7	7	6
	(ref.)	0.6 (0.2-2.1)	0.4 (0.06-3.6)	(ref.)	1.4 (0.5-3.8)	(ref.)	1.1 (0.4-2.9)

1. Data on medication during the last three days of life were missing for fourteen hospital patients, three nursing home patients and eight home care patients.
2. Chi square test.

Continuation Table 6.4

	Hospital patients	Nursing home patients	Home care patients	Baseline period	LCP period	Age < 70 years	Age ≥70 years
	Percentage Odds ratio (95% confidence interval)[1]						
Antiepileptic drugs	6	8	0	6	6	7	5
	(ref.)	1.4	0.002 (0.000-1.5)	(ref.)	0.9 (0.3-2.5)	(ref.)	0.6 (0.2-1.7)
Antidepressives	5	13	4	6	8	5	9
	(ref.)	2.3 (0.9-6.2)	0.6 (0.07-5.1)	(ref.)	1.3 (0.5-3.3)	(ref.)	1.5 (0.6-4.1)

1. Data on medication during the last three days of life were missing for fourteen hospital patients, three nursing home patients and eight home care patients.
2. Chi square test.

Options of last resort

Do-not-resuscitate agreements were much more common for patients who died in the hospital and the nursing home than for patients who died at home (Table 6.5). In the majority of cases, at least one of the options of the last resort to alleviate patients' suffering, that is, increasing the dosage of opioids, sedation, or voluntary euthanasia, were discussed with the patient. This especially holds for intensified alleviation of symptoms, which was discussed with 43-58% of all patients. The frequency of discussing options of last resort tended to be highest for nursing home patients. Discussion of these options not always resulted in their actual application. Physicians estimated that drugs that had been used to alleviate symptoms had potentially shortened life in 44% of all patients who died in the hospital, 30% of all patients who died in the nursing home and 14% of all patients who died at home. The extent to which such drugs may have shortened the patients' life was, however, estimated to have been limited to at most one week in the large majority of cases (>90%) in all groups (not in table). Sedation, defined as parenteral administration of benzodiazepines or barbiturates, was used for 27% of the hospital patients, 33% of the nursing home patients and 11% of the patients who died at home. Euthanasia was used for one patient in this study. No statistically significant differences in the actual use of options of last resort were found between the settings, although the use of sedation tended to be more common in the nursing home. Introduction of the LCP had no significant effects on either discussing or using options of last resort, except for the use of drugs that were estimated to have a potentially life-shortening effect, which was less common after (28%) than before (46%) the introduction of the LCP.

Table 6.5. Options of last resort (physicians' questionnaire)[1]

	Hospital patients	Nursing home patients	Home care patients	Baseline period	LCP period	Age < 70 years	Age ≥70 years
				(%)			
				Odds ratio (95% confidence interval)[1]			
Do-not-resuscitate agreement	87 (ref.)	87 1.3 (0.5-2.9)	37 0.1 (0.04-0.2)	81 (ref.)	84 1.3 (0.6-2.6)	86 (ref.)	79 0.6 (0.3-1.3)
Options of last resort that were discussed with the patient:							
Intensified alleviation of symptoms	43 (ref.)	58 2.0 (1.1-3.5)	54 1.6 (0.7-3.6)	46 (ref.)	50 1.1 (0.7-1.8)	50 (ref.)	46 0.7 (0.5-1.2)
Sedation	30 (ref.)	39 1.6 (0.9-2.9)	32 1.2 (0.5-2.8)	29 (ref.)	37 1.4 (0.8-2.3)	35 (ref.)	30 0.7 (0.4-1.2)
Euthanasia or physician-assistance with suicide	15 (ref.)	25 2.6 (1.3-5.4)	14 1.2 (0.4-3.9)	18 (ref.)	17 0.8 (0.4-1.6)	23 (ref.)	10 0.3 (0.1-0.6)
Actual use of options of last resort[2]							
Symptoms were alleviated with potentially life-shortening drugs[3]	44 (ref.)	30 0.6 (0.4-1.2)	14 0.2 (0.07-0.7)	46 (ref.)	28 0.5 (0.3-0.8)	44 (ref.)	29 0.6 (0.3-0.9)
Sedation[4]	27 (ref.)	33 1.5 (0.8-2.8)	11 0.4 (0.1-1.3)	27 (ref.)	27 1.0 (0.6-1.7)	32 (ref.)	21 0.5 (0.3-0.9)
The decision to use these drugs was made after explicit request/permission of the patient	69 (ref.)	87 3.8 (1.0-15.4)	100 >2000 (0.0->2500)	67 (ref.)	85 2.7 (1.0-7.9)	76 (ref.)	70 0.6 (0.2-1.6)
Use of drugs probably shortened the patient's life less than a week	98 (ref.)	92 0.2 (0.03-1.8)	100 170 (0-8.12E)	97 (ref.)	95 0.7 (0.09-6.0)	96 (ref.)	97 2.3 (0.2-27)

1 Odds ratio's were calculated in multivariate logistic regression models that included setting, LCP use and patients' age as independent variables.
2 Euthanasia was used for one patient.
3 Symptoms were alleviated with drugs that were estimated to have potentially life-shortening effects.
4 Sedation was defined as the use of parenteral sedatives during the last three days of life.

6.4 Discussion

The age distribution and symptoms that were most commonly reported for patients in our study were mostly typical for dying cancer patients.[16-21]. In all settings, a subtantial number of patients were reported to have suffered from psychological symptoms. The majority of patients were reported to have had feelings of depression and anxiety during the last three days of life. Patients who died in the hospital or the nursing home more often than patients who died at home had feelings of anxiety, and patients who died in the nursing home were more often confused than other patients. These results have to be interpreted cautiously, because the reliability of

relatives' estimates of the degree of suffering of dying patients from non-physical symptoms has been reported to be doubtful.[22,23] Nevertheless, despite the fact that possibilities to treat depression or other psychological problems at the end of life are often limited, the high rates of psychological symptoms may also be related to a certain extent of undertreatment. Caregivers may not be sufficiently trained to recognize these symptoms, because they are unaware of the available treatment options, or because psychological symptoms are considered to be a normal part of terminal illness.[24-27]

Cancer treatment was relatively often continued until late in the disease process for patients dying in the hospital. We have shown elsewhere that hospital patients also more often than patients dying in other settings receive other types of intensive treatment during the last months and days of life.[28,29] Further, the number of drugs patients received during the last three days of life was relatively high for hospital and nursing home patients. Several drugs that were relatively common in the hospital, such as antibiotics, anticoagulants and corticosteroids, were probably not primarily given to contribute to the dying patient's comfort. The differences in treatment during the last phase of life between settings are most likely the result of both patient selection and characteristics of the settings. On the one hand, patients who die in the hospital are probably often patients for whom prolongation of life, and sometimes even cure, is seen as a realistic care goal until late in the disease process, by either the patient, the physician, or both. Further, hospital patients were relatively young and possibly represent patients in whom the disease develops rapidly or has an unexpected or unusual course. On the other hand, hospital treatment of cancer patients may longer than treatment in other settings be focused at treating the underlying disease instead of providing comfort care. Such an inclination may not in all cases be in the best interest of the patient.

The most commonly used drugs were analgesics. The large majority of patients received opioids during the last three days of life, which seems to be in accordance with guidelines for the treatment of pain in terminal patients. Sedatives were the second most often prescribed type of drugs, especially in the nursing home. It has previously been shown that the use of sedatives is especially common at somatic nursing home wards, which was attributed to an inclination to suppress symptoms of agitation at such wards.[30] Time trend studies of end-of-life decision-making practices have found an increase in the use of sedation at the end of life, in hospitals, nursing homes, and at home.[31] This increase is probably due to growing awareness that

parenteral sedatives may be used to suppress otherwise refractory symptoms in dying patients.[29, 31]

Decisions to refrain from potentially life-prolonging treatment during the last three months of life were rather common in all settings and do not seem to have been made less frequently for patients who died in the hospital. Both withdrawing and withholding life-prolonging treatment had limited life-shortening effects. The degree to which forgoing treatment shortens life has been found to be more pronounced elsewhere.[32, 33] This may be due to the fact that our study only comprised cancer patients, in whom the prognosis and the extent to which life might be shortened by decisions not to use potentially life-prolonging treatment is often more clear than in other patients. Further, it cannot be precluded that we did not identify all non-treatment decisions. We could for example have missed decisions that were made earlier in the disease process by others than the physicians who attended the patients during the dying process.

Bereaved relatives of patients who died in the hospital were less positive about the decision-making than relatives of patients who had died elsewhere. Dissatisfaction about medical decision-making at the end of life for patients dying in the hospital has been found elsewhere too.[2, 3, 29] Bereaved relatives' evaluation of end-of-life care and medical decision-making is likely to be influenced by other factors than the quality of care and communication itself, such as the characteristics of the dying process. The complexity of the symptoms of patients who die in the hospital, the resulting intensity of medical treatment and decision-making where generally several physicians are involved, and the typical focus of hospital care at cure and prolongation of life probably also contribute to negative feelings among bereaved relatives. The dying phase was often relatively short in the hospital, due to which the adaptation of the focus of care had to occur in a short time span. Earlier recognition of the imminence of death might have contributed to the relatives' involvement with and support for the decision-making process in some cases. However, it has to be recognized also that death cannot be foreseen in all cases. As a result, the continuation of burdening treatment aimed at the prolongation of life until very late in the dying process cannot always be prevented, which might especially hold for the hospital setting.

Discussions of options of last resort were part of end-of-life care in the majority of cases. We did not observe large differences between settings in the characteristics of such discussions, except for do-not-resuscitate agreements which were much more

common in institutional settings. Alleviation of symptoms with drugs in dosages that might have hastened death was especially common in the hospital. This finding might represent an intensive treatment trajectory for patients who die in the hospital because of symptoms or complications that are not easily alleviated elsewhere. It might, however, also be the result of a raised concern about the potentially life-shortening effects of, e.g., opioids among hospital physicians, who may be inexperienced in the field of death and dying.

Introduction of the LCP did not significantly reduce the use of medication during the last days of life. It did not affect discussions about the use of options of last resort either, but use of the LCP was followed by a decrease of the level to which drugs to alleviate symptoms were estimated to have had life-shortening effects. This might be partly due to an actual decrease in opioid dosages. However, changed attitudes towards the impact of drugs such as morphine or sedatives in dying patients may also play a role, which might be either due to use of the LCP or to a general shift in such attitudes during the previous years.

Our study had several limitations. Firstly, patients were recruited at departments that volunteered to participate in the study because of their interest in end-of-life care, and are probably not representative for all departments that provide end-of-life care in the Netherlands. Secondly, the three settings studied were represented by a limited number of institutions and especially the number of home care patients was rather small. Thirdly, the hospital setting was amongst others represented by several university hospital departments where patients might be admitted because of complex problems or because of an explicit preference for life-prolonging treatment

We conclude that in all settings where cancer patients die end-of-life decision-making is an important aspect of end-of-life care. The impact and importance of such decision-making is especially pronounced in the hospital setting. LCP use has limited impact on end-of-life decision-making during the dying phase.

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7

Using the LCP: bereaved relatives' assessments of communication and bereavement

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Abstract

The Liverpool Care Pathway (LCP) is aimed at improving care and communication in the dying phase. We studied whether use of the LCP affects relatives' retrospective evaluation of communication and their level of bereavement. We applied an intervention study. During the baseline period, usual care was provided to dying patients. During the intervention period, the LCP was used for 79% of the patients. In total, bereaved relatives filled in a questionnaire for 57% of the patients, on average four months after death. In the intervention period, relatives had lower bereavement levels as compared to relatives of the baseline period ($p = 0.01$). Communication was evaluated similarly for both periods. We conclude that LCP use during the dying phase seems to moderately contribute to lower levels of bereavement in relatives.

7.1 Introduction

High quality end-of-life care includes adequate symptom control, support for patients and their relatives to deal with psychosocial and spiritual issues, and careful medical decision-making.[1-5] Patients are reported to feel that shared decision making strengthens their relationships and gives them a sense of control.[3 6] Both are valued as essential aspects of a good death.[3 7]Further, relatives have indicated a need for emotional support both before and after the patient's death.[1] Being able to prepare for an imminent loss has been shown to positively affect bereavement in bereaved relatives.[8 9] However, current practice not always provides patients and relatives with sufficient understanding of the patient's prognosis and treatment options.[4 10 11]

In the UK, the Liverpool Care Pathway for the Dying Patient (LCP) was developed to improve care for dying patients.[12] It promotes clear communication around the dying and death of the patient and it supports psychosocial and spiritual care to patients and their relatives, e.g. by promoting adequate communication and support giving relatives a brochure for bereavement after the death of the patient.[13]

We investigated the effects of using the LCP on communication during the last three days of life and on the level of bereavement in relatives after the patient's death.

7.2 Patients and methods

Patients

A university hospital (three oncology departments), a general hospital (a department of medical oncology), a complete nursing home (five general departments and one palliative care department), another nursing home (a general department and a palliative care department), a residential care organization (which provides nursing care to about 60 people who live independently), and a home care organization (which provides home care in a region of eight villages) in the southwest of The Netherlands participated in the study. All patients receiving care from either of these institutions between November 2003 and February 2006 were informed of the study. Patients of 18 years or older who died in this period were eligible for the study. Patients who had expressed objections against the use of their medical or nursing record were not included. About two months after the death of the patient, the relative who had been 'contact person' for the patient received a letter from the institution that had provided terminal care, asking him or her for consent to be approached by the research team to fill in a written questionnaire. In case the relative did not respond, a reminder was sent after two and six weeks, respectively.

Only relatives who gave their consent were mailed a questionnaire. The Medical Ethical Research Committee of the Erasmus MC approved the study.

Design

We compared the relatives' evaluation of communication and bereavement between relatives of patients who died before the introduction of the LCP (baseline period) and relatives of patients who died after the introduction of the LCP (intervention period). During the baseline period (November 2003 – February 2005), care was provided as usual in all settings. The intervention period (February 2005 – February 2006) started directly after the baseline period. At the start of the intervention period the LCP was introduced within each setting and subsequently used for all patients for whom the multidisciplinary team agreed that the dying phase had started. The Comprehensive Cancer Centre Rotterdam, which is experienced in supervising and supporting quality improvement initiatives in cancer care, supported the implementation of the LCP. According to the 'intention to treat principle', all intervention data were included in our analysis, whether or not the patient received LCP care.

Data collection

Three months after the death of the patient relatives were sent a questionnaire. They were asked to evaluate the communication with professional caregivers during the last three days of life concerning the patient's imminent death, the decision-making about medical treatment, and the personal and religious needs of the patient. The questions about whether and how the relative was told about the imminent death of the patient, about medical decision making, and about psychosocial support were based upon items from the Views of Informal Carers – Evaluation of Services (VOICES) questionnaire. The VOICES is an instrument specifically developed for proxies to evaluate the care and services received by patients and their relatives in the last months of the patient's life.[14 15] In order to measure the relatives' involvement in the medical decision making in more detail, we added two items: 'Did you receive sufficient information about the situation of your relative and about his care during his last three days of life?' and 'Was the information that you received comprehensible to you?'. Further, relatives were asked to fill in the Leiden Detachment Scale (LDS), which includes seven items about bereavement. The internal consistency of this questionnaire has been shown to be

satisfactory when measured four months and fourteen months after death of the patient (Cronbach's Alpha was 0.82 at both measurement periods).[16]

Analysis and statistics

Differences between the baseline period and the intervention period were statistically tested, using Chi-square tests and Student's t-tests where appropriate. Scores on the LDS were linearly transformed from a 1-4 to a 0-3 scale in order to obtain a theoretical lowest level of bereavement of 0 and the non-weighted sum score was calculated for each relative. The sum score had a minimum of 0 (no difficulty to detach from the person) and a maximum of 21 (much difficulty with detachment). Thus, a low score indicates a low level of bereavement, a high score implies a high level of bereavement. We assessed the associations between the comprehensiveness of information and LCP use and between the level of bereavement and LCP use, while correcting for differences in the gender of the patients, age of relatives, place of death, and relationship between the patient and the relative, using multivariate regression analysis. The significance level was set at 5%.

7.3 Results

During the *baseline period*, 220 of the 283 patients who died within one of the participating care settings could be included in the study. Sixty-three patients were not included, because they could not be informed about the study (51 patients), or expressed objections against the use of their medical or nursing record after their death (12 patients). Relatives filled in questionnaires for 131 of the included patients (59%). During the *intervention period*, 255 of the 292 deceased patients could be included. Thirty patients could not be informed of the study and 7 patients had objected against the use of their data. One patient could not be included because of missing data. For 140 of the 255 patients a relative filled in a questionnaire (55%). The LCP was used for 111 of these 140 patients. Patient characteristics were comparable between patients for whom the relative filled in a questionnaire and patients for whom the relative did not, except for diagnosis, 70% of the patients for whom the relative filled in a questionnaire had a malignancy, whereas this holds for 56% of the other patients.

Patient characteristics were mostly comparable between both periods (Table 7.1). The intervention period included slightly less male patients (41%) as compared to the baseline period (52%). Further, the intervention period included slightly less

hospital patients (38%) and slightly more patients who died at home or elsewhere (21%) as compared to the baseline period (45% and 12% respectively). Of the patients with a non-malignant disease, most patients had dementia, a condition after a cerebro vascular accident or heart failure. The multidisciplinary team recognized the dying phase for more than 75% of the patients in both groups.

Table 7.1: differences in characteristics of the patient and the relative between the baseline period and the intervention period.

			Baseline period N = 131 N (%)	**Intervention period** N = 140 N (%)	p-value[1]
Patient					
	Age (years)		74 (15)[3]	75 (14)[3]	0.66[2]
	Gender	Male	68 (52)	58 (41)	
		Female	63 (48)	82 (59)	0.08
	Diagnosis	Malignant disease	90 (70)	95 (70)	
		Non-malignant	39 (30)	41 (30)	0.99
		Dementia	*7 (19)*	*9 (23)*	
		CVA	*9 (25)*	*6 (15)*	
		Heart failure	*6 (17)*	*11 (28)*	
		COPD	*3 (8)*	*4 (10)*	
		Other	*11 (31)*	*10 (25)*	
	Place of death	Hospital	59 (45)	53 (38)	
		Nursing home	56 (43)	58 (41)	
		Home or elsewhere	16 (12)	29 (21)	0.15
	Caregivers recognized the dying phase		100 (76)	110 (79)	0.66
	Patient was conscious at some time during the last three days		117 (95)	128 (96)	0.66
Relatives					
	Age (years)		58 (14)[3]	56 (11)[3]	0.13[2]
	Gender	Male	44 (34)	49 (35)	
		Female	86 (66)	90 (65)	0.81
	Number of days between death of the patient and the assessment of the relative		130 (72)[3]	125 (50)[3]	0.51[2]
	Health	Good	102 (79)	112 (81)	
		Less than good	27 (21)	27 (19)	0.76
	Relationship with the patient	Partner	55 (42)	47 (34)	
		Other	75 (58)	93 (66)	0.14
	Relative had contact with patient at some time during the last three days		117 (93)	124 (93)	0.91

1. Chi-square test
2. Student's t-test
3. Mean (standard deviation)

The characteristics of the relatives were also mostly comparable between both periods. The mean age of the relative was 58 years for the baseline period and 56

years for the intervention period. Thirty-four percent of the baseline relatives and 35% of the intervention relatives was male. Forty-two percent of the baseline relatives and 34% of the intervention relatives was partner of the patient. The time interval between the death of the patient and the assessment of the relative was on average 4 months in both periods.

Table 7.2 concerns the relatives' evaluation of communication in the baseline period and in the intervention period. Communication was evaluated similarly in both periods, except that in the intervention period more relatives (93%) found the information about the patient's situation and care comprehensible, as compared to the baseline period (85%) ($p = 0.05$). Further, most relatives in both periods were positive about the way information was provided to them, the decisions that were made about the patient's care or treatment, and the caregivers' consideration of the patient's personal or religious beliefs. After the death of the patient, somewhat more relatives in the intervention period (66%) were told how to get further support with bereavement as compared to the baseline period (51%), ($p = 0.06$).

Table 7.2: Bereaved relative's evaluation of communication in the baseline period and the intervention period.

	Baseline period (N = 131) N (%)	**Intervention period** (N = 140) N (%)	p-value[2]
The relative received sufficient information about the situation of the patient and about his / her care during the last three days of life	115 (89)	125 (90)	0.70
The information was comprehensible to the relative	108 (85)	124 (93)	0.05
The relative was told that the patient was likely to die[1]	85 (65)	92 (66)	0.82
For those relatives who were told that the patient was likely to die:	(N = 85)	(N = 92)	
• The relative was given a chance to talk about this at the time[1]	78 (94)	83 (94)	0.92
• The relative felt to have enough privacy when he /she was told[1]	75 (88)	84 (91)	0.50
• The relative was told in a way that upset him/ her[1]	52 (63)	64 (70)	0.33
• The relative was told how to get further support[1]	43 (51)	59 (66)	0.06
Relative was involved in the decisions about the patient's treatment and care as much as he/ she wanted during the last three days of life[1]	113 (88)	123 (89)	0.82
During the last three days of life any decision was made about the care or treatment that the patient would not have wanted[1]	8 (6)	9 (7)	0.92
During the last three days of life any decision was made about the care or treatment that the relative would not have wanted[1]	14 (11)	15 (11)	0.93
During the dying phase the relative feels that the patient's personal or religious beliefs were taken into consideration by those caring for him /her[1]	100 (80)	113 (83)	0.61

1 Items of the VOICES section E and F.[15].
2 Chi-square test

Table 7.3 presents the relatives' assessment of the LDS items. The sum score of the LDS was significantly lower in the intervention period as compared to the baseline period (p = 0.01), indicating a significantly lower bereavement level in relatives of the intervention period.

Table 7.3: Level of bereavement of relatives of the baseline period and the intervention period.

	Baseline period N = 131[1]	**Intervention period** N = 140[1]	
Leiden Detachment Scale (LDS)48	N (%)	N (%)	
The relative has the feeling that the patient is still there	91 (70)	79 (57)	
Aloud or in one's mind the relative talks to the patient	78 (61)	80 (58)	
The relative catches oneself waiting for the patient	44 (35)	32 (23)	
Accepting the loss of the patient is very difficult for the relative	111 (86)	100 (72)	
The relative longs for the patient	114 (89)	103 (75)	
There are occasions where the relative thinks to see or hear the patient	46 (35)	33 (24)	
It is somewhat / very difficult for the relative to detach oneself from thoughts and grief about the patient and to turn one's mind to other, perhaps new obligations	87 (67)	73 (53)	
	N = 138 Mean (SD)[2]	N = 141 Mean (SD)[2]	p-value[3]
Sum score (minimum = 0, maximum = 21)	11 (5)	9 (5)	0.01

1. Relatives with the highest or second highest score on the item
2. SD = standard deviation
3. Student's t-test

Table 7.4 represents the multivariate regression analysis for the differences in comprehensibility of the information and in the level of bereavement of the relatives between the baseline and the intervention period. Place of death and the type of relationship between the patient and the relative largely explained the difference in comprehensibility of information between both periods. For relatives in the hospital setting, the information was less often comprehensible, as compared to relatives in the other settings. Further, partners of patients found the information less often comprehensible as compared to other types of relatives. However, the level of bereavement remained significantly lower for relatives in the intervention period (p = 0.04). Differences in place of death and relationship between the patient and the relative only partly accounted for the difference in the level of bereavement between both periods. Relatives in the hospital setting appeared to have higher levels of bereavement as compared to relatives in the other care settings. Further, partners had significantly higher bereavement levels, as compared to other relatives.

Table 7.4: Multivariate regression analysis for the differences in the number of relatives who found the information about the patient's situation and care comprehensible and for the level of bereavement.[1]

			Number of relatives who found the information comprehensible		
		N	N (%)	Beta	p-value
Gender of the patient	Male (ref)[2]	119	105 (88)	0	0.70
	Female	142	127 (89)	-0.02	
Place of death	Hospital (ref)	105	86 (82)	0	
	Nursing home	111	102 (92)	0.07	0.12
	Home	45	44 (98)	0.14	0.02
Age of the relative (year)	Continuous variable	268	74 (15)[3]	0.00	0.57
Partner relationship with the patient	No (ref)	164	151 (92)	0	
	Yes	96	80 (83)	-0.07	0.12
Period	Baseline (ref)	127	108 (85)	0	
	Intervention	134	124 (93)	0.06	0.12
			Level of bereavement		
		N	Mean (SD)	Beta	p-value
Gender of the patient	Male (ref)	121	10 (5)	0	0.68
	Female	144	10 (5)	0.25	
Place of death	Hospital (ref)	110	11 (5)	0	
	Nursing home	110	9 (6)	-0.96	0.18
	Home	45	9 (5)	-1.06	0.23
Age of the relative (year)	Continuous variable	268	10 (5)	-0.01	0.72
Partner relationship with the patient	No (ref)	165	9 (5)	0	
	Yes	99	13 (4)	3.80	0.00
Period	Baseline (ref)	127	11 (5)	0	
	Intervention	138	9 (5)	-1.27	0.04

1. Adjusted for all predictors in this table.
2. (ref) = reference category
3. Mean (standard deviation)

7.4 Discussion

We investigated the effect of the Liverpool Care Pathway for the Dying Patient on communication and on bereavement in relatives. After introduction of the LCP a higher number of relatives found the information comprehensible than before introduction of the LCP, but this difference was no longer statistically significant after adjusting for differences in characteristics of the patients and the relatives. Relatives in the intervention period had significantly lower levels of bereavement as compared to relatives in the baseline period. This difference remained significant after adjusting for differences in characteristics of the patients and the relatives.

The number of relatives who found the information comprehensible appeared to be related to the place of death. We showed before that hospital patients more often receive therapeutic interventions until the start of the dying phase as compared to

nursing home patients and home care patients.[17] Apparently in the hospital setting, the transition from 'cure' to 'care' often occurs very shortly before death. It seems plausible that the change of focus in such a short time span is difficult to comprehend for relatives. Providing comprehensible information to relatives during the transition from anticancer treatment to palliative care has been shown to be difficult before.[11] This holds for both caregivers and care recipients. Skilled communication methods are needed to inform relatives about the estimated prognosis and to make the atmosphere such that relatives feel free to ask questions.[11]

Besides, it is known that information is likely to be forgotten if someone is very anxious.[18] It can therefore not be precluded that anxious relatives miscomprehended adequate information. This may hold especially for partners of deceased patients, who were shown to less often find the information comprehensible than other types of relatives.

The level of bereavement was also related to the place of death and to the relationship between the patient and the relative. The higher bereavement levels in relatives of hospital patients may also be related to the relatively late transition from 'cure' to 'care' in this setting. Relatives of hospital patients were possibly more focused on the patient's survival than relatives of patients in other settings, and therefore less prepared to the patient's imminent death. Advanced warning of a patient's imminent death has been associated with less intense grief after death of the patient.[8] The lower bereavement levels in relatives of nursing home patients may be related to the fact that in this setting relatives typically know about the patient's prognosis, often quite some time before the patient's actual death. Relatives may also feel relieved for the patient that a long period of illness, often due to dementia, has ended.

In our study the level of bereavement was higher for partners as compared to other relatives, such as parents or adult children. This is in accordance with what other studies found.[16 19 20] Partners showed higher scores on the Leiden Detachment Scale as compared to bereaved adult children, when measured four and fourteen months after the death of the patient.[16] The death of a spouse has been shown to be more stressful than the death of a parent.[19] Losing a partner not only causes emotional stress, but often also results in loss of social support as maintained by the deceased partner, and loss of material and task support.[20]

LCP use seems to further explain the levels of bereavement, in addition to the place of death and the type of relationship. The evaluation of the relatives did not reveal substantial changes in communication after introduction of the LCP, but this does not rule out the possibility that decreased bereavement is related to improved communication in more subtler ways. In a study in which relatives of patients dying at an intensive care unit were stimulated to talk about their emotions and to ask questions, and were given a brochure on bereavement, the relatives' anxiety and depression was decreased ninety days after the death of patients.[21] The authors suggest that when caregivers pay attention to more personal and interactive communication with the relatives, this may lessen the relatives' burden of bereavement. Clear communication about the patient's approaching death may be helpful in preparing relatives to their imminent loss. As a relative in our study remarked: "Everything went so fast that even my husband didn't see it coming. Really saying good-bye for the children and me was no option anymore. This hurts a lot". Starting of the LCP explicitly marks the start of the dying phase, which could have stimulated caregivers to openly discuss the imminent death of the patient with the relatives. Besides, after the death of the patient a bereavement leaflet was given to the relatives.

Strengths and limitations

Relatives filled in questionnaires for 59% of the eligible patients in our study. The group of relatives who did not participate might have had higher bereavement levels. Communication and end-of life care were equally positively evaluated in both periods. Sinding suggests that articulating dissatisfaction with care after the patient's death seems useless to the surviving relative and only gives the relative a bad feeling.[22] Possibly, negative experiences were less reflected in the evaluation of the relatives, because they were inclined to positively evaluate the care anyway.

Conclusion

LCP use during the dying phase seems to moderately contribute to lower levels of bereavement in relatives.

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8
General Discussion

8.1 Introduction

This thesis addresses the professional care for and the quality of life of dying patients and their relatives, in the hospital, the nursing home and the primary care setting. The effect of introducing the Liverpool Care Pathway for the Dying Patient (LCP) on the content of care and the quality of life of the dying patient was studied. After the patients' death, physicians, nurses and relatives assessed the symptom burden, medication use, medical interventions, medical decision-making, and aspects of communication during the last phase of life. Besides, relatives reported on aspects of their own bereavement. In this chapter, first the strengths and limitations of the study (section 7.2) are discussed, followed by the main findings of the study for each research question successively (section 7.3). The chapter finishes with some recommendations for clinical practice and future research (section 7.4).

Care pathways

Care pathways basically are checklists for care processes that also function as care registration documents. They typically summarize care goals for a well-defined group of patients during a well-defined period of time.[1] These care goals are based upon practice experiences and expert opinions. Care pathways aim to facilitate good clinical practice through multidisciplinary cooperation. The documentation of care enables constant monitoring and subsequent evaluation of the care process. In addition, care improvements can be incorporated in the pathway and subsequently re-evaluated.[2] Originally, the design of care pathways arose from managed care initiatives that aimed to stabilize the healthcare costs in the USA.[3,4] During the past decade, care pathways have been increasingly applied in the western world.[5, 6] Caregivers have been shown to feel that the use of care pathways structured the care process and provided patients and families with the best care possible.[3,7-10] Nowadays, the World Health Organization recognizes the use of care pathways as a useful tool to facilitate care improvement initiatives.[11] On the other hand however, relatively little is known about the use of care pathways from the patients' and relatives' perspective.[6,12-13] The study in this thesis aimed to contribute to this knowledge by investigating the possible effect of introducing the LCP from the perspective of the patient and the relatives.

8.2 Strengths and limitations

Study population

In order to study a broad spectrum of dying trajectories, we included patients from several types of care settings. The institutions that participated in the study had an explicit interest in palliative care. The study settings may thus represent a selection of institutions that were to some extent experienced in adapting care to the dying phase. For example, the home care setting had a close cooperation with a nearby hospice and both the participating nursing homes had a specialized palliative care unit. Further, in the hospital setting mainly oncology departments participated in the study, where end-of-life care is provided more often as compared to other hospital departments. All together, the study settings are thus not fully representative of all settings where patients die. Since the LCP represents a palliative care approach, the effect of introducing the LCP might be more outspoken in care settings that not yet have a palliative care approach. Further, due to the fact that mainly oncology patients represented the hospital setting, the hospital results may be less representative for hospital patients with non-cancer diagnoses.

Implementation

In order to avoid a break in the routine of distributing the information letter to patients and in collecting the data, the intervention period directly followed the baseline period in each setting. As a result the intervention measurements started simultaneously with the introduction of the LCP. Previous to the start of the intervention period, the professional caregivers were informed about the practical implications of using the LCP. However, it was only from the moment on that the LCP was actually applied during the intervention period, that they became familiar with the content of the LCP. As a result, during the beginning of the intervention period, the professional caregivers had to become used to working with the LCP. In the UK, 6-18 months after the introduction of the LCP, the LCP appeared to be applied for about one half to two thirds of the patients in inpatient hospice settings.[14, 15] In our study, during the first six months the LCP had been applied to fewer dying patients as compared to the following six months of the implementation period (see also Table 8.1). Still, the LCP was used for 75% of the patients in the first half year, and to 81% of the patients in the second half year. In total, the proportion of LCP use in the intervention period was high enough to study the possible effects of LCP use within each setting.

Table 8.1: LCP use during the first half year and during the second half year of the implementation period.

	primary care		nursing home		hospital		Total	
Period	n/N	%	n/N	%	n/N	%	n/N	%
1st half year	16/29	55	45/55	82	33/42	71	94/126	75
2nd half year	16/20	80	56/59	95	31/48	84	103/127	81
Total	32/49	65	101/114	89	64/90	78	197/253	78

LCP use

The study measures concerned the last three days of life (72 hours), because this was considered to be the average duration time of the dying phase. However, the median duration time of LCP use was 30 hours, (min. 1 hours, max. 35 days). Thus, the period of time during which the LCP was used was shorter than the period of time that was measured. As a result, the extra hours during which the care was measured could have diluted the LCP effect, especially in the hospital setting, where the median duration time of LCP use was the shortest (see also Chapter 4).

Documentation

In order to measure the possible effect of LCP use on the documentation of care, the documentation of care was registered before and after the introduction of the LCP. The registration of care was not primarily aimed at measuring the content of care, because non-documentation of specific interventions does not prove that these interventions were not applied in all cases.

8.3 Findings

The study that is described in this thesis aimed to answer three research questions: What is the effect of LCP use on:

1. the quality of life of patients in the last three days of life?
2. the content of care for patients in the last three days of life?
3. the communication in the last three days of life and the level of bereavement of relatives?

8.3.1. Research question 1: quality of life

Symptom burden

The prevention and alleviation of pain and shortness of breath in the dying phase is often difficult to achieve. In studies on symptoms, substantial numbers of patients have severe pain and shortness of breath during their last days of life.[16-20] Other symptoms, such as fatigue and lack of appetite are also hard to prevent, e.g. because of lack of effective drug treatment.[21] In our study, pain and shortness of breath were the most frequent symptoms during the last three days of life (Chapter 3 and 4). Both the nurses and the relatives reported these symptoms. The higher pain levels in hospital patients in our study might be related to the fact that in the hospital setting the percentage of cancer patients was higher than in the other care settings. A cancer diagnosis has been related to higher pain levels.[16] Further, fatigue and lack of appetite were common symptoms during the last three days of life for cancer and non-cancer patients within each setting (Chapter 3 and 4).

Alertness on risk factors and on early signs of symptoms has been helpful in preventing the occurrence of symptoms such as delirium.[22, 23] Further, the availability of the appropriate medication has been shown to be a prerequisite for good symptom control.[11] In addition, in a study in which relatives cared for the dying person, background information about symptoms, decreased the relatives' trouble of seeing these symptoms in the patient.[24]

After introduction of the LCP, the nurses reported significantly less pain in the patient. Besides, the relatives reported less agitation, fear and respiratory tract secretions. This is a noteworthy result, because the LCP did not introduce new care methods, such as for example a new treatment to control pain. It seems likely that the routine assessment of symptoms in the LCP supported the care team to anticipate to the occurrence or presence of symptoms, leading to direct actions if problems occurred. Further, the prescription of medication as required may have increased the availability of medication when needed. Finally, information about symptoms can have contributed to the fact that relatives reported a lower symptom burden after introduction of the LCP.

8.3.2. Research question 2: content of care

Documentation

Thorough documentation is a prerequisite for the transfer of care between the caregivers and for the continuity of care.[94] Documentation might also help secure

that the care that is actually provided to the patients and their family, is in accordance with their wishes. One of the most explicit effects of the LCP concerns the increase of the documentation of care. After the introduction of the LCP, the documentation of various care items significantly improved (see also Chapter 4).

Content of care

Interventions often are, at least to some extent, bothersome to patients.[25] During the dying phase, interventions could even be more bothersome to the patient than the symptoms they aim to prevent.[21, 26] The difficulty lies in deciding whether and when possibly uncomfortable interventions are likely to have more beneficial than adverse effects for the dying patient.[27 28] An additional difficulty lies in the recognition of the dying phase by the multidisciplinary team. For old patients or patients with chronic diseases, the dying phase is often more difficult to recognize than for patients with cancer.[29-31] In Chapter 5, interventions were divided into two categories: therapeutic or diagnostic. Patients for whom the caregivers had recognized the start of the dying phase appeared to have received significantly less diagnostic interventions than patients for whom the caregivers had not recognized the start of the dying phase. Apparently, the caregivers considered these diagnostic interventions as being inappropriate for dying patients. Recognition of the dying phase however, did not affect the application of therapeutic interventions. Possibly, whether to apply such interventions or not had already been decided prior to the recognition of dying phase for many patients, because they were already known to be close to death anyhow.

Despite the fact that several goals in the LCP are explicitly aimed at adjusting interventions to the dying phase, neither the diagnostic interventions, nor therapeutic interventions aimed at treating the underlying disease were differently applied before and after the introduction of the LCP. Apparently, LCP use did not affect the application of interventions in the dying phase. It may be that our effect-measures were not refined enough to measure subtle differences in the application of interventions before and after the introduction of the LCP. Another explanation could be that the effect was diluted, because we measured interventions during the last 72 hours, whereas the median duration of use of the LCP was only 30 hours. LCP use did not affect the degree to which caregivers recognized patients to be in the dying phase, since the percentages of patients with a recognized dying phase were comparable between the baseline and the intervention period. On the other hand,

caregivers indicated that the LCP supported them in initiating discussions about care adjustments within the multidisciplinary team. This indicates that LCP use may still contribute to the agreement about the dying phase and its impact in the multidisciplinary team. It does not seem unlikely that in the course of time LCP use enhances the alertness of the multidisciplinary team on the possible imminent death of patients.

8.3.3. Research question 3: communication

Communication and bereavement

Communication is an essential part of quality end-of-life care.[32] During the last phase of life, important medical decisions need to be made, which demand careful communication between all parties.[33] The patients' and families' trust in the care they receive is directly dependent on the quality of communication and the information they receive from the caregivers.[34] Careful communication demands much of the caregivers' communication skills, because it encompasses support with decision making, a personal approach and a listening ear.[35-37] Support for relatives with emotions and events around the time of the patient's death positively affected bereavement after death of the patient in another study.[38] When patients died suddenly, or when relatives were not able to say goodbye to the patient, relatives had more severe grief reactions.[38, 39] Relatives who were given a brochure on bereavement and for whom an interactive communication strategy was used during the dying phase of the patient, reported lower levels of bereavement, as compared to relatives who did not receive this special care.[40] In addition, the type of care setting and patient characteristics have been associated with differences in grief levels of bereaved relatives.[41-45]

Despite the fact that the LCP explicitly pays attention to the communication with relatives about the dying phase and death of the patient, no differences were found in the relatives' evaluation of communication between the baseline and the intervention period (Chapter 7). It cannot be precluded that the study measures were ineffective in finding possibly subtle chances in communication. Relatives in the intervention period did have lower levels of bereavement as compared to relatives in the baseline period (Chapter 7). Since the study did not encompass the after death period, it remains unknown to what extent the lower levels of reported bereavement were related to other factors than LCP use. However, it does not seem unlikely that LCP use enhanced the support to the family after death of the patient, through for

example the provision of the bereavement information brochure. In addition, nurses indicated that the LCP use enabled them to discuss the dying and death of the patient more openly with the relatives. Possibly more openness in the communication better enabled the relatives to say goodbye to the patient, resulting in lower levels of self-evaluated bereavement in relatives after death of the patient.

8.4 Recommendations

Clinical practice

In this study, LCP use has been shown to contribute to better symptom control, to more comprehensive documentation of care, and to lower bereavement levels of relatives. Based upon these findings, it can be recommended for the care for dying patients. For clinical practice, LCP use implies that caregivers recognize the LCP care goals, and become familiar with using the LCP as the alternative and multidisciplinary patient's file in the dying phase.[5] This means that not only nurses, but also doctors should document care and decision making in the LCP. The documentation of care has been shown to be a point for enduring attention. In a setting that was used to working with the LCP for several years, documentation was occasionally missing (see also Chapter 2). It was suggested that a certain routine in working with the LCP possibly broke the habit of documenting each care detail. This however, may in the end invalidate the power of a document that to a large extent derives its effect from accurate documentation of care. Further, it is recommendable to start the LCP as soon as the multidisciplinary team recognizes that the patient is dying. Good symptom control often requires some time to adjust the medication. In a study in which the LCP was used, symptoms were measured eight hours before death.[15] Patients for whom symptoms were controlled appeared to have been monitored during a longer period than patients for whom symptoms were not controlled. Furthermore, it is important to recognize the role of the nursing staff. They often are the first to notice changes in the patient's situation and patient needs, and therefore often play an important role in recognizing the dying phase.[46] Nurses should be the key initiators for necessary care adjustments. On the other hand, the LCP is a multidisciplinary document, and it should be prevented that physicians start considering the LCP to be a 'nursing-document' only.

Implementation

Routine in working with the LCP can be supported by appointing a clinical facilitator to coordinate the implementation of the LCP, and to monitor and guard the process of using it.[66 125] In addition, teams that are less experienced in providing care to dying patients could occasionally call in the experience of a specialized palliative care team. Furthermore, in order to enable a process of continuous improvement of quality of care , care practice should be evaluated on a regular base.[5, 49]

Research

In order to further improve the use of the LCP, future studies should focus on the timely recognition of the dying phase and subsequent start of the LCP. Therefore it would be informative to gain more insight into the determinants of caregivers' recognition of the dying phase. In addition, it would be important to identify the prerequisites for a care team to build up a lasting routine in working with the LCP. Furthermore, there is relatively little known about what caregivers themselves value as important skills in providing care to the dying, and how these skills are possibly affected by use of the LCP. The specific role of each member of the multidisciplinary team should be further investigated, especially the role of the nurse and the physician. Both have special tasks when it comes to initiating care adjustments and communication with the patient and the family. Finally, the LCP as a care registration document produces an extensive source of patient information, which could be used in all kinds of studies. Possible study subjects may vary from describing the occurrence of symptoms and problems to evaluating the effects of care interventions.

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Summary

This thesis concerns the professional care and the quality of life for dying patients and their relatives in the hospital, the nursing home and the primary care setting. The effect of introducing the Liverpool Care Pathway for the Dying Patient (LCP) on the content of care and the quality of life of the dying patient was studied. The Liverpool Care Pathway for the Dying Patient (LCP) provides care goals to ensure that dying patients and their family receive the best possible comfort care. The LCP has been developed and used in the Marie Curie Hospice, Liverpool since the early 90ties. We applied a pre- and post intervention study in which patient and care characteristics were compared before and after implementation of the LCP. Data were collected after the death of patients. For each deceased patient we asked a nurse, a physician and a bereaved relative to fill in a questionnaire. The patients' physical symptoms, the content of care to patients and families, as well as some subjective aspects, such as the patients' psychological symptoms, and spirituality were assessed. Besides, relatives reported on aspects of their own bereavement. The questionnaires were partly based upon existing questionnaires, namely the EORTC QLQ-C30, the Views Of Informal Carers Evaluation of Services questionnaire (VOICES), the Palliative Outcome Scale (POS), and the Leiden Detachment Scale (LDS). Additional questions were developed based upon insights that were gained from former research concerning medical care and decision making in the last phase of life. The research questions concerned the effect of LCP use on

1. the quality of life of patients in the last three days of life,
2. the content of care for patients in the last three days of life,
3. the communication in the last three days of life and the level of bereavement of relatives.

Chapter 2 concerns the pilot study that preceded the main study described in this thesis. The pilot study was an audit in which the use and the applicability of the LCP in the Netherlands was tried out. The achievement of care goals was compared between cancer patients who died at the palliative care unit of a Dutch cancer hospital and a comparable group of cancer patients who died in the hospice in the UK where the LCP was developed. A translated version of the LCP was introduced at the Erasmus MC medical oncology department in Rotterdam in November 2001. We performed an audit of its use in the Netherlands by assessing the degree to which care goals were achieved in 40 patients. The results were compared with those in 40 cancer patients in Liverpool, who were matched for gender and age. The care goals at the start of the dying phase were achieved for on average 34 Rotterdam patients

and 30 Liverpool patients. During the last 24 hours preceding death, symptoms could be controlled without additional actions for on average 28 Liverpool patients and 30 Rotterdam patients. Care goals after death were achieved for on average 29 Liverpool patients and 30 Rotterdam patients. We conclude that the LCP is applicable in a Dutch tertiary hospital setting and that it provides useful insights in the delivery of care for the dying.

Next **Chapter 3** describes the most important differences in the baseline assessment of the main study between the hospital, nursing home and home care setting. We measured the burden of symptoms, medical and nursing interventions, and aspects of communication during the last three days of life within each of these settings. Two hundred thirty nine of 321 patients (74%) who died in one of the settings in the southwest of the Netherlands were studied between November 2003 and February 2005. After the patient's death a nurse filled in a questionnaire. Pain and shortness of breath were more severe in hospital patients as compared to nursing home and home care patients, whereas incontinence was less severe in hospital patients. Several medical interventions, such as a syringe driver, vena punctures or lab tests, radiology or ECG, antibiotics, and drainage of body fluids were more often applied during the last three days of life to hospital patients than to nursing home and home care patients. This also holds for measurement of body temperature and blood pressure. Communication about the imminence of death is more explicit during the last three days of life in the hospital than in the other settings.

Chapter 4 subsequently addresses **research question 1 and 2**. This chapter actually describes the effect of the LCP on the documented care during the dying phase, the symptom burden for dying patients, and several aspects of communication in the last three days of life within each setting. Between November 2003 and February 2005 (baseline period), the care was provided as usual. Between February 2005 and February 2006 (intervention period), the LCP was used for all patients for whom the dying phase had started. After the death of the patient a nurse and a relative filled in a questionnaire. In the baseline period, 219 nurses and 130 relatives filled in a questionnaire for 220 deceased patients. In the intervention period, 253 nurses and 139 relatives filled in a questionnaire for 255 deceased patients. The LCP was used for 197 of them (77%). In the intervention period, the documentation of care appeared to be significantly more comprehensive as compared to the baseline period, whereas the average total symptom burden was

significantly lower in the intervention period. LCP use thus contributed to the quality of documentation and symptom control.

During the dying phase, patients often undergo interventions not primarily aimed at promoting their comfort. **Chapter 5** concerns the effect of recognition of the dying phase on the application of medical interventions in the dying phase, and is related to **research question 2**. The analysis concerned information about therapeutic and diagnostic interventions that were applied during the dying phase. Data were gained from the nurse questionnaires and patient records. The dying phase was considered as being recognized when the patient's record contained any written documentation concerning the start of the dying phase. Caregivers recognized the dying phase of 380 patients (78%). The number of patients receiving diagnostic interventions was significantly lower when the dying phase was recognized (39%), as compared to when it was not (57%) ($p = 0.00$). Significantly more patients with a recognized dying phase were routinely turned (46%) and had a syringe driver set up (36%), as compared to patients without a recognized dying phase (25% and 12% respectively) (for both $p = 0.00$). Significantly fewer patients with a recognized dying phase underwent lab tests (15%), radiology or ECG (12%), blood pressure measurements (21%), and body temperature measurements (26%), as compared to patients without a recognized dying phase (39%, 22%, 48%, and 50% respectively) (for each $p < 0.05$). LCP use appeared not to affect the application of therapeutic or diagnostic interventions. Although recognition of the dying phase can reduce the number of undesirable interventions, for some interventions this is more difficult than for others.

Chapter 6 elaborates on **research question 2** with describing the effect of the LCP on medical decisions and medication during the last three days of life. Differences in the general focus of care between hospitals, nursing homes and home may affect the adequacy of end-of-life decision-making for the dying. We studied end-of-life decision-making practices for cancer patients who died in either of these settings, and assessed the impact of the Liverpool Care Pathway for the Dying Patient (LCP), a template for care in the dying phase. Physicians and relatives of 311 deceased cancer patients filled in questionnaires. The LCP was introduced halfway the study period. During the last three months of life, patients who died in hospital more often than patients in both other settings received anti-cancer therapy and medication to relieve symptoms. During the last three days of life, patients who died in the hospital or nursing home received more medication as compared to patients who died at

home. The LCP had no clear impact on the use of medication during the last days of life, except that the extent to which physicians thought that medication might have hastened death was reduced after introduction of the LCP. Relatives of patients who died in the hospital tended to be least positive about the patient's and their own participation in the decision-making. We conclude that cancer patients who die in the hospital are more intensively treated during the last phase of life than cancer patients who die elsewhere. The LCP has a limited impact on medical treatment during the dying phase. Communication about medical decision-making tends to be better in the nursing home and at home.

Chapter 7 finally concerns **research question 3**: the effect of using the LCP on communication, end-of-life care, and levels of bereavement in relatives from the relatives' perspective. In total, bereaved relatives filled in a questionnaire for 57% of the patients, on average four months after death. In the intervention period, relatives had lower bereavement levels as compared to relatives of the baseline period ($p = 0.01$). Communication was evaluated similarly for both periods. In conclusion, LCP use during the dying phase seems to contribute to lower levels of bereavement in relatives.

The last Chapter, **Chapter 8** concerns the discussion, in which the strengths and limitations of the study are discussed, followed by the main findings of the study for each research question, while finishing with some recommendations for clinical practice and future research. The main conclusion of the study is that the use of the LCP can be recommended for the care for dying patients. It is a noteworthy result that, according to the nurses and the relatives, LCP use contributes to better symptom control in dying patients. Further, LCP use facilitates and improves the documentation of care. It is suggested that the routine assessment of symptoms, the prescription of medication as required, and the explicit attention to informing the relatives about what to expect from symptoms during the dying phase contributed to this effect. Although the relatives' evaluation did reveal no significant changes in communication after the introduction of the LCP, it cannot be precluded that changes in the communication positively affected the bereavement of the relatives in the intervention period. Possibly more openness in communication better enabled the relatives to say goodbye to the patient, resulting in lower levels of bereavement in relatives after death of the patient. Adequate care in the dying phase demands timely recognition of the dying phase by the professional caregivers. LCP use may increase the alertness of the team to the start of the dying phase and to the

problems and needs of dying patients. Future studies should further investigate the role of the nurses in recognizing the start of the dying phase. Besides, it would be useful to shed more light upon how the LCP can become an integrated part of the care to dying patients.

Samenvatting

In het onderzoek 'Zorg en kwaliteit van leven in de stervensfase' is nagegaan welke bijdrage het Zorgpad Stervensfase (Liverpool Care Pathway for the Dying Patiënt, LCP) levert aan de professionele zorg voor stervende patiënten en hun naasten en de kwaliteit van leven in de stervensfase. Het Zorgpad Stervensfase is ontwikkeld in het Marie Curie Hospice in Liverpool, waar het sinds de eind jaren negentig wordt toegepast. Het Zorgpad Stervensfase is een checklist en een patiëntendossier in één. Het beschrijft zorgdoelen voor de stervensfase, zoals: 'de patiënt is pijnvrij', of 'de familie is ervan op de hoogte dat de patiënt stervende is'. Het Zorgpad Stervensfase bestaat uit 3 delen: 1. beoordeling van de patiënt bij het begin van de stervensfase; 2. continue registratie van de aspecten van zorg die van belang zijn om de zorgdoelen te bereiken en registratie van de eventuele aanpassing van de zorg; 3. zorg na het overlijden. Het onderzoek vond plaats rondom de introductie van het Zorgpad Stervensfase op een aantal afdelingen in ziekenhuizen, verpleeghuizen en twee thuiszorginstellingen. Patiënten die overleden in het jaar vóór de introductie van het Zorgpad Stervensfase (november 2003 - februari 2005) werden vergeleken met patiënten die overleden in het jaar ná de introductie van het Zorgpad Stervensfase (februari 2005 - februari 2006). De medische gegevens werden na overlijden van de patiënt verzameld. Voor iedere overleden patiënt vulden een verpleegkundige, een arts en een nabestaande (indien daartoe bereid) een vragenlijst in over de laatste drie dagen en de laatste drie maanden van het leven van de patiënt. De vragen gingen over de fysieke symptomen van de patiënt, de inhoud van de zorg aan de patiënt en de familie, alsmede over psychosociale symptomen en levensbeschouwing. Daarnaast beantwoordden nabestaanden gemiddeld vier maanden na overlijden van de patiënt vragen met betrekking tot verliesverwerking. De vragenlijsten waren grotendeels gebaseerd op de EORTC QLQ-C30, de Views Of Informal Carers Evaluation of Services questionnaire (VOICES), de Palliative Outcome Scale (POS) en de Leidse Rouw Vragenlijst (LRV). Aan deze lijsten werden enkele vragen toegevoegd, gebaseerd op eerder onderzoek naar medische zorg en beslissingen in de laatste levensfase.

De onderzoeksvragen betroffen het effect van het gebruik van het Zorgpad Stervensfase op:

1. de kwaliteit van leven van patiënten in de laatste drie levensdagen,
2. de inhoud van zorg voor patiënten in de laatste drie levensdagen,
3. de communicatie in de laatste drie levensdagen en de mate van rouw van nabestaanden.

Hoofdstuk 2 van het proefschrift gaat over een studie die vooraf ging aan het onderzoek. Hierin werd bekeken in hoeverre het Zorgpad Stervensfase kon worden toegepast in de zorg aan stervenden in een Nederlandse instelling.
In november 2001 werd een vertaalde versie van het Zorgpad Stervensfase geïntroduceerd op de unit voor palliatieve zorg en symptoomcontrole van het Erasmus MC - Daniel den Hoed Oncologisch Centrum in Rotterdam. Vervolgens werd de mate waarin zorgdoelen werden bereikt vergeleken tussen deze ziekenhuisafdeling in Rotterdam en het hospice in Liverpool. Voor het onderzoek werden de medische gegevens gebruikt van 40 Nederlandse patiënten die overleden waren tussen oktober 2001 en juli 2003 en 40 Engelse patiënten voor wie de leeftijd, het geslacht en de periode van overlijden overeen kwamen met die van de Nederlandse patiënten. De zorgdoelen voor het begin van de stervensfase werden bereikt bij gemiddeld 30 patiënten uit Liverpool en 34 patiënten uit Rotterdam. Gedurende de laatste 24 uur voor overlijden waren symptomen afwezig zonder dat aanvullende interventies nodig waren voor gemiddeld 28 patiënten uit Liverpool en 30 patiënten uit Rotterdam. De zorgdoelen ná het overlijden van de patiënt werden bereikt voor gemiddeld 29 patiënten uit Liverpool en 30 patiënten uit Rotterdam. Verder bleek dat in Liverpool van deel één van het Zorgpad Stervensfase vaker documentatie ontbrak dan in Rotterdam. Het is mogelijk dat ontbrekende documentatie over doelen die reeds bereikt zijn een zekere routine met het werken met het Zorgpad Stervensfase weerspiegelt. Ontbrekende documentatie over het wel of niet bereikt zijn van zorgdoelen brengt echter het risico met zich mee dat actie uitblijft wanneer een doel nog niet bereikt is. We concludeerden dat de mate waarin zorgdoelen bereikt werden vergelijkbaar is tussen de beide instellingen en dat het Zorgpad Stervensfase dus toepasbaar is in een Nederlandse zorginstelling. Daarnaast is blijvende aandacht noodzakelijk voor consistente documentatie van de zorg.
Hoofdstuk 3 bevat resultaten uit het hoofdonderzoek uit de periode vóór de introductie van het Zorgpad Stervensfase, de voormeting. Hierin worden de symptoomlast, de toepassing van medische interventies en aspecten van communicatie in de laatste drie levensdagen vergeleken tussen het ziekenhuis, het verpleeghuis en de thuiszorg. Verpleegkundigen vulden een vragenlijst in voor 239 van de in totaal 321 in deze periode overleden patiënten (74%). Pijn en benauwdheid bleken vaker aanwezig te zijn bij ziekenhuispatiënten dan bij verpleeghuispatiënten of patiënten in de thuiszorg. Incontinentie bleek minder vaak aanwezig bij ziekenhuispatiënten dan bij patiënten in de andere twee settings.

Verschillende medische interventies, zoals een spuitenpomp, bloedtesten, radiodiagnostiek, antibiotica en uitzuigen, werden bij ziekenhuispatiënten vaker toegepast in de laatste drie levensdagen dan bij verpleeghuispatiënten of thuiszorgpatiënten. Dat gold ook voor het meten van de bloeddruk of de lichaamstemperatuur. In het ziekenhuis werd in de laatste drie levensdagen vaker dan elders expliciet over het overlijden van de patiënt gesproken.

Hoofdstuk 4 vormt het kernhoofdstuk van het proefschrift en gaat in op onderzoeksvragen 1 en 2, waarbij de nameting wordt vergeleken met de voormeting ten aanzien van de documentatie en de symptoomlast en de communicatie in de laatste drie levensdagen, zoals beoordeeld door verpleegkundigen en nabestaanden. Tijdens de voormeting vulden 219 verpleegkundigen en 130 nabestaanden een vragenlijst in voor in totaal 220 patiënten. Tijdens de nameting deden 253 verpleegkundigen en 139 nabestaanden dat voor in totaal 255 patiënten. Het Zorgpad Stervensfase werd toegepast bij 197 van de 255 patiënten in de nameting (77%). Er werd in de nameting significant uitgebreider gedocumenteerd dan in de voormeting. Uit zowel de evaluatie van de verpleegkundigen als die van de nabestaanden bleek bovendien dat de symptoomlast voor patiënten in de nameting gemiddeld lager was dan in de voormeting. Nabestaanden evalueerden significant minder angst en hinderlijke slijmvorming en verpleegkundigen significant minder pijn. De communicatie werd door de nabestaanden vergelijkbaar beoordeeld in de voor- en nameting. De conclusie was dat de toepassing van het Zorgpad Stervensfase een positieve bijdrage levert aan de kwaliteit van leven in de stervensfase.

Hoofdstuk 5 richt zich op het effect van onderkenning van de stervensfase door zorgverleners op het toepassen van medische interventies in de stervensfase en vervolgens op het effect van het toepassen van het Zorgpad Stervensfase op de inhoud van zorg in de stervensfase. De analyse betrof de diagnostische en therapeutische interventies die gedurende de stervensfase werden toegepast. Gegevens waren afkomstig uit de patiëntendossiers en uit de door verpleegkundigen ingevulde vragenlijsten. De stervensfase werd verondersteld onderkend te zijn wanneer er schriftelijke informatie te vinden was in het patiëntendossier over het aanbreken van de stervensfase. Van de 613 patiënten die in het ziekenhuis, het verpleeghuis of thuis met thuiszorg overleden waren, konden er 489 (80%) in het onderzoek geïncludeerd worden. Zorgverleners hadden de stervensfase onderkend bij 380 patiënten (78%). Het aantal patiënten dat diagnostische interventies

onderging was significant lager wanneer de zorgverleners de stervensfase hadden onderkend (39%), dan wanneer dat niet het geval was (57%) ($p < 0.01$). Significant minder patiënten met een onderkende stervensfase kregen bloedtesten (15%), radiodiagnostiek (12%), bloeddrukmetingen (21%), en temperatuur metingen (26%), vergeleken met patiënten zonder een onderkende stervensfase (respectievelijk 39%, 22%, 48%, and 50% van de patiënten) (voor beiden $p < 0.05$). Significant meer patiënten met een onderkende stervensfase ondergingen wisselligging (46%) en kregen een spuitenpomp (36%), vergeleken met patiënten zonder een onderkende stervensfase (respectievelijk 25% and 12% van de patiënten) (voor beiden $p < 0.01$). Het onderkennen van de stervensfase bleek dus van essentieel belang voor het verminderen van een aantal onwenselijke interventies in de stervensfase. Toepassing van het Zorgpad Stervensfase heeft het effect van het onderkennen van de stervensfase op het toepassen van sommige interventies, zoals het toepassen van een spuitenpomp in de stervensfase vergroot, mogelijk doordat het expliciet benoemd wordt in het document.

Hoofdstuk 6 betreft de besluitvorming tijdens de laatste levensfase van kankerpatiënten die overleden in het ziekenhuis, het verpleeghuis of thuis en de mogelijke invloed van de introductie van het Zorgpad Stervensfase daarop (onderzoeksvraag 2). De resultaten zijn gebaseerd op 299 vragenlijsten van artsen en 184 vragenlijsten van nabestaanden. Tijdens de laatste drie levensmaanden ontvingen ziekenhuispatiënten vaker dan patiënten in de beide andere settings behandelingen tegen kanker en medicatie ter symptoombestrijding. Voor de meerderheid van de patiënten die in het ziekenhuis of het verpleeghuis overleden was afgesproken om deze patiënten niet meer te reanimeren, terwijl dit het geval was voor een derde van de patiënten die thuis overleden. In iedere instelling had de meerderheid van de patiënten wensen uitgesproken omtrent de medische behandeling. Naasten van patiënten die in het ziekenhuis overleden waren iets minder positief te zijn over de betrokkenheid van de patiënt en henzelf bij de besluitvorming dan naasten van patiënten die overleden in het verpleeghuis of thuis. Gedurende de laatste levensdagen ontvingen patiënten die in het ziekenhuis of het verpleeghuis overleden meer medicatie (het gemiddeld aantal medicijnen per patiënt bedroeg respectievelijk 5,7 en 5,6) dan patiënten die thuis overleden (gemiddeld 3,1 medicijnen). Patiënten die in het ziekenhuis overleden kregen vaker medicatie waarvan de arts dacht dat die het overlijden bespoedigd konden hebben. Van alle ziekenhuispatiënten werd 27% gesedeerd voor overlijden, tegenover 33% van de

verpleeghuispatiënten en 11% van de thuiszorgpatiënten. Na de introductie van het Zorgpad Stervensfase hadden minder artsen het idee dat medicatie de dood versneld kon hebben. Op basis van deze resultaten concludeerden we dat kankerpatiënten in het ziekenhuis intensiever behandeld worden in de laatste levensfase dan elders, dat de communicatie over medische beslissingen buiten het ziekenhuis beter lijkt te zijn, er thuis zelden een niet-reanimatie afspraak wordt gemaakt en gebruik van medicatie beperkt is. Het Zorgpad Stervensfase heeft enige invloed op de medische behandeling in de stervensfase.

Tot slot gaat **hoofdstuk 7** over onderzoeksvraag 3. In totaal vulden 271 nabestaanden gemiddeld vier maanden na het overlijden van de patiënt een vragenlijst in: voor 131 patiënten in de voormeting en 140 patiënten in de nameting (in totaal voor 57% van de patiënten). In de nameting was het Zorgpad Stervensfase toegepast voor 111 van de 140 patiënten (79%). Nabestaanden gaven in de nameting gemiddeld in mindere mate rouw aan dan in de voormeting ($p = 0.01$). Daarnaast bleek dat partners hogere rouwscores aangaven dan nabestaanden met een andere relatie met de patiënt, en dat nabestaanden van patiënten die in het ziekenhuis overleden waren hogere rouwscores hadden dan nabestaanden van patiënten die in het verpleeghuis of thuis overleden waren. Behalve dat nabestaanden in de nameting de informatie die zij kregen duidelijker vonden dan nabestaanden in de voormeting ($p=0.05$), evalueerden zij de communicatie niet significant verschillend tussen de voor- en nameting. Toepassing van het Zorgpad Stervensfase lijkt bij te dragen aan een mindere mate van rouw bij nabestaanden.

In het laatste hoofdstuk, **hoofdstuk 8**, worden de voorgaande hoofdstukken in een bredere context geplaatst. Het onderzoek toonde twee effecten aan van toepassing van het Zorgpad Stervensfase: een lagere totale symptoomlast bij stervende patiënten en een mindere mate van rouw bij nabestaanden. De verminderde symptoomlast is op zich een bijzonder resultaat, omdat het toepassen van het Zorgpad Stervensfase geen symptoomgerichte zorginterventie is. Het lijkt echter aannemelijk dat het routinematig 'controleren' van symptomen zorgverleners beter in staat stelt om problemen op te sporen en adequaat te behandelen. Het kan zijn dat aspecten van communicatie die niet zijn meegenomen in het onderzoek positieve invloed hebben gehad op de verliesverwerking van de nabestaanden in de nameting. Het expliciet benoemen van de stervensfase kan de naasten in de nameting beter in staat hebben gesteld om zich voor te bereiden op het overlijden van de patiënt, wat kan hebben bijgedragen aan een mindere mate van rouw dan bij nabestaanden in de

voormeting. Daarnaast levert de toepassing van de het Zorgpad Stervensfase uitgebreidere documentatie op, die uiteindelijk ten goede zal komen aan de zorg voor de patiënt en de familie. De hoofdconclusie van het onderzoek is daarom dat de toepassing van het Zorgpad Stervensfase kan worden aanbevolen voor de zorg aan stervende patiënten.

De verschillen in zorg die gevonden werden tussen de drie zorginstellingen kunnen te maken hebben met het feit dat de zorg in het ziekenhuis in de eerste plaats behandelingsgericht is, terwijl de zorg in het verpleeghuis en thuis meer verzorgend van aard is. Daarnaast vraagt het vaak complexere ziektebeeld van ziekenhuispatiënten over het algemeen een meer interveniërend type zorg. Beide kenmerken kunnen verklaren dat de omschakeling van behandelen naar verzorgen in het ziekenhuis vaak korter voor het overlijden van patiënten plaatsvindt dan in het verpleeghuis en thuis, met als mogelijke gevolgen: intensievere (therapeutische) interventies en meer uitgesproken communicatie in de stervensfase van ziekenhuispatiënten.

Adequate zorg in de stervensfase vereist tijdige onderkenning van de stervensfase door professionele zorgverleners. De toepassing van het Zorgpad Stervensfase kan de opmerkzaamheid van het team op het aanbreken van de stervensfase en op problemen en behoeften van stervende patiënten vergroten. De verpleegkundigen kunnen daarbij een sleutelrol innemen, omdat zij vaak als eerste veranderingen onderkennen in de toestand van de patiënt. Daarnaast, omdat het Zorgpad Stervensfase gedragen wordt door goede documentatie, is het van belang dat, zodra de stervensfase aanbreekt, álle leden van het team, ook de artsen, het document erkennen als patiëntendossier en erin registreren. Toekomstig onderzoek zou zich kunnen richten op het verbeteren van de toepassing van het Zorgpad Stervensfase. Er valt mogelijk nog winst te behalen met een snellere erkenning van de stervensfase en met meer inzicht in de specifieke capaciteiten van ieder teamlid bij het aanpassen van de zorg en bij de communicatie in de stervensfase.

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Paul. Dank je wel dat je mijn promotor hebt willen zijn. Ik vind het bijzonder dat je destijds als decaan voor de promovendivereniging, maar ook als mijn promotor zo toegankelijk bent geweest voor discussie en feedback. Het gaf me het gevoel persoonlijk deel uit te maken van de universiteit.

Dear John and Maureen. Thank you very much for cooperating with us in this interesting project. I enjoyed our meetings very much. The way that you support the use of the pathway is very inspiring.

Dank je wel allen die bij het project betrokken waren, in het bijzonder alle locale implementatiemedewerkers en contactpersonen in de instellingen Aïda Mrkalj, Bianca van Est, Cora Braat, Corina van Bellen, Diny van Vooren, Erwin Humer, Ewald Reyerink, Gerrieke Jongeneel, Janneke Lauws, Janneke van Dijke, Jannie van Eck, Johanna Rehorst, Jolanda van Oosterum, Jopie van den Berg, Karin Bokelaar, Marijke Schilt, Marion Wouters, Martine Folsche, Mieke de Sterke, René de Bakker, Rianne Joppe, Rianne Robijn en Yvette Engelen. Jullie hebben met jullie ervaring en enthousiasme het project echt gedragen in de praktijk! Onze bijeenkomsten vond ik altijd erg inspirerend en leerzaam. Ik vind het fantastisch dat jullie in jullie drukke werkschema's tijd hebben vrijgemaakt voor het onderzoek.

Ik had nooit kunnen bedenken dat één van de verpleegkundigen, bij wie ik altijd terechtkon met vragen over de praktijk zo jong zou overlijden. Gerrieke, ik zal je niet vergeten.

Dank je wel artsen, verpleegkundigen en nabestaanden van de patiënten in het onderzoek dat jullie een bijdrage hebben willen leveren aan deze studie. Ervaringen met sterven en dood raken je. Ik heb veel respect voor jullie betrokkenheid en moed.

Dank je wel Elsbeth, Siebe, Hetty, Karin en Marij voor de persoonlijke gesprekken. Ik werd geboeid door jullie visies op de praktijk, waardoor ik op verschillende manieren naar palliatieve zorg leerde kijken. Bij jullie riep elk antwoord zo weer drie nieuwe vragen op. Dat heeft me erg geholpen bij het schrijven van de artikelen.

Edith, jij hebt de implementatie van het zorgpad gecoördineerd de eerste twee jaar. Daar had ik als onderzoeker bijna geen omkijken naar. Ideaal, dank je wel! Dank je wel ook Petra voor de coördinatie van het 'zorgpadproject' toen en nu! Ik vond het fijn dat ik op je kon steunen in het laatste jaar van het onderzoek.

Dank je wel vrienden, en collega's (velen van jullie zijn beide voor me) voor jullie vriendschap en steun, variërend van het helpen schrijven van een artikel tot de dagelijkse peptalk bij de koffie. Mijn kamergenootjes: Chantal, Yvonne, Claudine, Rolf, Caroline, Nino en Meeke: ik vond het gezellig met jullie. Je woont toch een beetje samen op zo'n kantoor, dat heb ik nogal gemist tijdens mijn thuiswerkdagen! Merel, Wilma, Matejka, Jolanda, Ida, Astrid, Birgitte, Resi, Eveline, Cecile, Peter, Floor, Hans, Gitte, Hilde, Carola, Martijn, Tanja, Ewout, Tinneke, Judith, Oscar, Marloes, Marijn, Susanne, Lex, Karien, Dik, Esther, Gladys, Ed, Sonja, Frank, Katrina, Roel, Hein, Caspar, Willemieke, Sake, René, Isabel, Egil, Hilmar, Goedele, Hanny, Carlijn, Ilse, Michelle, Bram, Kees, Merel, Suzie, Suzanne, Mona, Jan Willem, Natasja, Annelies, Iris, Lennert, Valery, Tamarinde, Saskia, ……we hebben gewandeld, gevolleybald, hardgelopen, afscheidsliedjes gezongen, geborreld en ook gewerkt. Dankzij jullie heb ik een fijne tijd gehad bij MGZ en daarbuiten! Dank je wel Else, voor de boeiende gesprekken en het gezellige dansen. En dank je wel Peter, Karin en mededanseressen voor de danslessen waarmee ik meer dan eens wat stress of computerstijfheid heb weggedanst. Dank je wel huidige collega's voor jullie interesse en support bij het afronden van mijn promotie.

Dank je wel Victor, Debby, Mauricio, Thijs, Klazine en Hanan voor de lol die ik met jullie heb gehad bij Promeras. Soms wisten we gewoon niet waar we de tijd vandaan moesten halen, maar we hebben leuke dingen opgezet samen.

Dank je wel Tristan en Bob voor het ontwikkelen en invoeren van de invoermodule. Het was geen eenvoudige klus, maar het heeft mij veel tijd bespaard. Ik vond het leuk om op zo'n technische manier met jullie samen te werken. En dank je wel Merian voor de accesdatabase waarmee ik de logistiek het hoofd heb kunnen bieden. Dank je wel ook Anne Marie, Marcia en Rianne voor jullie nauwkeurige invoerwerk. Dank je wel Judith, Mirjam, Resi en Judith voor de lay-out en tips, fijn om te weten dat jullie kritisch meelazen en keken.

Dank je wel Jitske, Corinne, Paula, Kim, Joris, Pascal, Pim, Eveline, Martin, Maro, Casper, Martine, Thomas, Nienke, Million, Karen, Marieke, Esther, Reina, Barbara, Marjolein, Tessa, Reinout, Nathalie en Marcel voor jullie vriendschap die me vrolijk maakte en energie gaf, ook al zagen we elkaar soms een tijdje niet.

En dank je wel paranimfen: Siska en Irene. Sis, mede dankzij jou ben ik een tweede promotietraject begonnen, maar bijzonderder nog: heb ik deze ook afgemaakt. Je hebt me door een bestwel moeilijke periode in mijn leven heen geholpen met vitamine C, Kiran en wekelijkse telefoongesprekken. Dank je wel ook Jan en Maddy dat jullie zo betrokken bij me waren. Zusje, met jou als paranimf durf ik de verdediging wel aan! Je wilt het vast niet horen, maar ik bewonder jou om je ambitie en je talent om steeds weer nieuwe interessante projecten op te starten, alleen en samen met Simon. Er is ook niemand met wie ik zo kan lachen als met jou.

Papa en mama. Het afgelopen jaar vond ik het soms raar om met mijn promotie bezig te zijn. Het was mijn leven dat door ging, terwijl dat van jullie min of meer stil stond. Dank jullie wel dat jullie me altijd zo vrij gelaten hebben om mijn eigen keuzen te maken. Het voelt zo vanzelfsprekend dat jullie er voor me zijn, maar het is elke dag weer bijzonder…

Curriculum Vitae

Laetitia Veerbeek werd op 6 november 1977 geboren in Rotterdam. Zij behaalde in 1996 haar VWO diploma aan het Rotterdams Montessori Lyceum. Vervolgens studeerde zij Gezondheidswetenschappen aan de Universiteit Maastricht, waar zij in 2001 afstudeerde in de richting Biologische Gezondheidkunde. In het kader van haar afstudeerstage deed zij onderzoek naar hersenschade na perinatale asfyxie op de afdeling Psychiatrie en Neuropsychologie van het Academisch Ziekenhuis Maastricht en bij het Medical Health Research Institute aan de University of Michigan. In 2002 werkte zij als AIO bij Bloedbank Sanquin en de afdeling Hematologie van het Leids Universitair Medisch Centrum aan een celkweekmethode ter ontwikkeling van een transplantatieproduct uit navelstrengbloed stamcellen. Vervolgens startte zij in 2003 haar promotieonderzoek op de afdeling Maatschappelijke Gezondheidszorg aan het Erasmus Universitair Medisch Centrum Rotterdam dat leidde tot dit proefschrift. Zij volgde in deze periode een postdoctorale opleiding Public Health bij the Netherlands Institute for Health Services. Sinds april 2007 werkt Laetitia als projectmedewerker bij het Integraal Kankercentrum West in Leiden waar zij onder andere betrokken is bij een regionaal project ter verbetering van de zorg voor borstkankerpatiënten.

Appendix

Care of the Dying Pathway (LCP)
(Hospital version)

LIVERPOOL
Care Pathway
Promoting best practice for care of the dying

ADD OWN ORGANISATIONAL LOGO HERE

Name: ..... Unit no: ..... DOB: .....

Care Of The Dying Pathway (lcp) (Hospital)

References:

Working Party on Clinical Guidelines In Palliative Care (1997) Changing Gear – Guidelines for Managing the Last Days of Life in Adults. National Council for Hospice and Specialist Palliative Care Services, London (revised and reprinted January 2005)'

Ellershaw JE, Wilkinson S (2003) Care of the dying: A pathway to excellence. Oxford: Oxford University Press.

Instructions for use

1. All goals are in **heavy** typeface. Interventions, which act as prompts to support the goals, are in normal type.
2. The palliative care guidelines are printed on the pages at the end of the pathway. Please make reference as necessary.
3. If you have any problems regarding the pathway contact the Palliative Care Team.

Practitioners are free to exercise their own professional judgement, however, any alteration to the practice identified within this LCP must be noted as a variance on the sheet at the back of the pathway.

Criteria for use of the LCP

All possible reversible causes for current condition have been considered:

The multiprofessional team has agreed that the patient is dying, and two of the following may apply: -

The patient is bedbound	☐	Semi-comatose	☐
Only able to take sips of fluids	☐	No longer able to take tablets	☐

Consultant: ..... Named nurse: ..... Ward: .....

All personnel completing the care pathway please sign below

Name (print)	*Full signature*	*Initials*	*Professional title*	*Date*

Name: .....Unit no:.....Date/Time commenced: .....

Section 1	***Initial assessment***
Diagnosis & Demographics	**PRIMARY DIAGNOSIS:**..... **SECONDARY DIAGNOSIS**: ..... Date of In-patient admission:..... Ethnicity:..... DOB:..... NHS no:..... Female ☐ Male ☐
Physical condition	Unable to swallow **Yes** ☐ **No** ☐ Aware **Yes** ☐ **No** ☐ Nausea **Yes** ☐ **No** ☐ Conscious **Yes** ☐ **No** ☐ Vomiting **Yes** ☐ **No** ☐ UTI problems **Yes** ☐ **No** ☐ Constipated **Yes** ☐ **No** ☐ Catheterised **Yes** ☐ **No** ☐ Confused **Yes** ☐ **No** ☐ Respiratory tract secretions **Yes** ☐ **No** ☐ Agitation **Yes** ☐ **No** ☐ Dyspnoea **Yes** ☐ **No** ☐ Restless **Yes** ☐ **No** ☐ Pain **Yes** ☐ **No** ☐ Distressed **Yes** ☐ **No** ☐ Other (e.g. oedema, itch) **Yes** ☐ **No** ☐
Comfort measures	**Goal 1: Current medication assessed and non essentials discontinued** **Yes** ☐ **No** ☐ Appropriate oral drugs converted to subcutaneous route and syringe driver commenced if appropriate. Inappropriate medication discontinued.
	Goal 2: PRN subcutaneous medication written up for list below as per protocol (See sheets at back of LCP for guidance) Pain — Analgesia **Yes** ☐ **No** ☐ Agitation — Sedative **Yes** ☐ **No** ☐ Respiratory tract secretions — Anticholinergic **Yes** ☐ **No** ☐ Nausea & vomiting — Anti-emetic **Yes** ☐ **No** ☐ Dyspnoea — Anxiolytic / Muscle relaxant **Yes** ☐ **No** ☐
	Goal 3: Discontinue inappropriate interventions Blood test (including BM monitoring) **Yes** ☐ **No** ☐ **N/A** ☐ Antibiotics **Yes** ☐ **No** ☐ **N/A** ☐ I.V.'s (fluids/medications) **Yes** ☐ **No** ☐ **N/A** ☐ Not for cardiopulmonary resuscitation recorded **Yes** ☐ **No** ☐ (Please record below & complete appropriate associated documentation - policy/procedure) ..... **Deactivate cardiac defibrillators (ICD's)** **Yes** ☐ **No** ☐ **N/A** ☐ Contact patient's Cardiologist Refer to local policy and procedures Information leaflet given to patient / carer if appropriate Doctor's signature: ..... Date: .....
	Goal 3a: Decisions to discontinue inappropriate nursing interventions taken **Yes** ☐ **No** ☐ Routine turning regime – reposition for comfort only – consider pressure relieving mattress – & appropriate assessments re skin integrity - taking vital signs. If BM monitoring in place reduce frequency as appropriate e.g. once daily
	Goal 3b: Syringe driver set up within 4 hours of doctors order **Yes** ☐ **No** ☐ **N/A** ☐ **Nurse signature**: ..... **Date**: ..... **Time**: .....

Name: ..... Unit no: ..... Date: .....

Section 1	***Initial assessment - Continued***
Psychological/ insight	**Goal 4: Ability to communicate in English assessed as adequate** a) Patient **Yes** ☐ **No** ☐ **Comatosed** ☐ b) Family/other **Yes** ☐ **No** ☐
	Goal 5: Insight into condition assessed Aware of diagnosis a) Patient **Yes** ☐ **No** ☐ **Comatosed** ☐ b) Family/other **Yes** ☐ **No** ☐ Recognition of dying c) Patient **Yes** ☐ **No** ☐ **Comatosed** ☐ d) Family/other **Yes** ☐ **No** ☐
Religious/ Spiritual support	**Goal 6: Religious/spiritual needs assessed** a) with Patient **Yes** ☐ **No** ☐ **Comatosed** ☐ b) with Family/other **Yes** ☐ **No** ☐ Patient/other may be anxious for self/others Consider specific cultural needs Consider support of Chaplaincy Team Religious Tradition identified, if yes specify: ..... **Yes** ☐ **No** ☐ **N/A** ☐ Support of Chaplaincy Team offered **Yes** ☐ **No** ☐ In-house support Tel/bleep no: .....Name: ..... Date/time: ..... External support Tel/bleep no: .....Name: ..... Date/time: ..... Comments (Special needs now, at time of impending death, at death & after death identified) ....
Communication with family/other	**Goal 7: Identify how family/other are to be informed of patient's impending death** **Yes** ☐ **No** ☐ At any time ☐ Not at night-time ☐ Stay overnight at Hospital ☐ Primary contact name: ..... Relationship to patient:..... Tel no: ..... Secondary contact: ..... Tel no: .....
	Goal 8: Family/other given hospital information on:- **Yes** ☐ **No** ☐ Facilities leaflet available to address: Car parking; Accommodation; Beverage facilities; Payphones; Washrooms & toilet facilities on the ward; Visiting times; Any other relevant information.
Communication with primary health care team	**Goal 9: G.P. Practice is aware of patient's condition** **Yes** ☐ **No** ☐ G.P. Practice to be contacted if unaware patient is dying, message can be left with the receptionist
Summary	**Goal 10: Plan of care explained & discussed with:** a) Patient **Yes** ☐ **No** ☐ **Comatosed** ☐ b) Family/other **Yes** ☐ **No** ☐
	Goal 11: Family/other express understanding of planned care **Yes** ☐ **No** ☐ Family/other aware that the planned care is now focused on care of the dying & their concerns are identified & documented. The LCP document may be discussed as appropriate
If you have charted "No" against any goal so far, please complete variance sheet on the back page. **Health Professional signature**:..... **Title**: ..... **Date**:	

Name: ..... Unit no: ..... Date: .....

Codes (please enter in columns) A= Achieved V=Variance (not a signature)						
Section 2 *Patient problem/focus*	***04:00***	***08:00***	***12:00***	***16:00***	***20:00***	***24:00***
Ongoing assessment ***Pain*** **Goal: Patient is pain free** • Verbalised by patient if conscious • Pain free on movement • Appears peaceful • Consider need for positional change						
Agitation **Goal: Patient is not agitated** • Patient does not display signs of delirium, terminal anguish, restlessness (thrashing, plucking, twitching) • Exclude retention of urine as cause • Consider need for positional change						
Respiratory tract secretions **Goal: Excessive secretions are not a problem** • Medication to be given as soon as symptoms arise • Consider need for positional change • Symptom discussed with family/other						
Nausea & vomiting **Goal: Patient does not feel nauseous or vomits** • Patient verbalises if conscious						
Dyspnoea **Goal: Breathlessness is not distressing for patient** • Patient verbalises if conscious. • Consider need for positional change.						
Other symptoms (e.g. oedema, itch)						
Treatment/procedures ***Mouth care*** **Goal: Mouth is moist and clean** • See mouth care policy • Mouth care assessment **at least** 4 hourly • Frequency of mouth care depends on individual need • Family/other involved in care given						
Micturition difficulties **Goal: Patient is comfortable** • Urinary catheter if in retention • Urinary catheter or pads, if general weakness creates incontinence						
Medication **(If medication not required please record as N/A)** **Goal: All medication is given safely & accurately** • If syringe driver in progress check at least 4 hourly according to monitoring sheet						
Signature						
Repeat this page 24 hrly. Spare copies on Ward **If you have charted ''V'' against any goal so far, please complete variance sheet on the back page**						

Name: ..... Unit no: ..... Date: .....

Codes (please enter in columns) A= Achieved V=Variance		***08:00***	***20:00***
Mobility/Pressure area care	**Goal: Patient is comfortable and in a safe environment** • Clinical assessment of: Skin integrity Need for positional change Need for special mattress Personal hygiene, bed bath, eye care needs		
Bowel care	**Goal: Patient is not agitated or distressed due to constipation or diarrhoea**		
Psychological/ Insight support	***Patient*** **Goal: Patient becomes aware of the situation as appropriate** • Patient is informed of procedures • Touch, verbal communication is continued		
	Family/other **Goal: Family/other are prepared for the patient's imminent death with the aim of achieving peace of mind and acceptance** • Check understanding of nominated family/others / younger adults / children • Check understanding of other family/others not present at initial assessment • Ensure recognition that patient is dying & of the measures taken to maintain comfort • Chaplaincy Team support offered		
Religious/ Spiritual support	**Goal: Appropriate religious/spiritual support has been given** • Patient/other may be anxious for self/others • Support of Chaplaincy Team may be helpful • Consider cultural needs		
Care of the family /others	**Goal: The needs of those attending the patient are accommodated** • Consider health needs & social support. Ensure awareness of ward facilities		
Signature			

Health Professional Signature Early: ..... Late: ..... Night: .....

Multidisciplinary progress notes

Name: ..... Unit no: ..... Date: .....

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Health Professional Signature Early: ..... Late: ..... Night: .....

Multidisciplinary progress notes

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Signature			

Health Professional Signature Early: ..... Late: ..... Night: .....

Multidisciplinary progress notes

Name: ..... Unit no: ..... Date: .....

SECTION 3 Verification of death

Date of death: ..... Time of death: .....

Persons present: .....

Notes: .....

.....

Signature: ..... Time verified: .....

Care after death	**Goal 12: GP Practice contacted re patient's death Date __/__/__**	**Yes ☐ No ☐**
	• If out of hours contact on next working day Message can be left with receptionist	
	Goal 13: Procedures for laying out followed according to hospital policy	**Yes ☐ No ☐**
	• Carry out specific religious / spiritual / cultural needs - requests	
	Goal 14: Procedure following death discussed or carried out	**Yes ☐ No ☐**
	Check for the following: • Explain mortuary viewing as appropriate • Family aware cardiac devices (ICD's) or pacemaker must be removed prior to cremation • Post mortem discussed as appropriate. • Input patients death on hospital computer	
	Goal 15: Family/other given information on hospital procedures	**Yes ☐ No ☐**
	• Hospital information booklet given to family/other about necessary legal tasks • Relatives/other informed to ring Bereavement Office after 10.00am on next working day to make an appointment to collect death certificate	
	Goal 16: Hospital policy followed for patient's valuables & belongings	**Yes ☐ No ☐**
	• Belongings and valuables are signed for by identified person • Property packed for collection. • Valuables listed and stored safely	
	Goal 17: Necessary documentation & advice is given to the appropriate person	**Yes ☐ No ☐**
	• 'What to do after death' booklet given (DHSS)	
	Goal 18: Bereavement leaflet given	**Yes ☐ No ☐**
	• Information leaflet on grieving and local support given	
	If you have charted "No" against any goal so far, please complete variance sheet at the back of the pathway before signing below **Health Professional signature**: ..... Date:	
	Have you completed the last 4 & 12 hourly observation **Please contact the Palliative Care Team to inform them that this patient was on a pathway.**	

Name: ..... Unit no: ..... NHS no: .....

Variance analysis

What Variance occurred & why?	Action Taken	Outcome
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….

Name: ..... Unit no: ..... NHS no: .....

Variance analysis

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Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….
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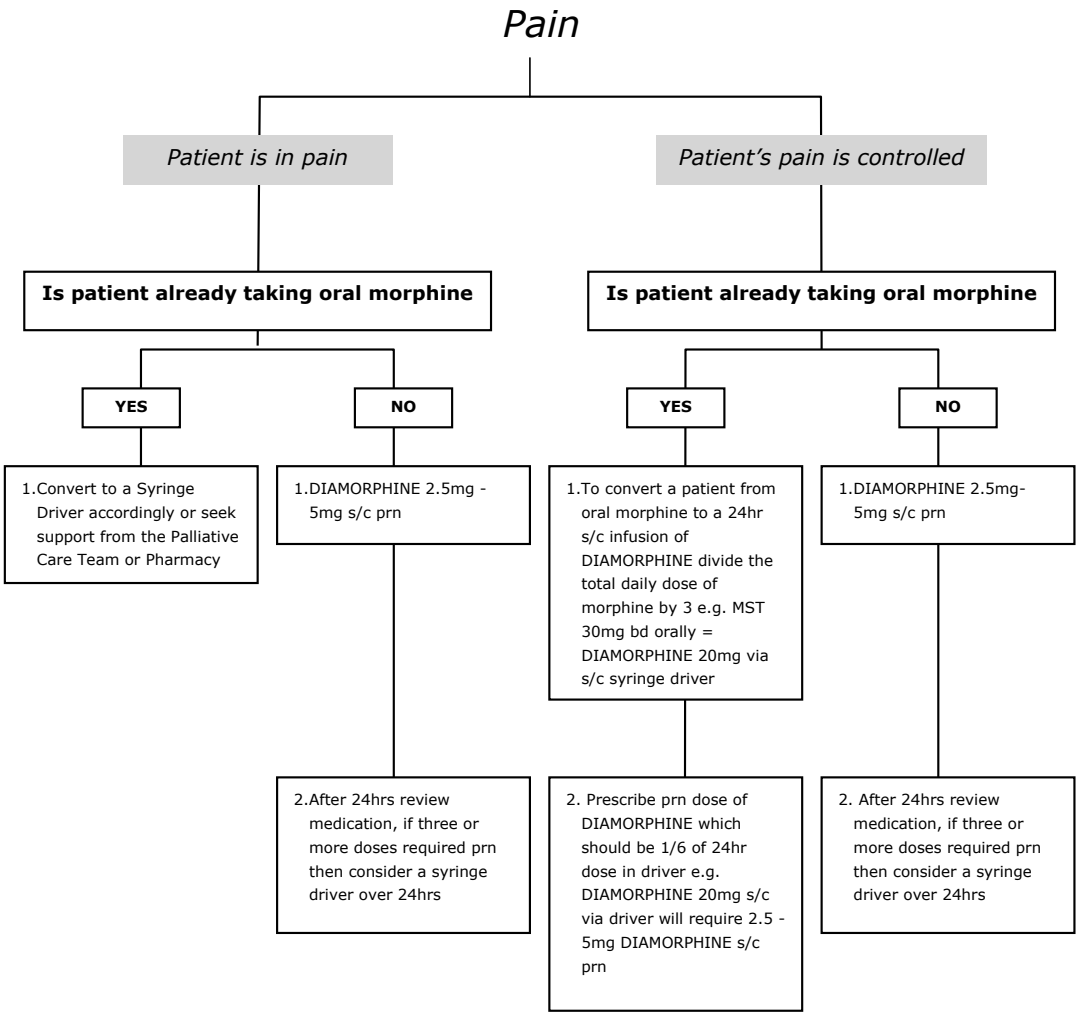
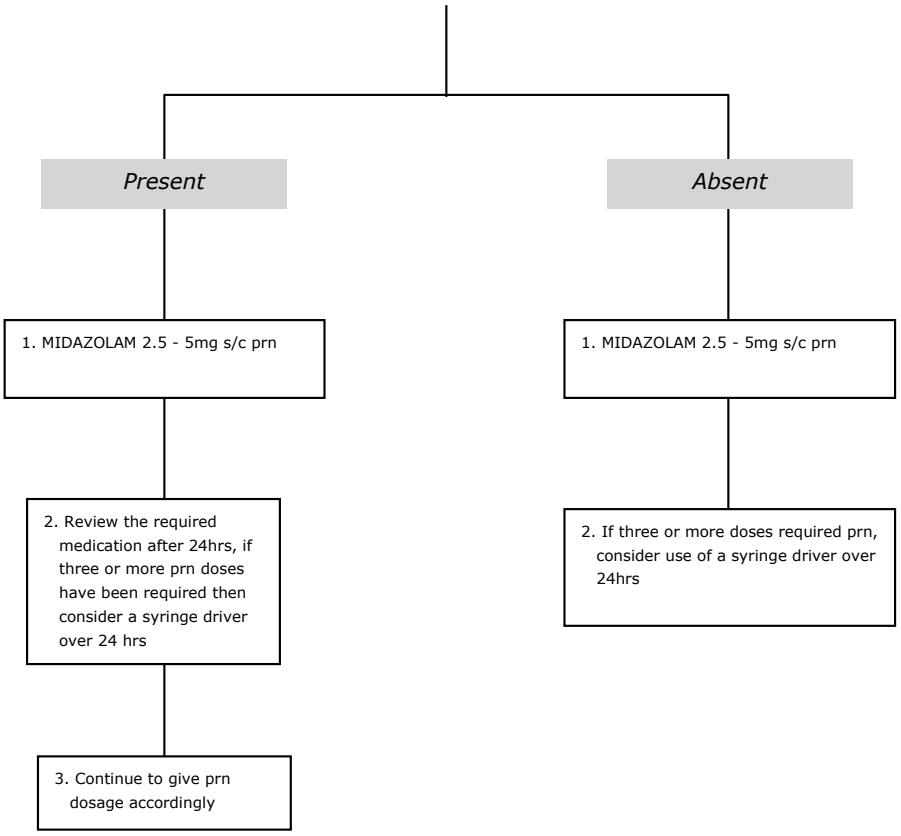
Signature……. Date/Time…….	Signature……. Date/Time…….	Signature……. Date/Time…….



SUPPORTIVE INFORMATION:

- To convert from other strong opioids contact Palliative Care Team/ Pharmacy for further advice & support as needed
- If symptoms persist contact the Palliative Care Team
- Morphine 5 – 10mg s/c prn may be utilized as an alternative
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use and reference them accordingly*

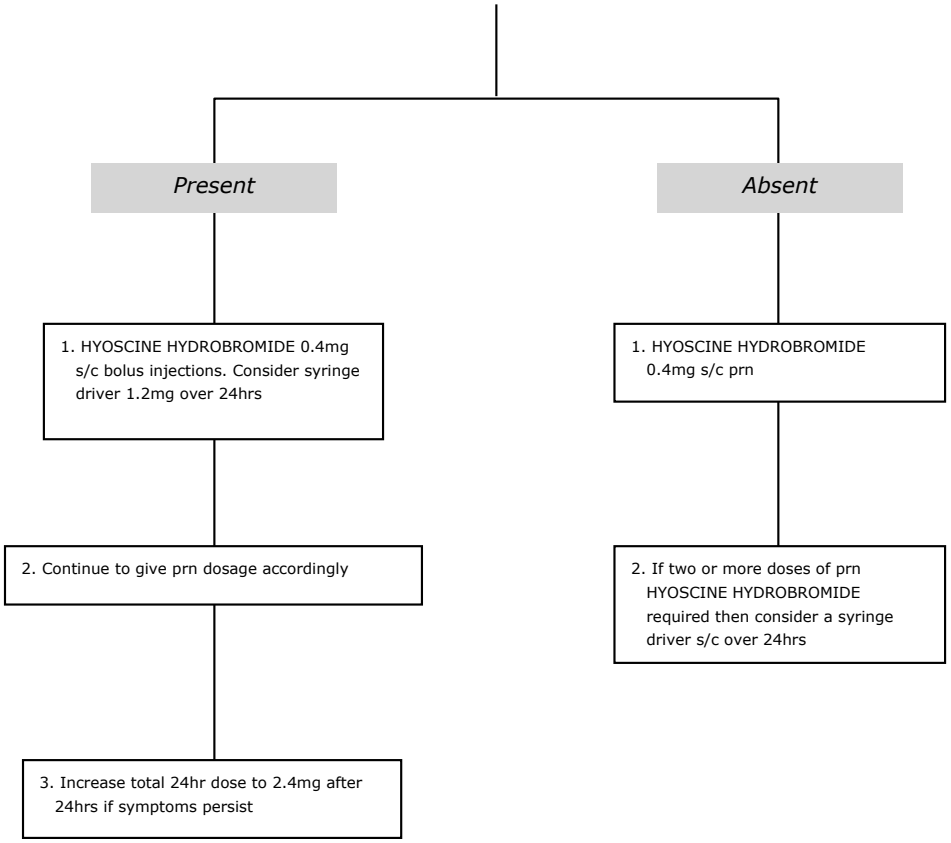
Terminal restlessness and agitation



SUPPORTIVE INFORMATION;

- If symptoms persist contact the Palliative Care Team
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use and reference them accordingly*

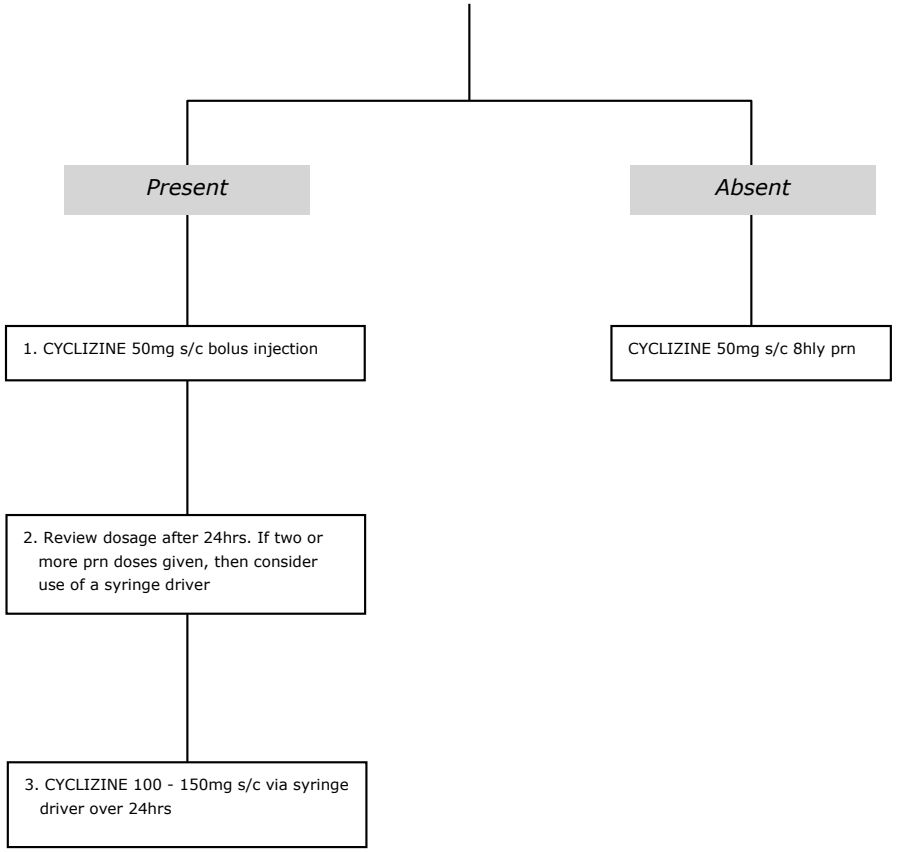
Respiratory tract secretions



SUPPORTIVE INFORMATION:

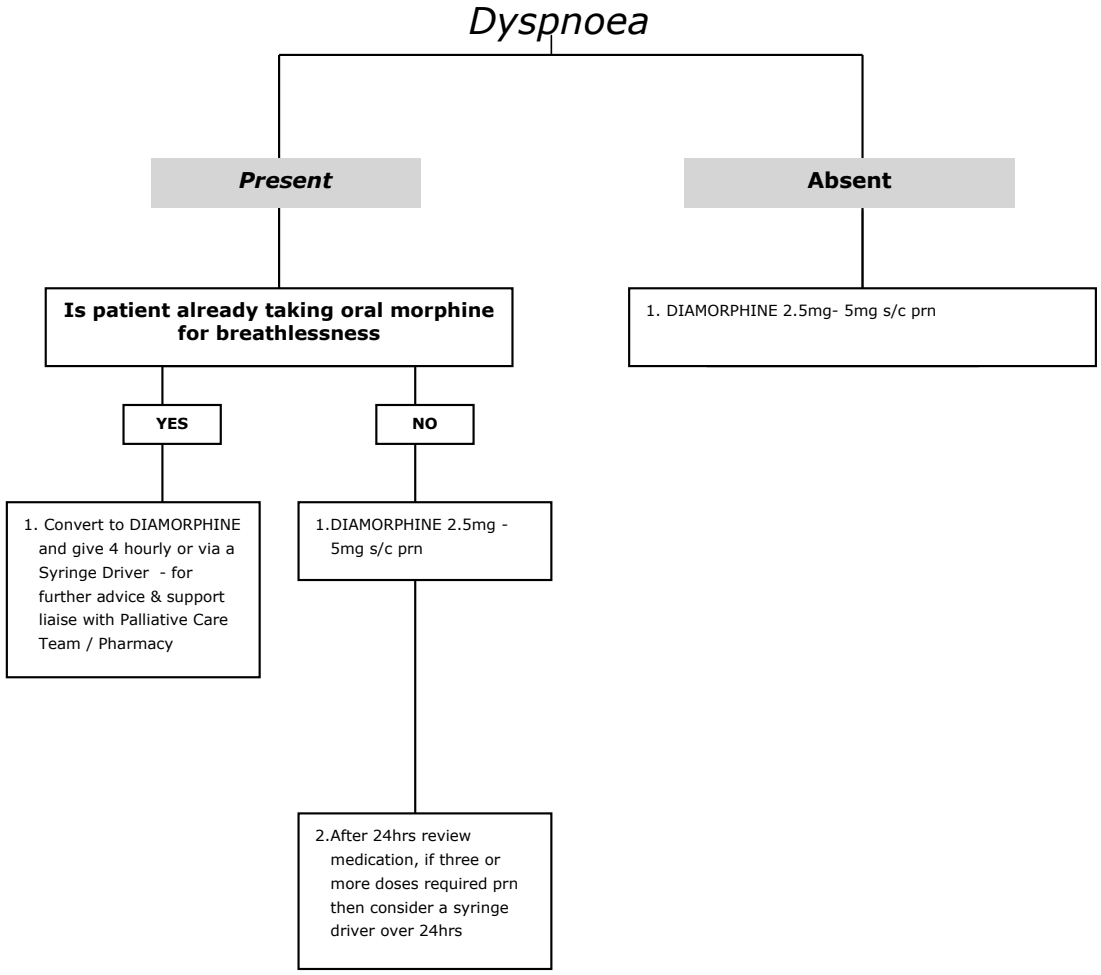
- If symptoms persist contact the Palliative Care Team
- Glycopyrronium 0.4mg s/c prn may be used as an alternative
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use and reference them accordingly*

Nausea and vomiting



SUPPORTIVE INFORMATION:

- N.B. Always use water for injection when making up Cyclizine.
- If symptoms persist contact the Palliative Care Team.
- Cyclizine is not recommended in patients with heart failure.
  Alternative antiemetics according to local policy & procedure may be prescribed
  e.g. ***Haloperidol s/c 2.5 – 5mg prn (5 – 10mg via a s/c syringe Driver over 24 hrs)***
  Levomepromazine s/c 6.25mg prn (6.25 – 12.5 mg via a s/c syringe Driver over 24hrs)
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use – many areas have complex algorithms as guidance for the management of nausea or vomiting, and may be referenced accordingly*



SUPPORTIVE INFORMATION:

- If the patient is breathless and anxious consider Midazolam stat 2.5mg s/c prn
- If symptoms persist contact the Palliative Care Team.
- Anticipatory prescribing in this manner will ensure that in the last hours / days of life there is no delay responding to a symptom if it occurs.
- *These guidelines are produced according to local policy & procedure & you may want to alter them for local use and reference accordingly*